Telling their Story: Perspectives of Young Women, Their Caregivers and Service Providers Regarding the Experiences of Growing Up with Perinatally-Acquired HIV in Malawi

By

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ABSTRACT

Background: Globally, the number of young people living with perinatally acquired HIV continues to rise, mainly in Africa, including Malawi. Advances in antiretroviral therapy mean that perinatally infected young people are increasingly surviving into adulthood. However, to date, this group has received relatively less attention in the field of HIV care. There is a need for the development of appropriate care and support services for this group. Although there is a growing body of knowledge about medical, sexual and reproductive health issues for this group, relatively less attention has been given to understanding other aspects of young people's life experiences. In 2010, HIV prevalence among young people aged 15 - 19 years in Malawi was significantly higher among females (4.2%) than males (1.3%). Additionally, young women affected by HIV may be particularly vulnerable to sexual abuse and/or normative expectations such as subordination in sexual relationships. There is a gap in our current understanding of the structures and mechanisms underlying young women's psychosocial and sexual experiences and challenges as they grow up with HIV. In addition, it is unclear whether HIV services meet the varying needs of the young women as they grow into adulthood. Hence, this thesis focuses on young women rather than both genders.

Aim: To determine the meaning of the experience of growing up with perinatally acquired HIV for young women aged 15-19 in Malawi, exploring the complexities of their lives in order to understand their health outcomes within the wider socio-cultural and structural context.

Objectives: were broadly formulated into two areas:

To explore the psychosocial, sexual and reproductive experiences of growing up with perinatally acquired HIV for the young women

- To determine the structural factors, perceptions, values and aspirations influencing young women's experiences as they grow up with HIV to adulthood.

To explore the health, sex and relationship challenges for young women growing up with perinatally acquired HIV and the impact of the current HIV related and sexual and reproductive health (SRH) services.

- To identify the psychosocial and SRH challenges of the young women as they are growing up to adulthood.
- To identify the issues and challenges encountered by caregivers as they look after young women growing up with HIV.
- To identify the issues and challenges encountered by service providers as they provide health care to the young women growing up with HIV.
- To assess the impact of the existing health services on the needs of the young women as they grow up to adulthood.
- To identify the most important and realistic strategies in meeting the needs of perinatally HIV infected young women as they grow up to adulthood in Malawi.

***Methods*:** A qualitative case study design was adopted whereby each 'case' comprised a young woman aged 15-19 years, a nominated primary caregiver and a service provider. In-depth interviews were used to collect data. The interviews with the young women were based on an innovative visual method, 'my story book' to encourage open discussion on sensitive topics. The case study approach enabled more comprehensive understanding of young women's experiences. The study included 14 cases (i.e. a total of 42 participants).

Findings: Young women endured multiple losses and HIV stigma that negatively impacted upon their sense of self and belonging. Many lived with an enduring sense of sadness that was rarely openly addressed. Emotional, material and social support were essential in helping young women to build a sense of identity and to carve out a successful life, but women's access to such resources were highly variable. Caregivers' resources were often over-burdened and several lacked the capacity to provide young women with an adequately supportive environment. Young women's strategies to seek love, acceptance or material advancement often led them into complex situations where they were taking sexual risks or had little control over their reproductive health. The study found that both service providers and caregivers often turned a blind eye to young women's sexual activities, leading to poor sexual and reproductive health

outcomes. Accessing SRH care was hindered by normative cultural practices that made it hard for providers, caregivers or young women to talk about relationships, sexual behaviour or contraception.

Conclusion: Addressing the complex and inter-linked needs of perinatally infected young women poses a key challenge for Malawi's HIV services. One way forward might be to explore ways in which services could develop integrated models of care, offering a 'one-stop shop' to this vulnerable group, including efforts to provide continuity of care, practical/material support, expanded contraceptive services and support for young women who become pregnant or have children. Such service developments will require a shift in providers' assumptions and attitudes towards young women's sexual needs in particular. Additional training may be required to help providers identify ways in which they can engage better with young women's myriad needs. The burden of care experienced by caregivers and the difficulties they faced in meeting the needs of their young women also indicate that HIV services need to include ways of 'caring for the caregivers'. Policy makers and non-governmental organisations need to aware of young women's material needs and get involved in empowering the young women with stable income generating activities or sources of income such employment (not hand-outs).

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CONFERENCE PRESENTATIONS FROM THIS STUDY

Capturing the voice of young women in research on sensitive topics: Use of 'my story' book in Malawi. Royal College of Nursing International Nursing Research Conference 2014 in Glasgow, UK.

Telling their story: Experiences of young women with perinatally acquired HIV regarding access to sexual and reproductive health services in Malawi. 16th Annual Conference of the National HIV Nurses Association (NHIVNA) 2014 in Cardiff, UK.

TABLE OF CONTENTS

ABSTRACT i

ACKNOWLEDGEMENT iv

CONFERENCE PRESENTATIONS FROM THIS STUDY vi

LIST OF ACRONYMS xvi

CHAPTER ONE 1

INTRODUCTION 1

1.1 Background to the study 1

1.2 HIV and AIDS epidemiological facts: global and sub-Saharan overview 2

1.3 HIV and AIDS estimates in Malawi: incidence and prevalence 4

1.3.1. HIV prevalence among young people in Malawi 5

1.3.2 National HIV response 5

1.3.3 HIV management strategy for young people in Malawi 7

1.4 Significance of this research study 7

1.4.1 Why we need to focus on young women who perinatally-acquire HIV 9

1.5 Structure of the thesis 13

CHAPTER TWO 17

LITERATURE REVIEW 17

2.1 Introduction 17

2.2 Adolescence 18

2.2.1 Psychosexual development 18

2.2.1.1 Identity formation 19

2.2.1.2 Sexuality 21

2.3 Adolescence in the Malawian Context 24

2.3.1 Cultural influence on sexual norms 24

2.3.2 Changing sexual norms 27

2.3.2.1 Sex and life skills education 28

2.4 Chronic disease impacts on adolescence 30
2.4.1 Impact of perinatal HIV upon young people 31
2.4.1.1 Physical impact and mental health 31
2.4.1.1.1 Stigma and discrimination 34
2.4.1.1.2 Being informed of their HIV diagnosis 39
2.4.1.1.3 Disclosing status to others 41
2.4.1.2 Family disruption 43
2.4.1.2.1 Parental care 43
2.4.1.2.2 Foster care 45
2.4.2 Coping with perinatal HIV 48
2.5 Promoting adolescent sexual and reproductive health 50
2.5.1 Condom use in Malawi 50
2.5.2 Sexual and Reproductive Health (SRH) services 53
2.6 Conclusion 56
2.7 Research aim and objectives 58
2.7.1 Research aim 58
2.7.2 Research objectives 58
CHAPTER THREE 60
RESEARCH METHODOLOGY AND METHODS 60
3.1 Introduction 60
3.2 Study design 60
3.2.1 Qualitative case study approach 60
3.2.1.1 Qualitative approach 61
3.2.1.2 Use of case studies in qualitative research 62
3.3 Methodology: Understanding the approach 64
3.3.1 Positivism and interpretivism 64
3.3.1.1 Critical realist perspectives 66

3.3.1.2 Including the feminist perspective within a critical realist approach 68
3.3.2 Research methods 72
3.3.2.1 Qualitative interviews.....72
3.3.2.2 Visual techniques.....75
3.4 Access and recruitment process 78
3.4.1 Study settings.....78
3.4.2 Process of approvals 78
3.4.3 Approach of prospective participants 79
3.4.4 Recruitment 80
3.4.5 Sampling.....83
3.4.5.1 Inclusion and exclusion criteria 85
3.5 Process of data collection 87
3.5.1 Procedure for data collection 87
3.5.2 Initial familiarisation phase.....88
3.5.3 Individual in-depth interviews 89
3.5.3.1 Use of 'my story' book to facilitate the interview process 91
3.5.3.1.1. Reflections on use of my story book.....93
3.6 Data analysis.....94
3.6.1 Data transformation and management.....94
3.6.2 Retroductive analysis 95
3.6.3 Within-case analysis.....99
3.6.4 Cross-case analysis.....102
3.7 Writing the case study report 105
3.8 Ethical consideration.....106
3.8.1 Mitigating potential risks 106
3.8.1.1 Vulnerable group 106
3.8.1.2 Issues of power.....106

3.8.2 Informed consent....107
3.8.3 Confidentiality and anonymity....109
3.9 Strategies to enhance trustworthiness of the approach....110
3.9.1 Credibility....110
3.9.2 Transferability....112
3.9.3 Confirmability....112
3.10 Reflecting on the research process....113
3.11 Conclusion....116
CHAPTER FOUR....117
DEVELOPING CASES: CONTEXTS AND DESCRIPTIONS....117
4.1 Introduction....117
4.2 Settings....117
4.2.1 Maziko HIV Management Centre (MHMC)....117
4.2.2 Chiyembekezo Trust (CT)....118
4.3 Brief case profiles....119
4.4 Conclusion....145
CHAPTER FIVE....147
LOSS AND BELONGING: THE IMPACT OF HIV ON YOUNG WOMEN'S SENSE OF SELF....147
5.1 Introduction....147
5.2 Losses....151
5.2.1 Loss of parental affection and support....151
5.2.2 Loss of physical attractiveness....154
5.2.3 Loss of mental capability and motivation....157
5.3 Stigma and discrimination....159
5.3.1 Stigma and discrimination at familial level....159
5.3.2 Stigma and discrimination at community level....161
5.3.3 Self-stigma and self-discrimination (felt stigma)....162

5.3.4 Stigma and discrimination within the health services 164
5.4 Enduring sadness 166
5.5 Conclusion 170
CHAPTER SIX 171
MOVING FORWARD, SOMETIMES BACK: COPING WITH LIFE'S CHALLENGES 171
6.1 Introduction 171
6.2 Coping with losses and adversity 175
6.2.1 Experiencing supportive and trustworthy relationships 176
6.2.2 Valuing counselling and psychosocial support 184
6.2.3 Trusting in God: faith, prayer and meditation 187
6.3 Seeking love, acceptance and recognition 189
6.3.1 Benefitting from peer acceptance and support 190
6.3.2 Male relationship boosting self-image 193
6.4 Struggling to earn a living and to achieve autonomy 196
6.5 Dealing with stigma and discrimination 200
6.5.1 Keeping HIV status a secret 200
6.5.1.1 Challenges of status disclosure 200
6.5.2 Resisting stigma through academic and vocational achievements 204
6.6 Burden of caring for the caregivers 207
6.7 Conclusion 210
CHAPTER SEVEN 212
BECOMING A WOMAN: NAVIGATING A COMPLEX MORAL AND SOCIAL TERRAIN 212
7.1 Introduction 212
7.2 Having a sexual relationship is normal 216
7.2.1 Fulfilling sexual desires versus societal and familial norms/expectations 217
7.2.2 Being susceptible to peers pressure on sexual activities 221
7.3 Status disclosure to sexual partners 223

7.3.1 Status disclosure vis-à-vis struggles to earn a living 228
7.4 Female gender and decision making challenges 233
7.5 Young women's experiences and perceptions of SRH services 239
7.5.1 Meeting young women's SRH needs 239
7.5.1.1 Benefitting from teen club meetings 240
7.5.1.2 Fear of pregnancy is a big deal, but not HIV 245
7.5.1.3 'If only we had access to other methods of contraceptives' 247
7.5.2 Cultural and religious beliefs influencing SRH experiences and services 251
7.5.3 "We need to be heard" 258
7.6 Conclusion 263
CHAPTER EIGHT 264
DISCUSSION OF THE FINDINGS 264
8.1 Introduction 264
8.2 Psychosocial experiences and challenges in growing up with HIV 266
8.2.1 Building a positive identity 266
8.2.2 Living with cultural silence 269
8.2.3 Coping capabilities 271
8.2.4 How caregiving influenced young women's psychosocial experiences 276
8.2.4.1 Lack of social support networks 277
8.2.4.2 Decision to disclose the positive HIV status to young women 280
8.3 Sexual and reproductive health experiences and challenges 283
8.3.1 Sex, relationship and health challenges for young women 283
8.3.1.1 Socio-economic factors versus gender and power issues 284
8.3.1.2 Service provision and service providers 288
8.3.1.2.1 Model of service provision 289
8.3.1.2.2 Nature of relationships with service providers 290
8.3.1.2.3 Content/focus of service provision 292

8.3.1.2.4 The need to be heard 294
8.3.1.2.5 The need for integrated services 296
8.4 Conclusion 297
CHAPTER NINE 299
CONCLUSION 299
9.1 Introduction 299
9.2 Summary of key study contributions 301
9.2.1 Psychosocial experiences and challenges in growing up with HIV 301
9.2.2 Sexual and reproductive health experiences and challenges 303
9.3 Implications of the study 306
9.3.1 Programme development and service provision 306
9.3.1.1 Interventions for the young women 306
9.3.1.2 Interventions for the caregivers 309
9.3.1.3 Intervention for service providers 311
9.3.1.4 Implications on models of care 312
9.3.1.5 Interventions for the community 314
9.3.2 Future research 315
9.3.2.1 Experiences of young women accessing non-specialised HIV care 315
9.3.2.2 Mental health outcomes in HIV infected young people 316
9.3.2.3 Adolescent-service provider relationships 316
9.3.2.4 Knowledge-implementation gap on condom use. 316
9.3.2.5 Integration of HIV care, SRH and antenatal services. 317
9.4 Study strengths and weaknesses 317
9.4.1 Study weaknesses 317
9.4.2 Study strengths 319
9.5 Conclusion 320
REFERENCES 321

APPENDICES 344

Appendix A: Letters of Ethical Approval 344

Appendix B: Study Participant Recruitment Poster 350

Appendix C: Observer Information Sheet for Service Providers 351

Appendix D: Observer Opt Out Slip for Service Providers 353

Appendix E: Observer Information Sheet for Adolescents 354

Appendix F: Observer Opt Out Slip for Adolescents 356

Appendix G: Information Sheet for Adolescents 357

Appendix H: Information Sheet for Caregivers 361

Appendix I: Information Sheet for the Service Provider 364

Appendix J: Consent Form for Adolescents 367

Appendix K: Consent Form for Caregivers 368

Appendix L: Consent Form for Service Providers 369

Appendix M: Guide for Observations 370

Appendix N: "My Story" Book - Definitive Images and Definitive Sentence Completion Exercise 371

Appendix O: Interview Guide for the Caregivers 379

Appendix P: Interview Guide for the Service Providers 382

LIST OF TABLES

Table 1 Global HIV estimates 3
Table 2 Characteristics of the young women 84
Table 3 Characteristics of caregivers and service providers 86
Table 4 Timeline for data collection process 88
Table 5 Summary of initial, repeated and follow-up interviews 91
Table 6 Summary of cases and pseudonyms used 146
Table 7 Cases to illustrate multiple losses 148
Table 8 Cases to illustrate coping strategies 172
Table 9 Cases to illustrate moral and social terrain 214

LIST OF FIGURES

Figure 1 The individual case 64
Figure 2 Critical realist's view of deep explanations in case study approach 67
Figure 3 Access and recruitment process 82
Figure 4 The modified coding procedure 98
Figure 5 Within-case and cross-case analysis 104
Figure 6 Key in adolescent's family structure 120
Figure 7 Structural realities in young women's trajectory to womanhood 262

LIST OF ACRONYMS

3TC	Lamivudine
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral (treatment)
AZT	Zidovudine
COMREC	College of Medicine Research and Ethics Committee
CSR	Centre for Social Research
d4T	Stavudine
FHI	Family Health International
HAART	Highly Active Antiretroviral Therapy
HCT	HIV Testing and Counselling
HIV	Human Immunodeficiency Virus
KCN	Kamuzu College of Nursing
LPV/r	Lopinavir/ritonavir
LS	Life Skills
MDHS	Malawi Demographic Health Survey
MoEST	Ministry of Education, Science and Technology
MOH	Ministry of Health
NAC	National AIDS Commission
NFPCM	National Family Planning Council of Malawi
NGO	Non-governmental organisation
NSO	National Statistical Office
NVP	Nevirapine
PIDC	The Paediatric Infectious Disease Institute
PMTCT	Prevention of Mother to Child Transmission
RPC	Research and Publications Committee
SAT	Southern African AIDS Trust

SRH	Sexual Reproductive Health
STI	Sexually Transmitted Infections
TASO	The AIDS Support Organisation
TB	Tuberculosis
TDF	Tenofovir
UNAIDS	Joint United Nations Program on HIV and AIDS
UNICEF	United Nations Children's Fund
UNFPA	United Nations Population Fund
USAID	United States Agency for International Development
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

1.1 Background to the study

An escalating number of young people who acquire HIV perinatally continue to survive into adulthood in high HIV prevalence countries including Malawi, yet their distinctive needs remain unaddressed by most health systems (Ross and Cataldo, 2010 , WHO and UNICEF, 2008 , Family Health International, 2005). The remarkable success of antiretroviral therapy (ART) in paediatric HIV has changed the face of the epidemic from a fatal disease to a chronic health condition among young people as they grow up to adulthood presenting distinctive needs and challenges. The challenges include HIV associated stigma, issues relating to having sex, accepting and disclosing their HIV status to other family members, peers and sexual partners, and life-long medication adherence. Some studies show that socially, these young people lack psychosocial support, autonomy from parents and peer acceptance (Collins, 2001, Lewis, 2001). Their social participation becomes complicated by the desire to conceal their HIV status due to fear of stigma, discrimination and rejection (Mandalasi et al., 2010 , Menon et al., 2007).

Existing evidence on perinatally infected adolescents has mainly focused on their medical, sexual and reproductive health (SRH) in mixed gender samples (Busza et al., 2013 , Obare and Van der Kwaak, 2010) with relatively less attention given to understanding other aspects of their life experiences. No study has specifically looked at young women to understand their lives better, in terms of the structures and mechanisms underlying their psychosocial and sexual experiences and challenges as they grow up with HIV. HIV services are often medically focused and it is unclear whether they meet the varying needs of these young people as they grow up into adulthood. The literature further shows that in 2010 HIV prevalence rates among young people aged between 15 and 19 years in Malawi were significantly higher among young women (4.2%) than among their male counterparts (1.3%) (Government of Malawi, 2012). Therefore, the current study focuses on young women with perinatally acquired HIV (rather than both genders) to better understand their lives from their own

perspectives and those of their caregivers and service providers. All the key individuals involved in provision of their care within the family and health systems were incorporated in the study to focus comprehensively on young women's experiences, needs and challenges of living with HIV, with the ultimate goal of improving and/or developing services to meet their multiple holistic needs and to mitigate the challenges they encounter.

1.2 HIV and AIDS epidemiological facts: global and sub-Saharan overview

Although there is an increase in HIV incidence in some parts of the world, globally the incidence of new infections shows an overall decline. Since 2001, the incidence of new infections in adults has declined by more than 20%. In 2011, UNAIDS reported 700,000 fewer new HIV infections than in 2001 (UNAIDS, 2012). Between 2001 and 2011, new HIV infections in 25 low- and middle-income countries dropped by more than 50%. Since 2001, the sharpest declines have been reported in the Caribbean (by 42%) and sub-Saharan Africa (by 25%). New HIV infections in children (acquired perinatally) have also declined by 43% from 2003 to 2011. In addition, since 2005 there has been a decrease in AIDS related deaths from 1.8 million in 2009 to 1.7 million in 2011, partly due to antiretroviral treatment scale-up and stable decline in HIV incidence. The following table defines the global epidemiological facts on HIV and AIDS.

Table 1 Global HIV estimates

Global estimates for adults and children in 2011	
Number of people living with HIV	34.0 million [31.4–35.9 million]
Adults	30.7 million [28.2–32.3 million]
Children (<15 years)	3.3 million [3.1–3.8 million]
People newly infected with HIV in 2011	2.5 million [2.2–2.8 million]
Adults	2.2 million [1.9–2.4 million]
Children (<15 years)	330 000 [280 000–390 000]
AIDS deaths in 2011	1.7 million [1.5–1.9 million]
Adults	1.5 million [1.3–1.7 million]
Children (<15 years)	230 000 [200 000–270 000]

Source: Adopted from UNAIDS 2012

The majority of HIV infection among young people aged under 15 is through maternal to child transmission (UNAIDS, 2012). It is likely that the number of perinatally HIV-infected young people will continue to escalate and that they will survive into young adulthood in the coming years. This is attributed to increased access to life-prolonging ART (Family Health International, 2009). Globally, it is estimated that 40% of new HIV infections (for the ages 15 years and over) are in young people aged 15–24 and are associated with sexual transmission. In other parts of the world, young women are more affected than the young men due to their increased vulnerability (UNAIDS, 2012).

Approximately 69% (more than two-thirds) of HIV infected individuals world-wide live in the region of sub-Saharan Africa. The region remains the hardest hit, with one in every twenty adults infected with HIV, yet the region accounts for only 12% of the global population (UNAIDS, 2012). Despite the 25% reduction in new HIV infections, the sub-Saharan region still accounts for 72% of new HIV infections globally. The majority of children infected with HIV live in the sub-Saharan region, accounting for 94% of the total. Globally, approximately 390,000 children acquired HIV through mother to child transmission in 2010, and over 90% of these cases occurred in the sub-Saharan region

(WHO et al., 2011). Although, new HIV infections in children declined by 43% from 2003 to 2011, more than 2,400 young people are reported to be infected with HIV each day (UNAIDS, 2012). This could signify the gravity of risky sexual behaviours among young people in the region.

Importantly, the number of people (including children) receiving ART in the region for the years 2009 to 2011 has increased considerably by 59%. The success of ART has led to a number of issues for perinatally HIV infected children who instead of dying in early childhood are now growing up to adolescence and young adulthood. There has been a concentrated effort to address the sexual and reproductive needs of this emerging group in the epidemic in order to achieve some of the 2015 global AIDS targets, such as reducing the transmission of HIV through sex by 50% and eliminating vertical transmission by 2015 (UNAIDS, 2010).

1.3 HIV and AIDS estimates in Malawi: incidence and prevalence

It is estimated that out of an overall population of 15.4 million, almost one million people are living with HIV in Malawi (Government of Malawi, 2012). Since 1985, when the first case of AIDS was identified in Malawi, HIV prevalence has significantly escalated among people aged 15-49, with 70,000 new infections annually (Government of Malawi, 2012). Most of these new HIV infections are due to (unprotected) heterosexual intercourse with infected individuals, followed by mother to child HIV transmission. In 1999, the prevalence reached a peak of 16.4% among people aged 15-49, before it started to decline in 2003 (Ministry of Health, 2011). In a period of six years, the national HIV prevalence declined from 12% in 2004 to 10.6% in 2010 (Government of Malawi, 2012). The HIV prevalence among women was higher (12.9%) than among their male counterparts (8.1%) in 2010. In 2004, the age group 15-19 accounted for the lowest prevalence at 3.7% in women and 0.4% in men. By 2010 the prevalence was still lowest for those aged 15-19, with 4% for young women, and the highest prevalence was among women aged 35-39 (24%). The high prevalence rates in women are attributed to several socio-cultural factors prevalent in Malawi including gender inequalities and women's inferior social and economic status, resulting in poor bargaining power for condom use, constituting a major driver of the HIV epidemic (Government of Malawi, 2010).

1.3.1. HIV prevalence among young people in Malawi

In Malawi, approximately 10% of people living with HIV are children[1]. Mother to child HIV transmission accounts for almost a quarter of all new infections (National AIDS Commission, 2009). Among pregnant women the HIV prevalence increased significantly since the diagnosis of the first case of AIDS in 1985. In 1999 the prevalence reached a peak of 22.8% and started declining in 2001. Malawi experienced a decline of mother to child HIV transmission from 21.3% in 2004 to 12.8% in 2010. Children living with HIV were estimated at 100,000 in 2009, and over 90% acquired HIV perinatally (National AIDS Commission, 2009).

There has been a decline in HIV prevalence among young people[2] over the period 2004 to 2010. Overall, the HIV prevalence among young people (15-24) decreased from 6% in 2004 to 3.6% in 2010. Just as the prevalence was higher among young women (9.1%) than men (2.1%) in 2004, in 2010 young women accounted for 5.2% while men comprised 1.9% of HIV cases. For young people aged 15–19, the overall HIV prevalence in 2004 was 2.1% (with women accounting for 3.7% and men for 0.4%), which increased to 2.7% in 2010 (4.2% for females and 1.3% for males) (Government of Malawi, 2012). The young people's HIV prevalence comprises both those who acquire HIV during adolescence and through vertical transmission and have lived to adolescence or young adulthood. The precise HIV prevalence data on perinatally HIV infected young people is currently not available for Malawi.

1.3.2 National HIV response

Although Malawi identified the first case of AIDS in 1985, the first National HIV and AIDS Policy was developed in 2003. The policy served as a significant milestone in combating HIV and AIDS. The national response to the epidemic between 1989 and 1999 was guided by the medium-term plans. The development of the National HIV and AIDS Strategic Framework 2000-2004 (National AIDS Commission, 2000), the National HIV

[1] Child in this context defined as an individual under the age of 15 (National AIDS Commission 2009), but in Malawian context a child is an individual under the age of 18 (Government of Malawi, 2010)

[2] Young person in this context defined as an individual aged between 15-24 years (WHO, 2012), but in this thesis young women refers to adolescents aged between 15 – 19 years. Hence, at times adolescents and young women are used interchangeably.

and AIDS Action Framework 2005-2009 (Office of the President and Cabinet, 2005), and the extended National HIV and AIDS Action Framework 2010-2012 represent serious and systematic attempts to address the HIV issue in Malawi (Office of the President and Cabinet, 2009). For the national response to remain focused and to achieve remarkable outcomes, other key documents including policies were developed and the existing documents were reviewed. This included the National HIV Prevention Strategy (2009-2013), the National HIV and AIDS Strategic Plan (2011-2016) and the National HIV and AIDS Policy which was revised in 2011. Ancillary policies developed with HIV in mind included the National Policy on Orphans and Other Vulnerable Children, the Male Circumcision Policy, various policies on HIV and AIDS in the workplace and the new Monitoring and Evaluation Plan (2011-2016). The revised National HIV and AIDS Policy encompasses seven priority areas with prevention, treatment, care and support ranked as a priority area (Government of Malawi, 2011).

The national strategic plans and policies guided both the biomedical and non-biomedical interventions implemented in response to the epidemic. The key biomedical interventions that are being implemented in Malawi include HIV Testing and Counselling (HTC); the provision of ART to HIV infected people; the implementation of prevention of mother to child transmission (PMTCT) services among pregnant women and voluntary surgical circumcision. The national expansion of HTC and ART has produced successful results, with an increase in the number of individuals accessing ART from around 4,000 in 2004 to 365,191 by the end of March 2011 (Ministry of Health, 2011). Country-wide ART sites increased from just nine in 2003 to 491 in 2009, 50% of which are community-based (i.e. more accessible) health services (Fasawe, 2013). The policy of universal and free access to ART has reduced annual HIV related deaths from 88,000 in 2005 to 53,000 in 2010 (Ministry of Health, 2011), and has resulted in many children surviving to adolescence and young adulthood. For instance, by December, 2009, Baylor Centre of Excellence had commenced 2,103 children (including young people) on HIV treatment, representing approximately 10 percent of all children ever initiated on ART in Malawi (Baylor College of Medicine, 2009). The remarkable success in the treatment of paediatric HIV has changed the face of the epidemic from a progressive fatal disease to a chronic health condition among young people as they grow up to young adulthood.

1.3.3 HIV management strategy for young people in Malawi

The World Health Organisation (WHO) suggests that to effectively address the needs of adolescents, appropriate approaches are required because their needs are different from those of small children and adults (WHO, 2008). However in Malawi, HIV management services are traditionally separated into paediatric and adult care, which overlooks the unique needs of adolescents. In addition, empirical data (WHO and UNICEF, 2008) reveals that apart from HIV teen clubs there are no specific sexual and reproductive health (SRH) services targeted towards individual SRH needs within HIV management strategy to promote optimal SRH outcomes. This is despite the Malawi National SRH and Rights Policy clearly defining young people' SRH as a key component of the national health strategy (Ministry of Health, 2009). Overall, despite great developments over the past decade, HIV management strategies and policies in Malawi remain inadequate, particularly because they do not explicitly address the unique needs of young people specifically those infected perinatally and who have grown up to adolescence and young adulthood.

1.4 Significance of this research study

Although effective antiretroviral treatment has changed HIV infection to be seen as essentially 'just another chronic condition', in practice the HIV-related challenges for young people still set it apart from other chronic conditions (Ely, 2006). The highly stigmatized status of HIV within some societies (particularly in culturally conservative societies and the developing world) predisposes young people to difficulties in accepting and disclosing their HIV status to family members, peers and sexual partners, hence increasing the likelihood that they engage in unsafe sexual practices. There is evidence both in developed and developing countries that during late adolescence, young people are more likely to engage in 'risky' behaviours (Bakeera-Kitaka et al., 2008, NSO and ORC Macro, 2004). Such behaviours include unsafe sexual activities, resisting authority figures and succumbing to peer, familial and social pressures. As they undergo the transition to adulthood, they begin to explore their sexuality, become or may consider becoming sexually active, engage in risky sexual behaviours (Birungi et al., 2007 , Family Health International, 2005) and advance their sexual and fertility

aspirations (Birungi et al., 2008 , Ezeanolue et al., 2006, Fielden et al., 2006 , Levine et al., 2006).

Many young women in sub-Saharan Africa initiate sex by the age of 15 or earlier, mostly with older or non-cohabiting sexual partners, and these encounters are overwhelmingly unprotected (UNFPA, 2007, Munthali et al., 2006). The consequences of unprotected sex are usually more evident and severe in young women than their partners (Nanyonjo, 2009, Bakeera-Kitaka et al., 2008). For instance, the Paediatric Infectious Disease Institute (PIDC) in Uganda has observed that even with effective ART treatment an escalating number of young women living with HIV (15-24 years) experienced unwanted outcomes of sexual activity, including unwanted pregnancies and infections with other sexually transmitted diseases (Bakeera-Kitaka et al., 2008). Empirical data in Malawi has revealed similar findings, especially unwanted pregnancies among perinatally HIV infected young women (National AIDS Commission, 2009). This shows that the young women have particular issues and vulnerabilities that require age and developmentally-appropriate services and support which are sensitive to their SRH needs and challenges. SRH information and services should enable young women to make informed decisions regarding their sexual practices, thus promoting optimal SRH outcomes (Birungi et al., 2008).

However, the HIV management strategy of young people in Malawi is not fully adjusted to address their additional needs as they grow up into adult life and an understanding of their transition to adulthood has not been established. This is consistent with the literature which shows that most services still do not address the specific needs of perinatally HIV infected young people (Ross and Cataldo, 2010 , WHO and UNICEF 2008), and adolescent care is not an established discipline in most countries (Eley et al., 2006). These challenges seem particularly acute in late adolescence and differ according to gender and residential area (urban and rural), making their transition to adulthood particularly difficult (SAT, 2011, Bakeera-Kitaka et al., 2008).

Most young women are more vulnerable to sexual abuse, early sex initiation and marriages, and unsafe sexual practices; usually with older partners due to gender power imbalances, or for material support and survival (Birungi et al. 2009, Munthali et al. 2006). This often results in unplanned pregnancies and early childbearing. These

challenges are particularly complex for the perinatally HIV infected young women because they need to negotiate the repercussions within a framework of having a stigmatised and chronic disease. In addition, the challenges likely make them potential sources of subsequent transmission to their sexual partners and to their babies. The sense of vulnerability, coupled with youthfulness, weakened health systems, increased poverty, male dominance and lack of support, predisposes young women to poorer health seeking behaviours, and SRH outcomes than their male counterparts (WHO, 2008 , Family Health International, 2005). The literature suggests that young women affected by HIV may be particularly vulnerable to social problems or sexual abuse (WHO, 2008). Yet little attention is given to this group to address their distinctive needs, policy direction and focused SRH services (National Youth Council of Malawi and UNFPA, 2010 , UNFPA, 2007), despite their increased vulnerability to social problems or sexual abuse resulting in poor SRH outcomes (WHO, 2008 , Family Health International, 2005). Hence, this thesis focuses on young women rather than both genders.

1.4.1 Why we need to focus on young women who perinatally-acquire HIV

The rationale for including only female adolescents rather than both genders in the current study was based on the fact that young women are most affected by the epidemic in terms of numbers. For instance, for young people aged 15–19, the overall HIV prevalence in 2004 in Malawi was 2.1%, (with women accounting for 3.7% and men for 0.4%) and increased to 2.7% in 2010 (4.2% for females and 1.3% for males) (Government of Malawi, 2012). In addition, in the AIDS epidemic, much of the early attention given to women globally centred on reproductive issues, portraying women predominantly as HIV carriers to their sexual partners and unborn children (Strode et al., 2012 , de Souza, 2010 , Gielen et al., 2001). Several studies have focused on general issues impacting on both male and female adolescents perinatally infected with HIV (Busza et al., 2013 , Obare and Van der Kwaak, 2010 , Birungi et al., 2009 , Birungi et al., 2008 , Fielden et al., 2006). However, those studies did not explore in-depth the experiences, issues, contexts and challenges that influence young women's agency or abilities to lead a purposeful life, hence reducing their risk of becoming potential sources of secondary transmission. As such, understanding their lives better through the current study will assist in improving and/or developing services that will holistically meet their multiple needs. In addition, there has been no research in Malawi that has

specifically focused on HIV positive young women's subjective accounts of growing up with the virus.

Feminists point to the need to fill this gap through empirical investigations of women as human beings with agency (Archer, 2000). Research is required to allow women to have their concerns heard and to examine their perceptions of living with HIV vis-à-vis other repressive or traumatic events surrounding their lives. Wylie (2004:339) affirms that "those that are marginalised in the society have a clearer understanding of their problems that need to be investigated and have had experiences that provide a more appropriate foundation for knowledge than those of dominant groups." The marginalised or the oppressed may be able to appreciate aspects of society that can be ignored by those who are relatively advantaged (socially, politically, economically), by what they undergo and how they comprehend their experiences. Thus, a female-centred approach aims to uncover the life contexts and experiences of young women, grounded by their status and language (Speedy, 1991).

Feminist scholars affirm that suppression of the opinions of females is distressing, particularly given the societal beliefs that often value men more than women, making women's 'voices' (views and needs) undervalued, causing their opinions to be disregarded (Harter, 1997). The study therefore sought to address these conventional expectations by empowering the young women, enabling them to express their experiences and share opinions about their rights and values in the context of social constraints, while reflecting on the realities of their experiences as influenced by culture, gender and power relations. This created an interest in the researcher to understand the particular needs of these perinatally HIV infected young women, especially now that they are surviving into young adulthood.

This study focuses on young women with perinatally-acquired HIV who are in the later stages of adolescence, aged 15-19 years. The reasons for focusing on this particular age group and on perinatally infected young women (rather than young women with sexually acquired HIV) are discussed below. First, I will consider the rationale for focusing on perinatally (rather than sexually) infected young women. This will be followed by a discussion of the rationale for the age range of the sample.

The normal developmental progression of adolescence to adulthood involves behavioural experimentation, risk taking, and confronting a host of difficult choices with regard to romantic relationships, sexual behaviour and identity formation (Arnett, 2004). The complexity of these choices is further complicated for adolescents with perinatally-acquired HIV, as they need to negotiate these developmental stages within the framework of having lived with a chronic and stigmatizing disease from the early stage of their lives. In contrast to those with sexually acquired HIV, perinatally infected young women have physical, psychosocial and sexual challenges early in life as they transition from childhood through adolescence into adulthood. Thus, they have specific needs for supportive psychosocial care, HIV status disclosure and developmentally appropriate sexual and reproductive health (SRH) services (Hazra, Siberry and Mofenson, 2010). Furthermore, perinatally HIV-infected young women who survive into adolescence usually are in regular contact with the health care system due to progressive ailments from an early age (WHO & UNICEF, 2008, Dhingra, 2007) and are in a good position to determine whether the services meet their varying needs or not. In contrast, young women infected during adolescence or after the onset of puberty generally manifest symptoms of HIV infection and become ill more slowly possibly because are relatively in early stage of infection. This group of adolescents is, therefore, much harder to recognize and follow. Many of them have no symptoms, and, as such, they may not seek health services regularly and or may have just been tested HIV positive. In addition, their parents may still be alive and supportive or more likely their serostatus not yet known.

Perinatally acquired HIV is not contracted through sexual activity by a young woman with the condition. While it could be assumed that blame and stigma of such young women should be less because their activity and behaviour has played no part in contracting it but this is far from the case. In fact, they may be more stigmatised during the adolescent years because of the visibility of the disease. For example, a number of qualitative studies have revealed that the association of HIV infection with sexual behaviour (considered unacceptable by many people in Malawian culture) exacerbates HIV related stigma (Tavory and Swidler, 2009, Chimwaza and Watkins 2004). Rydstrom et al., (2012) and Majumdar and Mazaleni, (2010) assert that individuals, particularly young women infected with HIV, point to the association between HIV and sexual

intimacy as the possible root of stigma and they may be blamed for unacceptable behaviour in the society or regarded as prostitutes. Therefore, the researcher was interested in talking to perinatally infected young women, who were likely experiencing this to determine how this manifested in their lives. In addition, the researcher aimed at exploring in-depth their distinctive needs, psychosocial and sexual experiences and challenges through adolescence to young adulthood.

With regard to the selecting the age range of the sample, the study focused on older young women aged 15 – 19 (rather than young women aged 10-14). This was based on the following assumptions:

- perinatally HIV infected young people are to encounter conditions like stunted growth, delay in onset of pubertal changes (menarche) and delay in progression through the normal developmental stages compared with their HIV negative peers (Lowenthal and Phelps, 2010 , Buchacz et al., 2003). As such, it was decided that those aged 15-19 were more likely to have been through these changes, and would be better able to discuss the broader experiences and challenges of living with HIV (including sexual behaviours) and would be able to reflect back on their experiences. The younger age group would have had a more limited range of experiences to discuss and would have been less able to articulate them to a researcher.
- young women aged 15-19 are more likely to be having sex and getting into longer term relationships. For example, a quantitative study conducted in Uganda revealed that 52 percent of 732 young people aged 15-19 were in a sexual relationship, 33 percent reported having had sexual intercourse and of these, 73 percent had consensual first sex, and 41 percent of the sexually active female adolescents had ever been pregnant. Forty one percent felt that there is no reason why someone who is living with HIV should not have sexual intercourse (Birungi et al. 2008). Therefore this study sought to hear older adolescents' voices as they try to settle down/establish themselves into long term relationships/have children with their condition which is far less likely to be the case in the younger group of 10-14 years.
- older adolescents would be more likely to know about their diagnosis by that age, as several studies have shown that caregivers often keep HIV status a

secret to younger people or are unsure of when and how to disclose HIV status to their children - hence tend to delay status disclosure (Biadgilign et al., 2011 , Rujumba et al., 2010 , Vaz et al., 2010 , Rwemisisi et al., 2008).

While the complexity and nature of perinatal HIV may pose several challenges to young women, it may equally be challenging to their caregivers and service providers. The current study also focused on exploring caregivers' and service providers' views in order to understand young women's experiences. Young women's experiences and distinctive needs are under-researched and there is no published study from either developed or developing countries specifically about this group, making it an important area to investigate. Therefore the current research used case studies to examine the challenging and complex experiences of this emerging group of young women (from different perspectives)and the risk they pose to others (potential partners and babies) as they grow up with HIV, to inform policy and health practice and to promote optimal SRH outcomes.

1.5 Structure of the thesis

This thesis has nine chapters. This introductory chapter gives a brief account of the research background and the significance of the study, including the researcher's interest in investigating young women growing up with perinatal HIV. Chapter Two reviews current literature relating to HIV infection in adolescence. The first section of the chapter presents psychosexual development in adolescence followed by adolescence in Malawian context and how chronic disease, specifically perinatal HIV, impacts on adolescence. The chapter also presents issues around the promotion of SRH among young people, particularly those perinatally infected with HIV. This chapter helps to situate the current study within the context of the wider literature and hence uncovers the key gaps in literature which informed the research aim and objectives for the current study.

Chapter Three presents the study design, the philosophical positions that informed the research design and the methodological approach. The chapter describes how the qualitative case study approach (comprising fourteen cases that incorporated a young woman, her caregiver and service provider per case) was selected in order to elucidate the research focus (experiences and needs of living with HIV for young women). The

chapter then describes the access and recruitment process and the process of data collection. Different stages of the research are presented (including the familiarisation phase, individual in-depth interviews and use of 'my story book'), then methods of data analysis are explained to demonstrate how data was constructed and interpreted. Finally, the ethical considerations, strategies that enhanced trustworthiness of the approach and reflections of the research process are discussed.

Chapter Four is divided into two sections, the first of which provides an overview of the two study settings and the second of which introduces the cases presented in the study. The section provides individual case profiles with their contexts and descriptions in order to be able to view each 'case' according to its particular merits and remain true to case study approach. The profiles are provided alongside the family structures depicting the number and type of people involved in the young woman's care and those affected by her positive HIV status. The chapter prepares the ground for a fuller presentation of the main qualitative findings in the three subsequent chapters (Chapters Five, Six and Seven), which present the findings from in-depth interviews with the young women, caregivers and service providers. Since the young women coped differently with their positive HIV status, some are used as exemplar cases across the chapters.

Chapter Five focuses on how HIV positive status impacted on the young women's development of self and sense of belonging. The chapter provides an in-depth understanding of the impacts of HIV in real life contexts at individual, familial, community levels and within the health services. Many young women had endured multiple losses and lived with an enduring sense of sadness that was rarely openly addressed, leading to negative mental health outcomes (including suicidal ideas and attempts).

Chapter Six focuses on how the young women coped with their complex situations and boosted their self-image. Social relationships and social support networks (including strong family structures and peer relationships) acted as a very important buffer – even when things went wrong or when they suffered a setback - as many did. Emotional, material and social support were essential in helping young women to build a sense of identity, but women's access to such resources were highly variable. Caregivers' resources were often over-burdened and several lacked the capabilities required to

provide young women with an adequately supportive environment. As such, some young women engaged in sexual relationships as a strategy for financial gains as they struggled to earn a living and autonomy and/or to boost their social status and identity. Young women's strategies to seek love, acceptance or material advancement often led them to take sexual risks and left them with little control over their reproductive health.

Chapter Seven explores young women's representation of their sexual well-being and how their sexual needs are met. The chapter highlights how young women navigated through a complex moral and social terrain within a particular set of normative expectations and service delivery options. It is evident that perinatally HIV infected young women engage in sexual activities, and they consider this to be normal. However, their sexual being was complicated by their HIV positive status. The socio-economic, religious and cultural factors (including normative expectations around sexuality and appropriate behaviours for a young woman and gender power relations) were some of the structural realities that shaped young women's sexual well-being. These factors further influenced young women's agency and decision making capabilities regarding health and sexual issues. Accessing SRH care was hindered by normative cultural practices that made it hard for providers, caregivers or young women to talk about relationships, sexual behaviour or contraception. This exposed a number of young women to early child bearing and poor SRH outcomes. The underlying theme across these three chapters was gender, power issues as it pulled together many cross cutting issues related to the other themes.

Chapter Eight discusses the key study findings, situating them in the broader literature base and national SRH policy and rights. The chapter has two main sections addressing the key findings in relation to the two overarching objectives that addressed young women's psychosocial and SRH experiences and challenges as they grow up with HIV. The first section focuses on identity issues, cultural silence, coping capabilities and caregiving challenges as key issues that influenced young women's psychosocial experiences. The section also discusses how caregivers' lack of support networks and decisions regarding informing young women about their HIV status influence young women's psychosocial experiences. The second section focuses on key issues in shaping young women's sexual experiences, including socio-economic status, service provision

and service providers. Gender, power and empowerment issues continue to be reflected in this chapter as it was an overarching theme in participants' accounts.

The final chapter concludes this thesis by synthesising and summarizing the key study findings. The potential implications of research findings for programme development and service provision are presented, along with recommendations for future research. The implications include interventions for young women, caregivers, the community, the service providers and models of care. The study identified some key areas that need further research, including the experiences of young women accessing non-specialised HIV care, mental health outcomes in HIV infected young people, adolescent-provider relationships, knowledge-implementation gap on condom use and integration of HIV care, SRH and antenatal services. Finally, the study strengths and weaknesses are discussed.

CHAPTER TWO

LITERATURE REVIEW

'HIV/AIDS is increasingly affecting the health and welfare of the perinatally HIV infected young people who are described as a new or emerging population in the epidemic and is undermining the hard-won gains in their survival in most countries which are hard hit with HIV including Malawi' (WHO & UNICEF 2008).

2.1 Introduction

This chapter begins by describing psychosexual development during adolescence and how chronic illness particularly HIV infection impacts upon adolescence physically, psychologically, socially and sexually. The key issues from the literature concerning the impact of perinatal HIV upon the young people and caregiving practices in the families are highlighted. Cultural and religious norms influencing sexuality in adolescence in Malawi and its implications for sexual and reproductive outcomes are also discussed. The literature suggests that young women affected by HIV may be particularly vulnerable to socio-economic problems, sexual abuse and/or normative expectations such as subordination of women in sexual relationships leading to poor SRH outcomes (Munthali et al., 2006 , Chu et al., 2005). Hence, this literature review focuses more on young women rather than both genders. An overview of chronic illness coping mechanisms (with a particular focus on HIV infection) and the promotion of sexual and reproductive health among young people in Malawi is also described. Finally, the chapter concludes by uncovering key gaps in the literature from which the research aims and objectives have emerged.

HIV is a disorder with a prolonged progression that can be fatal or associated with a comparatively normal life despite the compromised physical functioning (Scandlyn, 2000). This results in HIV infected young people encountering developmental and/or psychosocial challenges that their uninfected counterparts may or may not experience. This means that young people perinatally infected with HIV encounter a set of physical, sexual, psychological, and social issues that need to be explicitly addressed. This chapter discusses how young people are physically, psychologically and socially, affected by the

HIV and AIDS pandemic, including important aspects of their sexuality (particularly for the young women). The chapter further discusses the impact of HIV on their caregivers and how health care professionals are currently supporting young women in dealing with their life challenges, specifically sexual issues, as they are growing up to adulthood.

2.2 Adolescence

Adolescence[3], is the period involving the second decade of life and bridging the complex transition from childhood to adulthood (UNFPA, 2007). It is a key phase of human development as young people find themselves in an in-between world, creating conflict between the meaning of 'self' and strive for social identity (Aka Dago-Akribi and Cacou Adjoua, 2004). It is during adolescence that young people often may struggle with behavioural experimentation, risk-taking, assertion for independence and personal identity (Battles and Weiner, 2002). A theory of psychosexual development argues that a young person undergoes a series of stages to develop personality/behaviour, in which psychosexual energy or libido becomes the driving force (Jürgensen et al., 2013). From this perspective, both biological and psychosocial factors influence a young person's psychosexual development.

2.2.1 Psychosexual development

According to Jürgensen et al. (2013), adolescence is a stage characterised by the young person's transition to a more independent life. It is the stage when self-worth, social and sexual identities are established. From a biological perspective, it is during adolescence that young people develop primary and secondary sex characteristics. This stage is termed as 'puberty' thus signifying sexual maturity, as young people become fertile, experience a mature physical appearance and increased sexual libido (Jürgensen et al. 2013). However, young women undergo puberty earlier than their male counterparts (of the same chronological age) and there is a rapid change in their sexual experiences and their body satisfaction. At a time when new sexual experiences are being discovered and new inclinations and behaviours are being experienced, any negative feelings about one's body especially for the young women might be harmful (Schooler et al., 2008). Physical changes, perceived as negative may have psychological

[3] An adolescent in this thesis is defined according to WHO as, 'any person between the ages of 10 and 19 (WHO, 2003)

consequences as the young women adjust to their changing bodies (with the onset of puberty), amend their self-image, establish identities and cope with their emerging sexuality.

2.2.1.1 Identity formation

Close (2010) adds that adolescence is a developmental stage broadly characterised by erratic behaviours, emotional turmoil and mental insecurities as young people seek a new identity and acceptance in the adult world. While early adolescence is characterised by substantial emphasis on physical changes prompted by the occurrence of pubertal events; middle adolescence is intensely marked by the development of identity as manifested by peer activities and in some instances, rebellious behaviours. Adolescents may experience conflict with adults, in particular, and may fluctuate between co-operation and rebellion (Li et al., 2010). Rew (2005) further adds that it is during this stage that young people develop crucial abilities such as decision making skills, greater short and long term memory, critical thinking and identification with peers. Young people tend to compare themselves with others particularly their peers to establish their identity and gain a sense of who they are (Close, 2010). The sense of identity depends on the actions within a social context and is based on the acceptance or rejection of their decisions by the others in the group. The advent of puberty and the need to manage its changes are major features of adolescence and sexual identity experiences. Insecurity and struggles often accompany the onset of sexual feelings. Culturally normative expectations also influence the psychosocial aspects of adolescent development particularly in determining the sexual conduct and the meaning young people attach to sex (Birungi et al., 2008). For instance, culturally endorsed differences in gender roles and expectations of sexual relationships contribute to difficulties for women in sexual negotiation as reflected in Section 2.2.1.2. Therefore, adolescence is a key phase of personal and social development, when the young persons are strengthening their sense of self, constructing their sexual and gender identities and 'facing various pressures regarding the exercise of their sexuality not only from society at large (parents, religion, media) but also from peers' (Weber et al., 1994:43).

It is during adolescence that relationships between parents and their children are transformed, as the young people desire to make decisions autonomously and function independently. Lewis, (2001) notes that adolescence is a time when young people struggle to assert their own identity and independence of adults. Parent-child conflicts often significantly increase, coupled with a less unified familial bonds as the young person strives for autonomy and separation from the family and attachment to a peer group. Young people may query family rules and roles, creating conflicts over issues such as dressing, appearance and sexual activities (Collins, 2001). This alienation in the relations between the young people and parents may be a normal, evolutionary process of puberty, for one can argue it has a practical significance for young people. For instance, it promotes their autonomy and stimulates them to experiment or investigate issues affecting their lives on their own to develop sense of self-worth. Arnett (2004) concludes that during late adolescence, individuals become involved in identity formation, behavioural experimentation, risk taking, and confronting challenges of romantic relationships and sexual behaviour. However, their social group becomes progressively more influential as they seek affection and recognition outside of the family unit (Crockett and Petersen, 1993). For example, a study affiliated with a large national survey with young people aged 15 to 24 years in rural Malawi revealed that young women expressed being pressurised by peers to engage in sexual relationships, or they themselves emulated their close friends who themselves engaged in relationships with males (Poulin, 2007). In contrast, young men were driven by physical attractiveness in young women such as beauty or good body structure which may disadvantage those who the society perceive as less physically attractive. Schlegel (1995) affirms that adolescence is marked by a susceptibility to health risks as young women engage in unsafe sexual activities to conform to the expectations of their social groups (Munthali et al., 2004). This may lead to poor reproductive health outcomes like unwanted and unplanned pregnancies and STIs. The young women's vulnerability is fully discussed in Section 2.2.1.2. Nevertheless, vulnerability to health risks during adolescence seems more conspicuous in young women than their male counterparts. Despite this, there is a paucity of literature on identity formation and vulnerability to risks in HIV infected young women. This is the gap that the current study will explore in more depth. However, in order to understand the gender differences, it is important to understand how sexuality emerges.

2.2.1.2 Sexuality

Sexuality is important for a young person as a source of pleasure, personal fulfilment and well-being (Birungi et al., 2009 , Birungi et al., 2008 , Undie et al., 2007). However, the construction of masculine and feminine sexuality reflects the inequalities of the social and economic spheres of life (Heise and Elias, 1994). As a result, it is frequently reported that young men initiate and control sexual interactions and choices more than young women, thereby potentially exposing their female counterparts to sexual abuse. Although the pressures on young women to enact cultural norms of femininity are present throughout childhood, these may intensify during adolescence (Wichstrøm, 1999). This signifies that young women (as they learn to navigate the demands of femininity to become adult sexual beings) often experience immense pressures to behave like culturally sanctioned females. This occurs in their personal relationships with others and through their relationship with their bodies and behaviours. They are expected to supress their own feelings, opinions, desires or avoiding conflict and to conform to prevailing images of beauty and attractiveness (Tolman et al., 2006). Review of empirical studies revealed that young people living with chronic illness (particularly for young women), with visible diseases often feel different from their peers and change in their physical appearance has detrimental effects on their relationships with others and mental well-being (Pinquart, 2012). This is because women base their self-worth on physical appearance. This engenders two arguments that are relevant to HIV infected women's experiences as they negotiate adolescent development. The first argument could be that young women struggle to uphold significant relationships and instead have fleeting encounters with peers which may increase their susceptibility to expressing emotional distress or experiencing diminished self-worth. Secondly, young women's susceptibility to negative images of their body may be associated with decreased mental well-being in relation to pressures to achieve socially acceptable standards of attractiveness that values physical appearance (Brown and Gilligan, 1992 , Fredrickson and Roberts, 1997). This means that young women's acceptance by their

peer groups is influenced by their physical appearance (Aka Dago-Akribi and Cacou Adjoua, 2004), which often challenges their sexual agency[4].

The culturally prescribed and endorsed gender roles shape young women's opinions of the supremacy of their sexual relationships over their personal and social identities (Blanc, 2001). In many African countries, women have relatively less power over sexual decision making[5], and subordinate to the authority, demands, desires and choices of their male partners (UNAIDS, 2006 , Logan et al., 2002). While condom use is the best protection against heterosexual transmission of HIV, studies have identified that globally many young women find it difficult to negotiate for safe sex (Turmen, 2003 , Wood et al., 1998). The sexual script of the feminine traits often means having little power to question men's dominance in sexual issues but rather to satisfy men's needs, become pregnant and bear children (Lewis, 1998), while a Swedish study identified that masculine dominance make young men adopt risky or coercive sexual behaviours (Christianson et al., 2007). The women's lower social status restricts their opportunities to control their circumstances making them subordinate to their male partners and unable to negotiate for use of male or female condom (UNAIDS, 2011). Cultural and social norms (as discussed in Section 2.3.1) that accept male partners' high-risk behaviours, when coupled with women's low socio-economic status (hence dependence on their male partners), further highlights the critical role of control and empowerment in HIV prevention strategies (Kathewera-Banda et al., 2005). The tension between cultural and religious norms (abstinence and/or being subservient to male partners) denotes the difficulties the normative expectations place on sexual well-being of young people especially young women even in Malawi. This situation may be particularly complicated for young women growing up with HIV, however, there is a paucity of literature on how young women can be empowered to overcome the prevailing gender power inequalities, cultural and social norms.

[4] Sexual agency in this study refers to young women's ability to reflect and act on sexual issues affecting their lives including SRH related, make active, informed, effective, responsible sexual decisions and transform the choices into optimal SRH outcomes (Schooler, 2006).

[5] Sexual decision making refers to "decisions, preferences and resolutions made by an individual regarding the conditions, such as timing of the intercourse or contraceptive use, under which sexual relations occur" (Vagra, 1997:52)

Qualitative studies in Africa show that certain patterns of sexual relationships are common. Young women, who are dependent on men for financial support have less power over decision making and mostly engage in relationships with older partners (Obare and Van der Kwaak, 2010 , Woodsong and Alleman, 2008 , Masanjala, 2007). The wider age difference significantly links with gender power inequalities reducing young women's power in decision making, thus increasing their vulnerability. For instance, results of a mixed-method study (a process evaluation) in Malawi and Zimbabwe conducted on microbicide acceptability (specifically norms for sexual pleasure and use of microbicide gels to prevent HIV from the perspectives of female participants) revealed that it is largely men who decide when sex will occur. The study enrolled 1,084 female trial participants, their male partners, healthcare workers and stakeholders in the community. The individual interviews revealed that in actual practice male sexual pleasure is culturally valued, women seldom verbally indicate a desire for sex and they find it difficult to refuse sex (Woodsong and Alleman, 2008). In this study, both men and women reported that the consequences of a woman refusing sex may include physical and verbal abuse, lack of financial support from their male partner and/or their partner taking another partner which appears to be the most feared concern by women. Although acceptability of the microbicide gels was found to be high, it was revealed that sex is connected to power and gender issues that make women vulnerable to sexually transmitted infections including HIV. In another qualitative study by de Bruyn (2000) in Namibia, it was shown that young women often have less decision-making power concerning sexual issues when compared with older women, particularly because they tend to have older male partners who can dominate them both age- and gender-wise. In addition, their parents strictly control their access to condoms or contraceptives. This further complicates the power relationships that exist during adolescence. However, there has been no work in Malawi to specifically identify the effective interventions or programmes to evenly distribute the powers in decision making regarding sexual issues and empower young people to create a balance between rights and responsibilities.

Nevertheless, advocates of empowerment in young people suggest that positive adolescent sexuality would be characterised by the ability to express agency[6]. Evidenced in studies across the continents (e.g. Africa, UK and USA), this involves the young person's capability to understand and deal with her own sexual needs despite the aforementioned structural challenges (like unequal gender power relations) as a central component of sexual health (Ansell, 2014 , Spencer, 2013 , Tolman et al., 2003). Similarly, Russell (2005) promotes a notion of young women's sexual competence that is dependent upon their capability to negotiate sexual relationships that satisfy the emotional and physical health for both partners. In this regard, it can be noted that sexual agency - the capability to make active, informed and responsible sexual decisions, is an ideal to be pursued as part of promoting adolescent sexual health. However, there is no research that has demonstrated an understanding of interpersonal dynamics, mechanisms and structural realities influencing the sexual agency as a cornerstone of adolescent sexual health in Malawian context, particularly in young women growing with HIV. The current study will contribute to this limited knowledge.

2.3 Adolescence in the Malawian Context

As in other countries, adolescence in Malawi is viewed as the transition period from childhood to adulthood *(defined to span ages 10 to 19),* and thus the time social identities associated with being male or female are reinforced (Munthali et al., 2004). According to social construction of gender, societies 'naturally' make collective efforts to ensure that adolescents develop into responsible and productive adults. However, during adolescence, the whole process of socialization is rooted in gendered norms and cultural values that tend to reinforce male dominance and subordination of women in sexual relationships (Ministry of Youth, 2006 , Munthali et al., 2006).

2.3.1 Cultural influence on sexual norms

In Malawi, cultural norms embedded in religion and traditional social values expect young women to abstain from sex until they are married (Munthali et al., 2006). Females are taught to follow gendered norms and be subservient to male partners in

[6] Agency defined as the power to act in situations and to monitor others' actions, where the interaction depends on others (Christianson et al. 2007:56). In this study agency refers to young people's ability to reflect and act on sexual issues and their difficult situations.

sexual and reproductive health matters, and control their own sexual behaviours (Centre for Social Research (CSR), 1997). The male dominance and control in sexual issues, and submission of young women to their sexual partners is culturally reinforced from very young ages. However, gender roles play an important part in moulding and influencing sexual behaviour of young people in Malawi (Centre for Social Research (CSR), 1997, USAID Malawi, 1997). Gender norms and peer pressure for male young people to have multiple partners as proof of masculinity (Chu et al., 2005) often dictate that young women are passive about sex (Ministry of Youth, 2006 , Munthali et al., 2006). This social attitude pervasively violates females' sexual rights and makes them prone to other risks like sexual abuse. Lack of autonomy influences their decisions concerning child bearing, use of contraceptives and outcomes of disclosure of HIV status, making the lives of HIV infected young women yet more complicated.

Similarly, young women are treated as sexual beings, whose prime objective is to please men, as shown in another study in Malawi that in 92% of sexual relationships, it was the male partners who initiated sex and the females had limited power to deny sex or negotiate protected sex (Save the Children (UK), 2000). As a result, sexual communication among young people is difficult because young women are brought up to look at male partners as superior about sexual issues and if a young woman initiates sex she risks being labelled a 'loose' person (Strategic Planning Unit and National AIDS Control Program, 1999, Namate and Kornfield, 1997). This cultural attitude can significantly limit young women's agency to exercise their sexual and reproductive health rights. There is also evidence that young women are vulnerable to or coerced into unhealthy sexual relationships especially with older men due to gender power imbalances, male dominance, social inequalities, increased poverty and lack of support (UNICEF, 2008). Issues associated with gender power imbalances and sexual abuse is a concern in several countries in Africa including Malawi. For instance in Malawi, data from a large nationally representative sample survey (including women aged 15-49 years) showed that, overall, 15% of women aged 15-49 years, who experienced sex, reported having coerced sex during their first sexual experience (Government of Malawi, 2010). Similarly in Tanzania,

> ‘The community was concerned about the high prevalence of HIV infection and early pregnancy in girls aged 15-19. When men and women mapped the places where girls might be exposed to risky sex, they realised that the girls were at risk everywhere: in their own homes, at the well, on the road to school and in school itself. They realised that male attitudes and behaviour around gender and age was putting all girls at risk and making it difficult for them to avoid unwanted sex’ (International HIV/AIDs Alliance, 2010:13).

A number of qualitative studies in Malawi have revealed that gender power differences are also reflected in how differently young men and women are socialised about their productive roles in Malawi (Masanjala, 2007 , Centre for Social Research (CSR), 1997). While parents and the society at large exercise strict controls and closely monitor young women’s sexual behaviours, young men are given greater social freedom to explore relationships (Munthali et al., 2004, Centre for Social Research (CSR), 1997, Namate and Kornfield, 1997). Although most of this work was conducted more than a decade ago, the findings still hold true. For instance, young men (particularly in rural settings) are encouraged to become independent, managing their own lives through piece works or with parental support, yet young women are encouraged to do household chores which are non-paying (Masanjala, 2007 , Centre for Social Research (CSR), 1997). This signifies that young women cannot be economically independent and have to depend on their male partners to earn a living; hence the majority of young women succumb to their male partners’ desires in order to secure financial and material support. Furthermore, in Malawi premarital sex and child bearing outside wedlock is strongly disapproved of and some pregnant young women are disowned by their parents (Munthali et al., 2004 , Pathfinder International, 1998). Yet, reports show early sex debut (as early as 12 years) and high incidences of teenage pregnancies in Malawi (Government of Malawi, 2010 , Ministry of Health, 2009, Munthali et al., 2006). Studies have shown that the majority of sexually active young women initiate sexual relationships with older men in order to exchange sex for material or financial benefit especially because they are very poor (UNAIDS, 1998). Other studies have discovered that some are pressurised into early marriages or transactional sex for financial gains, when family members are unable to meet their basic needs (Poulin, 2007). However, there is no work that has specifically focused on structural realities, mechanisms, and

processes surrounding these familial and sexual pressures and challenges among the young women growing up with HIV. The current study will explore this gap from the perspectives of the HIV infected young women and their primary caregivers to identify appropriate and realistic strategies of supporting them within the family unit and in society.

2.3.2 Changing sexual norms

It is evident in Malawian and most societies that sex is an aspect of individual choice and gratification as well as reproduction (Munthali et al., 2006, Hickey, 1999); which means that to some young people it is a matter of pleasure despite the prevailing cultural and social norms. Though communities are aware that unprotected premarital sex is common and increases adolescents' vulnerability to poor sexual and reproductive health outcomes, young people are still disempowered to control their sexual lives because of objections of traditionalists to promote sexual education in family units and accessibility of SRH services by the adolescents (Ministry of Education Science and Technology, 2002). In Malawi, it is considered a taboo for parents to discuss sexual matters with adolescents (Munthali et al., 2004, McAuliffe and Ntata, 1994). Hence other adults such as grandparents, aunts and traditional advisors/counsellors appear to have taken over the responsibility to socialise young people with regards to sexual and reproductive issues. However, some authors suggest that the traditional structures have been destabilized by the influence of western religions and education systems and that socialization roles have been shifted to modern structures such as schools, the media and religious institutions which often do not provide traditional sex education due to differences in values and goals (Munthali et al., 2004 , Byamugisha, 2000).

Most religious groups in Malawi strongly oppose the use of contraceptives amongst young unmarried people (including condoms) on the basis that this promotes early and irresponsible sexual practices (Munthali et al., 2004). This depicts the ambivalences in Malawian culture which exposes young people to unsafe sexual practices. It is evident from this background that in Malawi there are some cultural norms and traditions that compromise or reduce a young woman's power or agency to refuse sexual advances from male partners or negotiate for safer sex or force them adopt certain socially accepted behaviours which becomes more complicated for young women perinatally

infected with HIV. The limited research available does not demonstrate how cultural and religious beliefs might affect provision of SRH education and services in Malawi as the service providers are adults, who will be influenced by dominant cultural and religious norms. This is a gap that the current study will examine in more depth to understand the intrapersonal dynamics, structures, mechanisms and processes surrounding young women's lived experiences within the families and service health systems. By combining the perspectives of young women perinatally infected with HIV, their caregivers and service providers involved in their care, the study will provide a comprehensive picture of how normative expectations shape their lived experiences and be able to recommend the most important and realistic strategies about how their changing needs can best be met by health services.

2.3.2.1 Sex and life skills education

Young people in Malawi engage in sexual activity as early as 12 years (Ministry of Health, 2009), despite premarital sex being strongly disapproved (Munthali et al., 2004 , Pathfinder International, 1998). Early sexual debut and marriages are the main causes for teenage pregnancies which accounts for high dropout rates of young women at all grades[7] in Malawian schools (Kalanda, 2010 , UNICEF, 2006). However, there are no significant differences in school dropout rates between females and males, but 17% dropped out at standard eight in 2010, an increase of 10% from 2004 (Government of Malawi, 2010). Rural young people are more likely to drop out of school at all grades than those in the urban settings due to lack of appropriate knowledge about sexual issues and lack of economic resources to meet their basic and academic needs, which influences them to adopt risky sexual behaviours as a survival strategy (Munthali et al., 2006). To address these challenges, the Malawi government introduced 'life skills' and sexual and reproductive health education (LS/SRH) at all grades in all schools in 2002 (Kalanda, 2010). The World Health Organisation (2001:3) refers to life skills as the

[7] In Malawi, official primary school age is six to thirteen years; students enter primary school at the age of six years. Students attend primary school for eight years, and at the end they write examinations to attain Primary School Leaving Certificate (PSLCE). Students who attain the certificate proceed to secondary education level. Students attend secondary school for four years. Secondary education is divided into two sets of two-year courses. By the end of the first two years, students write Junior Certificate of Education (JCE) examination. At the end of the second two years, students write Malawi School Certificate of Education (MSCE) examinations or General School Certificate of Education (GCSE). In Malawi tertiary, education comprises of public and private universities and technical colleges (Government of Malawi, 2010:11)

"abilities for adaptive and positive behaviour that enable individuals to deal effectively with the demands and challenges of everyday life." In particular, life skills are described as a group of psychosocial and interpersonal competences that assist young people (both in and out of school) with informed decision making, problem solving, critical and creative thinking, effective communications, building of healthy relationships, identifying with peers and coping with and managing their lives in a healthy, purposeful and productive manner (Kalanda, 2010). A curriculum was introduced in primary school (standards five to eight) and secondary school (forms one to four). All students in these classes are taught LS/SRH as a subject alongside all other subjects (Kishindo et al., 2006).

In addition, several life skills programmes were introduced nationwide for both in and out of school young people to assist them to become competent and contributing adult members of the society (Ministry of Youth Development and Sports, 2009). These include Anti-AIDS clubs and the "Why Wait" educational programmes (Munthali et al. 2004). Anti-AIDS clubs use interactive and participatory methods to present HIV/AIDS and sexual health information through dramas, debates, role plays, quizzes and sports to help young people identify and change their risky behaviours. The "Why Wait" programme was introduced nationwide in primary and secondary schools in 2004 and is based on Christian principles. It is an abstinence-based programme that emphasises moral ethics in formation of 'healthy' relationships and helps young people to make informed decisions regarding their future (Munthali et al., 2004:35). Some studies have evaluated the effectiveness of the life skills programmes in engendering behavioural change for HIV prevention, sex and sexuality among young people in Malawi and have demonstrated a significant reduction in pregnancy cases (Kalanda, 2010 , UNICEF, 2006 , Munthali et al., 2004). Behavioural changes identified included improvement in decision making and problem solving among students. However, the programmes are more focused on prevention of HIV, not the challenges and needs of HIV positive infected young people in the academic environment. Although the behavioural change is associated with change in attitudes and establishing healthy relationships among young people, there is no work in Malawi on how the life skills education has mitigated the negative psychosocial impacts of HIV on HIV positive learners and how it has facilitated students' acceptance and support of peers to boost their self-worth and coping

mechanisms in an academic environment. Nevertheless, every chronic illness including HIV can have impact upon young people.

2.4 Chronic disease impacts on adolescence

Chronic illness at any stage of life can disturb an individual's effective functioning psychologically, socially, economically and spiritually. According to Charmaz (1990: vii), chronic illness fundamentally disrupts a person's normal life. Consequently, young people diagnosed with chronic illnesses like diabetes, arthritis, cystic fibrosis, asthma, heart disease, epilepsy and HIV infection may be regarded as vulnerable to mental health problems, as a result of psychological trauma and general interruptions caused by the lifelong illness (Aujoulat and Marcolongo, 2008). Research shows that a chronic illness can threaten the young person's self-worth, self-determination, sense of security and bodily control, leading to feelings of powerlessness due to lack of medical knowledge and skill to deal with the illness (Menon et al., 2007). Young people's autonomy from caregivers or parents, peer acceptance and participation in their social world becomes complicated by their desire to keep their condition a secret and fears of social exclusion (Menon et al., 2007). This is often associated with very high levels of psychological distress (Aujoulat and Marcolongo, 2008). However, this thesis does not allow for the full discussion of impacts of all chronic illnesses on adolescence hence Section 2.4.1 will focus primarily on the impact of perinatal HIV on young people growing up to adulthood.

There is paucity of literature on the effect of chronic HIV infection on psychosexual development and fertility (Aka Dago-Akribi and Cacou Adjoua, 2004). However, it is likely to affect a young person's body image, self-confidence and self-worth and may lead to difficulties in their psychosexual development particularly for the young women, who base their self-worth on physical appearance (Aujoulat and Marcolongo, 2008). Healthcare professionals play a key role in promoting young people's optimal sexual health and need to be comfortable and confident in discussing a wide range of issues regarding sexual development and sexuality (Aka Dago-Akribi and Cacou Adjoua, 2004). The paucity of literature on the sexual and reproductive needs of young women with chronic illness such as HIV infection continues to be an impediment to developing appropriate interventions. Therefore the current study will contribute to this limited

knowledge in identifying appropriate interventions to meet young women's sexual and reproductive needs as they grow up with HIV.

2.4.1 Impact of perinatal HIV upon young people

The existing evidence about perinatally infected adolescents has mainly focused on their medical, sexual and reproductive health (SRH) (Busza et al., 2013 , Obare and Van der Kwaak, 2010, Birungi et al., 2009 , Birungi et al., 2008 , Fielden et al., 2006) with relatively less attention given to understanding other aspects of their life experiences. However, other studies show that young people growing up with HIV are particularly vulnerable during adolescence, as they experience disproportionate rates of social isolation, normative expectations, financial constraints, sexual and physical abuse and mental health concerns (Ferguson, 2010, Thorne et al., 2002). Qualitative studies in Africa show that HIV related stigma, the effects of strict treatment regimens, complexity of choices about relationships, the burden of secrecy, fear of rejection and changes in physical appearance (lipodystrophy, visible skin marks and muscle wasting) make their developmental process to adulthood particularly difficult (Ferguson, 2010, Li et al., 2010). Achieving autonomy in decision making for young people is more frightening because it can have serious health outcomes (Battles and Weiner, 2002) as illustrated in the next section.

2.4.1.1 Physical impact and mental health

Physically, perinatally HIV infected young people, will, if not treated, get infections related to their suppressed long term immunity exposing them to a particular risk for problems related to physical and mental development and functioning. They may encounter delay in onset of pubertal changes and progression through the normal developmental stages than their peers (Lowenthal and Phelps, 2010 , Buchacz et al., 2003), and conditions like stunted growth, mental retardation, recurrent conditions – opportunistic infections, dermatological problems and anatomical changes particularly lipodystrophy[8] also affecting their physical outlooks (Carr et al., 2003). The perinatally HIV infected young women may be smaller than their HIV negative counterparts

[8] Lipodystrophy (peripheral lipoatrophy, central fat accumulation, and lipomatosis) is a common and disfiguring problem in adult patients with HIV-1 infection on antiretroviral treatment (Carr et al. 2003).

(Buchacz et al., 2003), which can result in a difference between their mental age and chronological/physical age and appearance (Knight et al., 2000). Since this state of chronic ill health tends to be associated with delayed menarche in young women, the situation can be very damaging to the self-image of the growing young woman. Onset of menarche constitutes major indicators of the sexual maturity and the beginning of the biological capacity of young women to bear children, when compared to the other pubertal changes that young women experience (Bauermeister et al., 2009). This implies that delays in puberty and growth particularly onset of menarche in young women not only affect the physical but also the social and sexual development of a young woman.

Another essential part of young women's well-being concerns their mental well-being. Although mental health of young people is given little attention (Li et al., 2010), the WHO acknowledges that mental well-being of a young person comprises more than an absence of mental disorders. Instead it embraces, "a state of well-being in which the individual realises her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her society" (WHO, 2003:17). In this context, it is evident that positive mental health increases a young person's ability to direct his or her life. However, the mental health of young women living with HIV may be affected by the ordinary pressures of adolescence, along with other several anatomical changes (see below) which are specifically related to their HIV positive status and use of antiretroviral therapy (Tien et al., 2006).

For many young people, the impact of developmental delay, cognitive deficit and changes in physical appearance may affect friendships, complicating decisions around HIV disclosure and impact on their sexuality (Bauermeister et al., 2009). Though antiretroviral therapy progressively relieves physical symptoms and challenges of HIV, the ARVs often have adverse effects which affect young people's mental well-being and physical outlook hence social identity and status (Carr et al., 2003). The anatomical changes caused by ARVs may include lipoatrophy of the extremities or the face, prominence of superficial blood vessels or fat accumulation in the abdomen, neck, back (dorso-cervical fat pad, the so-called 'buffalo hump') breasts (enlargement) and other sites in a localised form (Tien et al., 2006 , Carr et al., 2003 , Dieterich, 2003 , James et al., 2002). Facial lipoatrophy associated with progressive loss of facial fat stimulates the

appearance of skin furrows, increasing regions of depression and visualisation of the skull leading to wrinkling of the face which precociously ages the young woman – a visible marker attributed to an HIV carrier (Collins et al., 2000). This clearly signifies that changes in physical appearance associated with HIV infection and treatment may upset young women psychologically and reduces their sense of belonging and self-worth (Carr et al., 2003). However, there is no evidence on how the anatomical changes impact on young women's sexuality. This is a factor that will be explored in the current study in order to suggest effective interventions to promote optimal sexual and reproductive outcome.

Most significantly, the anatomical and cognitive changes caused by HIV infection have been linked with feelings of depression (Tadesse et al., 2012) and negative self-image (Aka Dago-Akribi and Cacou Adjoua, 2004). Qualitative studies in Sweden and Uganda have shown that among young people living with HIV, depression is associated with poor school performance, drug non-adherence, and significantly exposes young women to the likelihood of engaging in unsafe sexual practices (Rydstrom et al., 2012 , Birungi et al., 2009), thus increasing their vulnerability. With these stressors, it can be postulated that young women growing up with HIV are vulnerable to poor mental health. However, few studies have tried to examine this hypothesis by quantifying the incidence of mental health disorders in young people growing up with HIV. One study in sub-Saharan Africa quantified mental health disorders in young people with HIV positive status aged between 11 and 15 years in Zambia. The youth version of the Strengths and Difficulties Questionnaire was administered. The findings were compared with the results from the British sample of HIV negative adolescents of the same age and gender (Menon et al., 2007). The findings suggested that HIV positive young people face significant mental health challenges. When they compared the results to British norms, the HIV positive young people in Zambia were four times more likely to show emotional symptoms, two times more likely to have mental disorders, and seven times more likely to experience problems with their peers (Menon et al., 2007). However, using the control group from Britain rather than their Zambian counterparts makes it difficult to validate the degree to which the differences in mental health disorders were attributed to their positive HIV status or other environmental or social factors. While statistical findings are worthwhile for highlighting trend of emotional disorders in HIV positive

young people, little attention has been drawn to the significance of contextual factors in influencing the mental disorders among the HIV infected young people and the outcomes. It is hoped that this study will contribute to this limited knowledge.

Lyon and D'Angelo writing on teenagers, HIV and AIDS in developed and developing countries reported that majority of the perinatally HIV infected young people expressed feelings of sadness, depression, loneliness and discrimination from peers and within families (Lyon and D'Angelo, 2006). Loss of parent/s or having chronically sick parent/s often expose them to increased vulnerability, risky sexual behaviours and they face a greater degree of neglect and abandonment (Family Health International, 2005 , Miah, 2004 , Lewis, 2001). A 2008 worldwide study on psychosocial support interventions for HIV infected young people, explored service providers' accounts and found that many reported significant psychosocial problems among the young people (Greifinger et al., 2008). The main psychosocial problems they encountered included stigma and discrimination and difficulties disclosing their status to others including sexual partners and anxiety about having children as discussed below.

2.4.1.1.1 Stigma and discrimination

HIV is a stigmatised illness that is transmitted sexually or acquired perinatally or through blood transfusion, which exposes the young people affected to a complex mix of issues. Goffman defines stigma as an "attribute that is deeply discrediting, reducing an individual from a whole and usual person to a tainted, discounted one or bodily signs designed to expose something unusual and bad about moral status of the signifier" (Goffman, 1963:63). This definition denotes that individuals who are stigmatized have or are believed to have an attribute (like being HIV positive) that marks them as different or deviant and leads them to be devalued in the eyes of others. The ascribed inferior, disgraceful or unacceptable qualities of a young woman with a stigmatised condition like HIV infection likely diminish their self-worth hence affecting their social identity.

Goffman's original insight, slightly over 50 years ago, concerning the impact of stigma in the construction of a 'spoiled identity' has been extended and modified in relation to a wide range of conditions. These include epilepsy (Jacoby, 1994, Scambler and Hopkins 1986), leprosy (Opala and Boillot, 1996, Gussow and Tracy, 1968), mental illness (Phelan et al. 2000), infertility (Riessman, 2000, Miall, 1987) and HIV and AIDS (Green and Sobo, 2000, Weiss et al. 1992). Weiss et al. (1992) argued that stigma has two perspectives, the insider's view as the 'emic' perspective and the outsider's view as the 'etic' perspective. The emic perspective refers to how the stigmatised (in their own terms) think about their world, themselves, their health and their health problems (culturally defined experiences). The etic perspective refers to how others (those who stigmatise) view or think about the stigmatised (professionally defined outcomes/consequences of any disease studied). For instance, health professionals may quickly see the consequences (the etic view) of perceived stigma (the emic view), such as the decision not to be tested or not to visit an HIV clinic. Weiss and colleagues' work has influenced greatly the work on HIV/AIDS stigma. In their work, cultural norms and perceptions were viewed as affecting both the person living with the condition and others who were observing it. While most of this early work on stigma has focused on how others view a stigmatised person and on the contexts in which stigma occurs, this thesis considers two key developments in relation to people's responses to stigma (see Sections 5.3. and 6.5). These are Scambler and Hopkin's framework of 'enacted' and 'felt' stigma which was first recognised among people with epilepsy. Felt stigma is an expansion of emic stigma and enacted stigma relates to etic stigma (Holzemer et al. 2007). These allow for consideration of anticipated and actual responses to stigmatised identity (Scambler and Hopkins, 1986) (Section 5:3) and the possibilities of rejecting a stigmatised identity as developed by Riessman (2000) (Section 6.5).

Scambler and Hopkins (1986) defined enacted stigma as instances of discrimination on the basis of perceived unacceptability or inferiority. They defined felt stigma as the fear or experience or anticipation of enacted stigma[9]. In their work with participants with epilepsy, they argued that the fear or anticipation of a negative reaction was a prime obstacle that their participants had to deal with. As such, they suggested that it is potentially more disruptive as stigmatised individuals anticipate discriminatory

[9] Enacted stigma refers to actual experience of discrimination (Scambler and Hopkins 1986).

responses hence are likely to adopt policies of concealment and secrecy. This particularly occurs when they fear societal attitudes and potential discrimination arising from their positive HIV status or come to accept or internalise society's negative views on them which damages their self-image. For example, young women with perinatally acquired HIV may anticipate social rejection due to their physical visible marks or progressive ailments. This may elicit painful inner struggle related to having HIV and AIDS at an early age and they may be vulnerable to developing feelings of self-blame, self-depreciation and self-hatred (Greeff et al., 2008 , Brown et al., 2003 , Lee et al., 2002). Thus, felt stigma often results in behaviours like denial of the positive HIV status, reluctance to disclose the status and unwillingness to seek and accept quality healthcare and social support (Greeff et al., 2008 , Miller and Rubin, 2007 , Simbayi et al., 2007).

Goffman (1963) emphasised that stigma occurs when the construction of social categories is connected to socially stereotyped beliefs that label individuals as 'self/normal and other/abnormal' (Abadia-Barrero and Castro 2009:1221) or as discreditable and discredited persons. Goffman makes a useful distinction between the discreditable and the discredited individuals. The discreditable individuals are those whose stigma is hidden or not immediately perceivable or is not known about (Green and Sobo, 2000), such may be young women who acquire HIV through sexual contact (whose infection may be relatively in early stage and not visible physically or through particular behaviours). In contrast, discredited individuals are those whose stigma is visible or known about (Green and Sobo, 2000), which is common for young women who acquire HIV perinatally (who may have progressive ailments, visible marks, lack adult support networks and look different from their peers). The visibility of physical marks like scarring from HIV infection can be extremely disruptive for the young women as the marks expose them to social stigma (Collins et al., 2000). Although the HIV related changes are visible in the extremities, lipodystrophy is most conspicuous on the face signifying a visible marker of HIV infection. This mark of shame or disgrace can trigger disturbances in social and family relationships leading to social isolation of the young person or the affected family thus negatively affecting their psychological well-being (Collins et al., 2000). In this context, the discreditable young woman can decide who to tell, how, and when or to lie or not to lie (information control). The discredited

young woman has to manage tension which may be generated during social contacts with the 'normals', hence may adopt strategies to try to conceal their positive HIV status to resist being stigmatised (Goffman, 1963). Therefore, this study will explore in-depth on how the young women with perinatally acquired HIV manage social interactions and/or deal with stigma and discrimination.

Although the concept of stigma is often used interchangeably with that of discrimination (Population Council, 2002), Manser and Thomson (1999) argued that their meanings are different. Nyblade et al. (2003) defined discrimination as an unfavourable attitude towards a group or its individual members, or negative acts (that result from stigma) that serve to undervalue the life opportunities of those being stigmatised. Other researchers argued that discrimination emphasises on observable behaviour, which means the unjustifiably different treatment is given to different people or groups (Brown et al., 2003, Bond et al., 2002, Manser and Thomson, 1999). Sociological analyses of discrimination, however, "concentrate on patterns of dominance and oppression, viewed as expressions of a struggle for power and privilege" (Marshall, 1998:552). This sociological emphasis on the structural dimensions of discrimination signifies the need for researchers to conceptualize stigma and discrimination as social processes that can only be understood in relation to broader notions of power and domination (Parker and Aggleton, 2003). Therefore to properly understand issues of stigma and discrimination in relation to HIV and AIDS, it requires apt understanding about how some individuals come to be socially excluded, and about the forces that create and reinforce exclusion upon different groups and in different settings. As such, this study focuses on in-depth understanding of the underlying structures and mechanisms of young women's psychosocial and sexual experiences and challenges holistically (within the family and the health systems) in real life contexts.

A secondary analysis of baseline data collected from HIV positive women and men in developing countries show that HIV stigma can be expressed in different forms such as rejection, verbal abuse, imposed restrictions on the person and eviction (Lee et al., 2002, Bond et al., 2002). Young people may be victims of gossiping and name-calling thereby disrupting their self-image (Campbell et al., 2010). Different countries use different stigmatizing languages. For instance, in some parts of Tanzania, an HIV

infected person is named ‘nyambizi,’ or submarine. In this cultural context, the name implies that the HIV infected person is furtive, threatening and lethal (Nyblade et al., 2003 , ICW, 2002). HIV/AIDS itself has generated a striking number of euphemistic and metaphorical expressions that indirectly describe the terms (Greeff et al., 2008 , Campbell et al., 2007 , Uys, 2003). Less than exact (or ‘coded’ or cryptic) words are used by people including health care professionals to identify the HIV infected individuals to avoid being considered negligent to culturally sensitive issues, but not necessarily rejecting the diagnosis of HIV and AIDS (Duffy, 2005). For example, health workers in Malawi calling HIV, ‘ELISA disease’, immunosuppression or in a vernacular language, people calling HIV infection ‘kaliwondewonde’ meaning ‘slim disease’ (Muula and Mfutso-Bengo, 2005). It is reported that medical professionals often avoid documenting AIDS as a diagnosis on the death certificates to avoid embarrassment (McGeary, 2001). This clearly shows that young people are growing up with a disease that they cannot discuss with people they interact with on daily basis.

Furthermore, several qualitative studies have revealed that the association of HIV infection with particular sexual behaviour that is considered unacceptable by many people in the society exacerbate HIV related stigma (Ulasi et al., 2009 , Wood and Lambert, 2008 , Campbell et al., 2007 , Otolok-Tanga et al., 2007). Rydstrom et al., (2012) and Campbell et al. (2007) stressed that the presumed link between HIV and inappropriate behaviour (sexual) still remains a concern for both older and young people infected with HIV because of the associated shame and embarrassment. Many qualitative studies assert that individuals, particularly young women infected with HIV, point to the association between HIV and sexual intimacy as the possible root of stigma (Rydstrom et al., 2012 , Majumdar and Mazaleni, 2010 , Bond et al., 2002). They may be blamed for unacceptable behaviour in the society or regarded as prostitutes. For example, a qualitative study conducted in Zambia exploring mother to child transmission revealed that the shame of having a positive HIV status was culturally linked to prostitution and promiscuity and as such, was creating social rejection (Bond et al., 2002). Similarly, if the parental HIV positive status is known publicly, this further increases young people’s sense of alienation hence reinforcing silence and secrecy around their status.

Although HIV psychologically affects young people in different aspects of their lives, there is little evidence about how they cope with stigma and discrimination as most studies on this are conducted with adults (Campbell et al., 2007). The problems of keeping HIV positive status a secret have been reported by several researchers as very distressing for young people, promoting social isolation and bitterness as it expedites negative self-image (Battles and Weiner, 2002 , Lewis, 2001 , Brown and Lourie, 2000). A qualitative study with HIV positive young people aged 12 to 24 years in Canada revealed social and structural limitations as barriers to their full participation in society (Flicker et al., 2005). Stigma was cited as a major barrier to societal participation including school activities. The majority shared painful stories of harassment, discrimination and cruelty upon disclosure of their HIV status to their loved ones or individuals in authority. Fear of being discovered HIV positive was also high in this sample and kept the majority of young people from finishing school, participating in school activities, finding employment or building close social networks (Flicker et al., 2005). A recent study in Sweden has revealed that in schools and among peers, young people pretended to be normal and as healthy as the others in order to protect themselves from the risk of being stigmatised (Rydstrom et al., 2012). From this perspective, stigma and discrimination significantly influences the status disclosure to others including sexual partners, when and how young people get informed of their diagnosis (Parker and Aggleton, 2003).

2.4.1.1.2 Being informed of their HIV diagnosis

While the question of status disclosure becomes increasingly important, the secrecy surrounding HIV positive status and the death of a parent due to AIDS may lead young people to believe that having the disease is shameful. Recent qualitative studies with young people in Uganda and Sweden show that HIV infected young people are preoccupied with secrecy around HIV (Rydstrom et al., 2012). A qualitative study in Sweden with HIV infected young people aged between 15 to 21 years (some with African and others Swedish background) show that in families, HIV discussion was often a taboo and was rare even with close family members (Rydstrom et al., 2012). Qualitative content analysis was employed to analyse the data and the results revealed that it was often difficult for families to be open about their positive status including the cause of death for fear of social stigma. This may deprive the young people of the usual

buffering social supports they may desperately need. A few other studies investigating communication about HIV/AIDS between children and parents in Africa have noted that African cultural taboo about the discussion of sexuality and death between generations inhibits communication about HIV within families as it is sexually transmitted (Wood et al., 2006 , Liddell et al., 2005). However, a weakness in these studies was that they approached disclosure of HIV positive status among young people as a single event rather than as a process, involving long-term consequences especially upon the young women, who are already marginalised in the society and dependent on men for financial support.

Essentially, many previous studies on status disclosure highlighted that being older was found to be a determinant factor for disclosure of HIV positive status to young people (Biadgilign et al., 2011, Oberdorfer et al., 2006 , Blasini et al., 2004 , Flanagan-Klygis et al., 2002 , Thorne et al., 2002 , Armistead et al., 2001 , Ledlie, 1999). The researchers reported that most caregivers have a preference to delay status disclosure to young people up to older ages - over the age of 12, as parents believed that at early age, the child lacked cognitive maturity necessary to comprehend the disease and its implications. For example, Cohen et al. (1997) reported that 95% of young people older than 10 years were aware of their HIV status in Massachusetts. The view that adolescence is the ideal stage for status disclosure is consistent with the idea that during this phase of life, young people are capable to comprehend and cope with information about their positive status and address issues they encounter as they become sexually active, specifically secondary transmission and child bearing. In contrast, a qualitative study of teenagers who lost a parent/s in Zimbabwe suggests that parental disclosure within households, including to older teenagers was rare (Wood et al., 2006). These teenagers were not told directly, despite the young people's own knowledge and awareness about AIDS related symptoms, and strong suspicions about their or parents' illness which caused them pain and frustration. For young people who are aware of their positive HIV status, adults encourage them to remain silent about their status to avoid social rejection, the potential loss of relationships, and as a desire to protect family members from the emotional effects of living with HIV (Ulasi et al., 2009 , Wood and Lambert, 2008). However, silence as a moral coping strategy was

emotionally difficult, mostly for older teenagers, who had taken over the caring responsibility of their younger siblings (Wood et al., 2006).

There is a growing body of evidence about the benefits of HIV diagnosis disclosure to young people. These include enabling them to understand their condition, increased opportunity for social support, and participation in health care decision making (Rujumba et al., 2010 , WHO, 2003 , Mellins et al., 2002 , Schonfeld, 1997). However, status disclosure to young people perinatally infected with HIV in resource constrained settings continues to be deferred until older teenage years and beyond (Vaz et al., 2010, Wiener et al., 2007 , Mellins et al., 2002). The delay in HIV status disclosure to young people in some cases results in accidental disclosure, which can lead to confusion, feelings of resentment, and diminished opportunities to comprehend the information in a supportive milieu (Vaz et al., 2010). Qualitative studies in Africa show that the low rates of status disclosure to young people are attributed to lack of communication skills about how to disclose the HIV status among the caregivers (Domek, 2010 , Rwemisisi et al., 2008). Additionally, there is lack of guidelines to enable caregivers and service providers to make decisions about when and how to disclose the positive HIV status to young people. By contrast, considerable attention is given to guidelines on HIV status disclosure among adults (Kallem et al., 2010 , Rujumba et al., 2010 , Wiener et al., 2007 , Moodley et al., 2006 , Myer et al., 2006). While studies have captured caregivers' concerns about status disclosure to young people, there is limited knowledge on adolescents' perceptions and concerns about their status disclosure. This is a gap that the current study will explore in more depth particularly within sexual relationships, in order to identify strategies of minimising negative consequences encountered by young women following status disclosure to sexual partners.

2.4.1.1.3 Disclosing status to others

HIV status disclosure to a sexual partner is similarly a significant preventive strategy of secondary HIV transmission because it can promote the adoption of protective measures in a sexual relationship (Birungi et al., 2009). However, where young women internalise HIV related stigma, there is a possibility of feeling shameful about their HIV status, and are sensitive to the real and foreseen social rejection by peers (including sexual partners). This adversely affects their status disclosure and sexual practices.

There is evidence that risky sexual practices result from failure to disclose HIV status to sexual partners (Kalichman, 2000). In addition, young women's attempts to initiate relationships and negotiate condom use become more complicated with their knowledge of living with a stigmatised disease, particularly when they fear exposure of their HIV positive status (Bakeera-Kitaka et al., 2008). As such, they may desire to look 'normal' in the eyes of their peers and to fit in their social groups by conforming to social activities which include sexual relationships. For instance, in a study in Uganda just over 38% of the young people that were in sexual relationships had disclosed their HIV positive status to a sexual partner for fear of social rejection (Birungi et al., 2008). However, the young person's choice not to disclose their status to a sexual partner can lead to increased risk of engaging in unsafe sexual practices thus becoming potential sources of secondary transmission and risk to themselves.

A number of qualitative studies exploring young people's experiences of living with HIV in sub-Saharan Africa has shown that perinatally HIV infected young people feel uncomfortable discussing sexuality, struggle with disclosure to partners, struggle with discussing or using condoms, and bear children early (Busza et al., 2013 , Hodgson et al., 2012 , Li et al., 2010 , Obare and Van der Kwaak, 2010 , Birungi et al., 2009). The majority of participants were concerned with their lack of skills regarding how to communicate their positive HIV status to sexual partners and the anticipated responses including rejection by partners. Where their caregivers were themselves HIV positive, their own feelings as parents limited their capability to assist the young women navigate the onset of their sexual lives (Aka Dago-Akribi and Cacou Adjoua, 2004). This in turn significantly affected young people's health seeking behaviours particularly SRH services.

In many African societies, discussion about sexual issues between adults and young people is considered a taboo (Wittenberg et al., 2007 , Munthali et al., 2004). As such, the cultural norms might affect the provision of sexual and reproductive service as the service providers are adults who are also influenced by the prevailing cultural and religious norms of the society. This is supported by a study conducted in Uganda which revealed that where sexuality is discussed during counselling with perinatally HIV infected young people, it tends to be around deterrence of sexual initiation or refraining from sexual activity (Birungi et al., 2007). These experiences, coupled with counselling

focused exclusively on abstinence, may lead to denial of appropriate information about safe sexual practices. Similarly, the way the young women deal with their emerging sexuality and positive HIV status may have effects on their consequent approaches towards sex, sexual identity, health seeking behaviours and SRH outcomes which is particularly complicated for young women. This necessitates the need to know more about how young women interact and discuss these issues with service providers.

In essence, this section has focused on how HIV acquired perinatally affects young people physically, mentally, socially, economically and sexually. Young people face a greater degree of social exclusion that influence the way they get informed about their diagnosis, their status disclosure to peers including sexual partners. However, issues of status disclosure within the family get complicated due to disrupted family structures.

2.4.1.2 Family disruption

2.4.1.2.1 Parental care

HIV is mainly a disease that has wide impacts on families, as it is globally reported to affect familial structures, relationships, roles and responsibilities in different ways (UNAIDS, 2011 , Ferrand et al., 2007). Either one or both parents may be infected and siblings infected or affected. The family may often have experienced multiple bereavements and losses within their social and family networks. Therefore, holistic consideration of the social and economic impacts of HIV infection upon the family is crucial to understand the influence of care provided by parents to their children who are infected with HIV. Within the families, parents may be significantly concerned about increased caring responsibilities, fear of social rejection, shame or the gossip regarding the illness in their household and that can greatly affect their social identity (Muyinda et al., 1997). Stigma associated with HIV shapes the burden of care, as parents struggle to deal with pressure between the secrecy surrounding the infection and the openness needed in care provision and in seeking the social support they desperately need (Ferrand et al., 2007). Since parents may anticipate negative fears related to stigma ('felt stigma'), disruptions in relationships, they have to deal with challenges of secrecy, seek to balance the perceived risks and benefits of disclosure and deal with personal fears, hence the disclosure of positive HIV status to young people is often delayed (Biadgilign et al., 2011).

Studies have revealed several reasons for parents' status non-disclosure. For instance, in several studies, explaining about how the young person got infected, responding to questions concerning sexual activities as the prime mode of HIV transmission was the most difficult issue for most biological caregivers (Kirshenbaum and Nevid, 2002 , Armistead et al., 2001 , Ledlie, 1999 , Lee and Johann-Liang, 1999). This was mainly in situations where the young people were assumed to acquire the HIV perinatally and their parents acknowledged that HIV is transmitted sexually. In this regard, it is clear that parents voiced concerns about disclosing the positive HIV status to the infected young people. Some parents did not know when and how to disclose the status and expressed the desire to be helped by the health workers to disclose status to their children (Heeren et al., 2012 , Vaz et al., 2010 , Moodley et al., 2006 , Oberdorfer et al., 2006 , Gerson et al., 2001). Caregivers believed that if the young people were made aware of the positive status early, they would be relieved of the tension between keeping the status a secret and openness about the status to avoid the likelihood of accidental disclosure. Another study reported that when the caregivers sensed that the young person had known their health problem or positive HIV status, it lessened the tension of disclosing the positive HIV status (Naeem-Sheik and GrayGlenda, 2005). Similarly, according to Murphy et al. (2001) young people's awareness of parental HIV status is linked to an increase in their psychosocial well-being including enhanced self-worth hence positive coping.

The limited research available on caregiving for young people infected with HIV reveals that the majority of female parents remain vulnerable to chronic poverty, so disclosing the young people's HIV status exposes them to social exclusion that stems from structural inequalities and hegemonic gender norms hence loss of their social support (Evans, 2005). A study conducted in Tanzania with families affected by HIV and AIDS suggested that while different generations of women were affected by the burden of care, children especially girls and mothers demonstrated greater resilience and self-dependence. They developed different survival strategies to mitigate the socio-economic impacts of the HIV upon their family (Evans, 2005), especially after loss of productivity or the breadwinner in the household. However, these strategies posed risks to their health, psychological and social well-being.

2.4.1.2.2 Foster care

Studies have shown that after the death of a breadwinner in the household or loss of productivity due to parental HIV related illness, drastic changes in the family structure and roles may lead to profound psychological impacts and lack of support structures especially for the young people (Evans and Becker, 2009, Hosegood et al., 2007). Young people in certain social situations are faced with food insecurity, withdrawal from school, loss of assets, having to find income. Young women in particular, who report feeling financially or emotionally unsupported by their caregivers in foster families have an increased likelihood to engage in sexual activities at a younger age (Youngblade et al., 2007) to secure financial and material support. In addition, they face unequal gender power relations leading to unwanted pregnancies (Kuo and Operario, 2009 , Van Blerk and Ansell, 2007). However, in sub-Saharan Africa, HIV affects women by significantly escalating the burden of care (Evans and Becker, 2009). In most societies in Africa, female relatives particularly grandmothers are regarded as traditional caregivers, expected to bear the psychosocial burdens of HIV infection and care for the young people, although they are often already experiencing extreme poverty and may not be able to afford the material and emotional needs of the young people (Van Blerk and Ansell, 2007). Most female caregivers have limited control over, or access to material and financial resources to enable them cope effectively with their caring responsibilities as rarely men share domestic responsibilities, care of the family and financial management with their partners (Kuo and Operario, 2009).

The caregiving role is socially shaped by gender and women are mostly regarded as the usual caregivers (Global Coalition on Women and AIDS, 2005). It is often presumed that women especially mothers, grandmothers, wives, sisters and aunts should be carers for the sick including young people. Several studies in Africa have demonstrated that the elderly and young people, particularly girls and young women, are involved in caring for family members afflicted with AIDS, including younger siblings (Chimwaza and Watkins, 2004 , Young and Ansell, 2003 , Steinberg et al., 2002). Significantly, a systematic review of studies on caregivers for HIV infected young people showed that caregiving duties involving elderly women are often associated with evident financial burdens and the likelihood of loss of social support networks (Kuo and Operario, 2009) thus weakening the family systems and power to make significant decisions. Normally elderly

grandparents expect to be cared for by their adult children in old age. However, since AIDS disproportionately affects the most productive and reproductive age group, grandparents find themselves in the role of caregiver for the orphaned young people, despite prospective threats to their own physical and psychological well-being. The triangulated results of a mixed-method study (interviews supplemented with a survey) in Malawi focusing on care offered and support received by caregivers from relations and significant others in the community discovered that caregiving was not regarded as a problem because the caregivers felt they were closely related to the patients (Chimwaza and Watkins, 2004). However, they described caregiving as physically and financially demanding as they encountered financial constraints and lack of income generating activities. Likewise, African families/homes where caring responsibility of young people infected with HIV/AIDS is adopted experience significant financial stress (Stover et al., 2007 , Howard et al., 2006 , Miller et al., 2006). Interestingly, a study conducted in Botswana has shown that in situations when the maternal grandmother was the new caregiver, the young people who had lost parents experienced greater stability despite the financial burdens to meet basic survival needs and the emotional distress (Daniel and Thamuku, 2007). But, when the caring responsibility over the young people was assumed by an aunt or uncle, there was an increased likelihood that the young people have to migrate (and adjust to living with new peers), making them vulnerable to physical and psychosocial abuse. It could be that young people were moved between households for support or to share caregiver burden or some families might not want to associate themselves with the infected young person for fear of their own social rejection.

Stigma becomes more significant in caregiving of HIV infected young people particularly within foster care. Studies have stressed on how stigma can hinder young people's access to quality care and health workers' provision of age-appropriate healthcare (Simbayi et al., 2007). While some young people may receive good care, others may encounter injustice and abuse in foster families (Biadgilign et al., 2011). Several studies show how young people in foster families may experience blatant neglect, being treated differently to the caregiver's biological children, or given a disproportionate amount of household chores, may have limited access to food or clothing and punished more harshly (Daniel and Thamuku, 2007, Deacon and Stephney, 2007 , Van Blerk and Ansell,

2007 , Madhavan, 2004). Contrary to biological caregivers, who find it difficult or delay HIV disclosure to their children, as they are anxious about their children learning about the stigmatised illness, studies show that the other caregivers tend to disclose the status to young people earlier than the biological caregivers (Mahloko and Madiba, 2012 , Biadgilign et al., 2011 , Lesch et al., 2007 , Thorne et al., 2002). Nevertheless, the caregivers' readiness about HIV status disclosure to young people seems to be centred on their emotional feelings and availability of social support networks within the context of the HIV related stigma and discrimination.

There is a paucity of literature on formal support for caregivers (Punpanich et al., 2012). A qualitative study conducted in Namibia affirms that while informal support for caregivers is made available in the early phases of the sickness, if the sick person does not recover, help is less forthcoming and the main carer becomes increasingly isolated (Thomas, 2006). This was often associated with stigma and relatives suspicions about the nature of the person's illness. However, another study revealed that there is clear evidence that caregivers make every effort to provide the best care within their capacity but overtime this can create pressure on the family as the resources get depleted and also impact detrimentally on intra-household relations leading to ill-feeling and tensions between the caregiver and the infected young person (Lewis, 2001).

It is evident in literature that the caregiving of young people infected with HIV creates enormous workloads, physical strains, increased social isolation, escalating caring burden particularly with limited financial and support resources. Overextended caregiving demands, challenges and diminishes caregivers' physical stamina (Joslin and Harrison, 2000) and self-image as majority of them are challenged by effort to keep the status a secret in various social contexts. This signifies that the life challenges of caregivers concurrently impact negatively on young women. However, families are the most central social system influencing young women's effective coping with HIV positive status and lasting behavioural change as well as protection and financial security (Bachanas et al., 2001).

2.4.2 Coping with perinatal HIV

HIV infection like other chronic illnesses requires lifelong involvement with the health care services. However, coping with the chronic illness is beyond complying with medical instructions as it involves dealing with psychological and social issues of living with the illness (Gately et al., 2007). A growing body of literature on coping with chronic illness suggests that coping requires the active involvement of the young person. The young women should specifically be involved in making decisions affecting their health, solving the consequent problems and promoting their capabilities to share responsibilities for setting and achieving their goals, and creating healthcare plans with their health care professionals to achieve better outcomes (Creer et al., 2004 , Bodenheimer et al., 2002). Effective coping with physical, psychological and social aspects of the chronic illnesses such as diabetics, arthritis, cystic fibrosis, asthma and heart diseases is globally promoted for the affected (including the young people). This thesis does not allow for the full review of coping with all chronic conditions rather would focus on HIV infection. Although the medical prescriptive approach to coping mechanisms is extensive, a growing literature on coping with chronic illness reveals that the emphasis is on adherence to directions given by health care providers, ignoring the 'self' in the coping capabilities (Johnston et al., 2012 , Koch et al., 2004). The limited literature on coping with positive HIV status is no exception, as most recommendations in coping mechanisms encourage the infected individuals to adhere to prescriptive approach overlooking the cultural expectations (Miller, 2008). Thus, they are expected to comply with medical management instructions which may have little relevance to the contextual experiences of living with HIV on daily basis.

The limited research that has described unique challenges, medical and psychosocial aspects of care for perinatally HIV infected youths have shown that a supportive environment is crucial for the youths to cope with their positive status (Hazra et al., 2010) and to avoid risky sexual behaviours as they develop into adulthood (Spiegel and Futterman, 2009 , Storm et al., 2005). Social support is described as an important aspect of psychological adjustment for young people living with HIV. Studies on social and emotional well-being have shown that HIV infected young people who have close friends, supportive family or relations in dealing with their emotional and illness related challenges report fewer feelings of sadness and hopelessness (Kalichman et al., 2003 ,

Leask et al., 1997 , Bor, 1996). Kalichman et al. (2003) assert that social support can buffer the stress associated with living with HIV and can promote a sense of psychological well-being. In addition, strong relationships with peers were also considered a source of happiness and sense of belonging. For instance, young people gained support when they disclosed their HIV status to close friends and their friends assisted in normalising their illness. Similarly, participating in support groups creates an environment for HIV-specific health promotion among young people, open dialogue about living positively with HIV and anticipating productive adult lives (Funck-Brentano et al., 2005). Several studies with young people have shown that peer support groups improve confidence, social support and uptake of health services hence widening young people's access to sources of required information and support (Hodgson et al., 2012 , Rydstrom et al., 2012 , Watt et al., 2010 , Naar-King et al., 2009). However, there is limited research on factors that can assist service providers to facilitate and establish good supportive environments for young people growing up with HIV to achieve optimum coping capabilities.

Religious institutions have also been documented as playing supportive roles towards young people infected with HIV (Miller and Rubin, 2007 , Chimwaza and Watkins, 2004). For example, studies conducted in Sweden and South Africa showed that religion was discovered to be a source of support as church members addressed psychological and emotional needs of the infected and affected young people (Rydstrom et al., 2012 , Majumdar and Mazaleni, 2010). Simultaneously, the young people infected with HIV perceived that faith and belonging to a church was significant in coping with their HIV. They believed that being religious gave them an opportunity to pray and trust God for his divine intervention upon their difficult situations (Majumdar and Mazaleni, 2010). However, there is a paucity of literature on how this can be integrated in health service provision to promote positive coping with HIV status. In addition, further research is needed to understand interventions that uphold adoption of healthy coping strategies among young people, thus minimising negative coping with their HIV status particularly for young women.

2.5 Promoting adolescent sexual and reproductive health

In Malawi, young people initiate sex as early as 12 years (Ministry of Health, 2009). According to 2010 Malawi Demographic and Health Survey, 14% of women aged 15 to 24 years and 22 percent of men aged 15 to 24 years initiated sexual activity before the age of 15 years. 15% of young women from the rural setting have initiated sex by the age of 15 years versus 11% of urban young women. Seven percent of women aged 25-49 had given birth to their first child by the age of 15 years, and 65% had become mothers by age of 20 years (Government of Malawi, 2010). Similarly, as long as HIV infected young women are asymptomatic and not physically challenged, they may wish to lead a normal sexual life such as dating, engaging in sexual relationships, marrying and bearing children like their HIV negative counterparts (Busza et al., 2013 , Obare and Van der Kwaak, 2010 , Birungi et al., 2009). This is supported by a study conducted in Uganda which revealed that the majority of perinatally infected adolescents aged 15-19 felt that it was almost impossible to refrain from sex (Birungi et al., 2009 , Birungi et al., 2008). As such, it is evident that most young people in Uganda, who acquire HIV perinatally are either sexually active or desire to become sexually active in the future (Birungi et al., 2009 , Bakeera-Kitaka et al., 2008). Nevertheless, studies documented that the majority of young people who are sexually active often do not adopt protective measures (Obare and Van der Kwaak, 2010 , Birungi et al., 2009 , Bell et al., 2007).

2.5.1 Condom use in Malawi

Condom use among young people in Malawi remains relatively low (Government of Malawi, 2010). Despite extensive efforts in promoting condom use, 98% of young people aged 15-19 have ever heard about a modern method of contraceptives and 20% have ever used the methods including condoms, yet 50% are sexually active and not married (Government of Malawi, 2010). This results in a challenge between having knowledge and the actual practice of condom use. However, there is significantly limited information on use of condoms amongst the young people in Malawi. The limited published work available on youth's condom use in Malawi mostly relies on quantitative (survey) methodologies, and takes on a so-called knowledge-attitudes-practices format which tends to be descriptive (Government of Malawi, 2010). In this context condoms are often considered as a supplementary contraceptive method not as

an overt focus, which makes it difficult to differentiate factors linked specifically to condom use or identify the underlying forces behind the practices.

Challenges with accessing contraceptives (including condoms) are the major contributing factor to the high incidences in pregnancies among young women in Malawi (Government of Malawi, 2010). However, use of condoms has been a difficult subject for individuals, within marriages and at community level (Chimbiri, 2007) which confuses young people, thereby affecting efforts in HIV prevention strategies (Muheriwa et al., 2013). At community level, condom use is perceived as promoting immoral behaviours among young people. From individual and couple's perspectives, people consider the perceived social costs associated with condom use. These include adverse effects on the user, decreased sexual pleasure and beliefs that condoms increase health risks such as causing diseases that lead to AIDS (Namate and Kornfield, 1997), cancer, sores, as well as possibility of tearing and sticking to the womb causing infertility or death (Tavory and Swidler, 2009 , Kaler, 2004). While others believe that condoms are thought to be part of the Western or government conspiracy to reduce population numbers (Tavory and Swidler, 2009 , Kaler, 2004) some believe that condom use is sin (McGeary, 2001). These misconceptions are reflected in the trends of condom use among young people.

There is increased evidence that the frequent objection from men regarding condom use in Malawi is the decrease in sexual pleasure. Men believe that sex should be 'skin to skin' because 'a sweet cannot be eaten in a wrapper' (Tavory and Swidler, 2009 , Kaler, 2004). Like in other parts of Africa, in Malawi, the most common metaphor for the sexual pleasure is that of 'sweetness' (for Kenya see Dilger (2003), for South Africa see Hunter (2002)). This metaphor refers to release of semen into the woman and the pleasure of the sexual act in general, which devalues use of condom and make it become more problematic. Thus, use of condoms in the Malawian context, is considered to completely eliminate sensuality by preventing both partners from experiencing 'the sweet' (Tavory and Swidler, 2009). For both men and women, release of semen is the height of sexual sweetness and contact of semen and vaginal fluids is believed to be the essence of sexual pleasure; as such use of condoms does not only diminishes sexual sensation but also removes its essential element. Several studies have reported men's preference and value for tight and dry skin to skin sexual contact as

facilitating sexual pleasure as compared to condom use (Muheriwa et al., 2013, Woodsong and Alleman, 2008). For instance, qualitative studies conducted among young people in Malawi and in Zambia has shown that there is a strong belief that condoms cause cancer, are not nice for they reduce sexual satisfaction and lead to permanent infertility (Mukuka and Nevo, 2006 , Hackney, 2002). These perceptions about condom use may thwart efforts of the service providers in promoting condom use as a preventive strategy against HIV transmission or other STIs and early child bearing among young women.

In addition, gender-based violence and difficulties in negotiating condom use in sexual relationships leads to a context that creates lower than expected adoption of preventive measures including condom use (Government of Malawi, 2012). Power inequality in sexual relationships and fear of partner violence is pervasive at every level of society and paralyses women's efforts in bargaining condom use (Jewkes, 2010). Women's low socio-economic status and limited power often escalates their reliance on men for support leading to coerced sexual activities which are often unprotected, naturally promotes early sexual debut (UNAIDS, 2001), sometimes at an early age with older men giving them position of power on sexual issues including decisions on condom use. Thus, power inequalities between older men and younger women might also affect decisions on frequency of sex and condom use (Luke, 2005). This male-dominated character of societies in Malawi demands new and innovative approaches that empower young women financially and socially (Oguntibeju et al., 2009). However, the approaches need proper consideration for their acceptability and potential for seamless incorporation into Malawian culture and national HIV programmes that consider HIV infected young women.

While parents/adults often disapprove of single parenthood in Malawi, efforts to ensure financial and social security exposes perinatally HIV infected young women to unsafe sexual practices (Evans and Becker, 2009 , Hosegood et al., 2007) which can lead to early child bearing. In a sexual relationship in which the young woman is financially and socially dependent on the partner, a young woman's capability to negotiate for safer sex or to quit the high-risk sexual relationship is limited (Masanjala, 2007). Evidence from Malawi suggests that for most women on the margin of impoverishment coupled with unequal social relations and access to productive resources has limited their

capacity to adopt sustainable coping strategies (Bryceson and Fonseca, 2005). Instead their low status has created situations in which sex (often unprotected) for financial gains has become the normal means of survival and coping to secure support for themselves or the younger siblings. Simultaneously, in Malawi the importance of having children is expressed to females from a very young age, with subtle and other pressure exerted by the family, partners and the community (Stewarts et al., 1998). This means that young women may experience familial and social pressure on reproductive health issues, which may be challenging for those with perinatally-acquired HIV as they have to meet societal expectations against parental and medical restrictions associated with positive HIV status. This needs to be explored further to develop appropriate SRH interventions. While young women prioritise survival as compared to physical well-being, health systems need to reinforce condom use as the most effective strategies to avoid other sexually transmitted infections and HIV secondary transmission hence promoting optimal SRH outcomes.

2.5.2 Sexual and Reproductive Health (SRH) services

Out-of-wedlock and non-marital childbearing is greatly disapproved of by Malawian society (Munthali et al., 2006) and further predisposes these female young women to poor health seeking behaviours and SRH outcomes as compared to their male counterparts. Since culturally young women in Malawi are taught to abstain from sex until they are married (Tavory and Swidler, 2009, Masanjala, 2007), research shows that it becomes a challenge for the majority of them to access contraceptives offered by adults as they might not want to be seen as not conforming to cultural and social norms (Munthali et al., 2006). Furthermore, empirical data on HIV management of perinatally HIV infected adolescents in Malawi reveals that apart from HIV teen clubs there are no specific SRH services targeted at individual SRH needs as they grow up into adulthood. In line with service provision, the literature reflects that health professionals encounter challenges in addressing their distinctive needs especially SRH needs (Ross and Cataldo, 2010, WHO and UNICEF, 2008). This could be attributed to service providers being ill-equipped to discuss sexual issues with young people or that HIV management services being traditionally conceptualized into two distinct groups namely paediatric and adult care (UNFPA, 2007). This means that young people who no longer fit under paediatric services and who feel uncomfortable with adult services lack programs that address

their unique needs (Ross and Cataldo, 2010 , WHO and UNICEF, 2008). While challenges on discussing sexual issues with young people are well documented elsewhere (Bastien et al., 2011 , Close, 2010 , Diop and Diagne, 2008 , Phetla et al., 2008 , Mbugua, 2007), similarly in Malawi premarital sex and parent-child discussion on sexual issues is culturally forbidden for the fear of influencing young people to initiate sex too early or because sexual discussions are customarily held in secret within families (Wittenberg et al., 2007 , Munthali et al., 2004). Possibly the assumption made is that perinatally HIV infected adolescents are not and should not be sexually active despite their sexual needs. This issue needs more exploration. Health professionals might be conforming to cultural norms of not talking directly about sexual issues with young people by providing understated warnings about the possible adverse outcomes of sex rather than practical SRH education, advice and support (Munthali et al., 2006).

This is supported by findings of a survey conducted in Uganda, which revealed that counselling for HIV positive young women and men aged 15 to 19 years concentrated entirely on abstaining from sex despite the 33% of 732 adolescents were sexually active and 86% of those who had not yet initiated sex desired to do so in the future (Rujumba et al., 2010). Similarly, in other qualitative studies in Africa, service providers emphasise on abstaining from sexual activities (Busza et al., 2013 , Birungi et al., 2009), while the young people desire otherwise. However, the number of teenage pregnancies among perinatally HIV infected young women is a signal that service providers in most countries still face challenges in their HIV and AIDS management and the efforts on prevention as the patterns are indicative of poor preventive practices (Obare and Van der Kwaak, 2010 , Birungi et al., 2009). For instance, the survey that was conducted in Uganda revealed that 41% of the sexually active HIV positive young women had ever been pregnant (Birungi et al., 2008). The AIDS Support Organisation (TASO) by 2006 had cumulatively recorded 184, the Paediatric Infectious Disease Clinic (PIDC) had nine and Mildmay Centre had seven pregnancies among perinatally HIV infected young women accessing HIV treatment, care and support. In addition, 87% of the young women strongly desired to have offspring in the future, which made the researchers suspect that possibly the young women succumbed to familial and societal pressure to have offsprings early in anticipation of their untimely death (Birungi et al., 2007). Empirical data in HIV management centres in Malawi have similar experiences of teenage

pregnancies among perinatally HIV infected adolescents. This clearly indicates that living with HIV does not considerably influence young women's attitudes towards sex and child bearing, hence they indulge in risky sexual practices like their HIV negative counterparts.

There is now growing evidence that service providers and counsellors advise perinatally infected young people to refrain from sexual activities (Busza et al., 2013 , AIDS Support Organization (TASO) and Population Council, 2007 , Birungi et al., 2007). For instance, a qualitative study in Tanzania about perinatally HIV infected adolescents aged 15-19 revealed that service providers found it challenging to reconcile young people's sexuality with their positive HIV status (Busza et al., 2013). While some caregivers felt adolescents were too young for sexual information or should simply postpone sex, others perceived that sex was not acceptable for the HIV infected young people. However in this study, both caregivers and healthcare providers demonstrated judgemental attitudes towards sex in young people with HIV. They perceived that early sexual activity was generally disapproved (Busza et al., 2013). However, they also emphasised that HIV infected young people needed to safeguard their health as they could specifically be susceptible to health risks. These contradictory messages could contribute to adolescents' rebellious behaviours. Conversely, a qualitative study conducted in Uganda revealed that young people expressed stronger preference in relation to discussing sexual issues with service providers than their caregivers (Birungi et al., 2008). On the other hand, many HIV infected young people are reluctant to share the intimate issues affecting their lives with service providers/counsellors or even caregivers/parents, whom they perceive have judgemental attitudes towards their sexual behaviours and routinely advise them to avoid sexual relationships (Birungi et al., 2007). This clearly indicates that young people need to be recognised as sexual beings requiring developmentally-appropriate SRH services and open discussions with service providers and caregivers to promote their optimal sexual health outcomes. Several studies in sub-Saharan Africa have revealed similar challenges encountered by service providers in managing SRH in perinatally HIV infected adolescents and recommend establishment of developmentally appropriate sexual and reproductive health services empowering young women with risk reduction strategies thus preventing HIV secondary transmission and early child bearing as some of the strategies to meet their

specific needs (Obare et al., 2011 , SAT, 2011 , Bakeera-Kitaka et al., 2008 , Birungi et al., 2008).

A survey of 606 HIV positive young people aged 15-19 years in Kenya sums up the challenges encountered by perinatally HIV infected young people as being vulnerable on account of several factors including their young age coupled with living with a chronic and stigmatised illness, many losing a parent/s, majority especially young women are out of school and only 50 percent belonged to any psychosocial support group (Obare and Van der Kwaak, 2010). While these challenges are critical and complex for perinatally HIV infected female adolescents, they are often cared for in paediatric oriented services where their SRH needs may not be regularly addressed and they may rarely access SRH services, hence being inadequately prepared for satisfying their sexual lives and risk reduction strategies like disclosure of status to potential and existing sexual partners, negotiating for safer sex and productive adult life (Busza et al., 2013 , UNICEF, 2008 , Birungi et al., 2007). While the existing HIV management and support strategies seem to inadequately address the sexual and reproductive needs of this rapidly growing population of young people, there is no research that has demonstrated how the young women with perinatally infected HIV navigate this complex psychosocial, cultural and sexual trajectory as they are growing up to adulthood in order to identify appropriate and realistic SRH strategies.

2.6 Conclusion

In summary, adolescence is a key phase of human development during which young people move towards independent life, develop decision making skills, become involved in identity formation and confront challenges in relation to sexual behaviour. In Malawi, the construction of masculine and feminine sexuality and the whole process of socialization are rooted in cultural and social norms and values that reinforce the subordination of women in sexual relationships. This gives men position of power in sexual issues while limiting women's autonomy and decision making power. This may become more complicated for young people who acquire HIV perinatally (particularly young women) as they experience disproportionate rates of social isolation, financial constraints, sexual and physical abuse (Ferguson, 2010, Thorne et al., 2002). Existing social norms and values may significantly affect their sexual choices and health seeking

behaviours, hence rendering them vulnerable to particular health risks. Although there is a growing body of knowledge about medical, sexual and reproductive health (SRH) among young people with perinatally acquired HIV, all previous studies have focused on mixed gender samples (Busza et al., 2013, Li et al., 2010, Obare and Van der Kwaak, 2010, Birungi et al., 2009). There is no study that has specifically looked at young women. The previous studies have shown that young people with perinatally acquired HIV engage in sexual activities and are bearing children like their HIV negative counterparts. It is evident that vulnerability to health risks among this group is more conspicuous in young women than their male counterparts (Rydstrom et al. 2012, Poulin, 2007). However, there is relatively less attention given to understanding of other aspects of their lives as they grow up with HIV. There is a gap in our current understanding of the gender dynamics underlying perinatally infected young women's experiences and challenges.

The literature further suggests that young women affected by HIV may be particularly vulnerable to social problems or sexual abuse leading to unwanted pregnancies and infections with other sexually transmitted diseases (National Youth Council of Malawi and UNFPA, 2010, UNFPA, 2007). Despite the young women's increased vulnerability, little attention is given to this group to address their distinctive needs (including their sexual well-being) resulting in poor SRH outcomes (WHO, 2008 , Family Health International, 2005). Additionally, there is limited research on how young women engage with SRH services and it is unclear whether HIV services meet the varying needs of this group as they grow up into adulthood. As such, the current study focuses on young women rather than both genders in order to understand their lives better and improve and/or develop services that will holistically meet their multiple needs and mitigate their challenges.

Furthermore, there are several methodological weaknesses in the current body of evidence that leads to limitations in our current understanding of young people's experiences. Previous work has drawn on mixed gender samples, preventing a more in-depth focus on issues specific to particular sub-groups. Whilst it has been positive to examine young people's experiences from their own perspective, given that their lives are so strongly shaped by their family situation and health service access, it is important to understand how their experiences are shaped by hearing from all those involved in

their care. Otherwise, prior researchers got one-sided view and yet adolescents' experience with perinatally acquired HIV is known to be a complex situation. In addition, prior studies have sought to understand the problems encountered by caregivers in their own terms, rather than exploring the adolescent's experiences and perceived issues from the caregiver's and service provider's perspectives. Hence, the current study involved caregivers and service providers as key actors in provision of young women's care in order to understand young women's psychosocial and sexual experiences from a broader and holistic perspective. Chapter Three describes the research design, methodology and the methods of data collection that addressed the aim and objectives of the current study.

2.7 Research aim and objectives

2.7.1 Research aim

The main aim of this study was to determine the meaning of the experience of growing up with the perinatally acquired HIV specifically for young women aged 15-19 in the Malawian context. The study aimed to explore the complexities of young women's lives in order to understand health outcomes within the wider social, cultural and structural context that shaped their experiences and options from their own, their caregivers' and service providers' perspectives.

2.7.2 Research objectives

Research objectives for this study were broadly formulated into two areas:

To explore the experiences of growing up with perinatally acquired HIV for the young women

- To examine the psychosocial experiences of growing up with HIV
- To identify the sexual and reproductive experiences of the young women as they are developing into womanhood.
- To determine the structural factors, perceptions, values and aspirations influencing the young women's experiences as they grow up with HIV to adulthood.

To explore the health, sex and relationship challenges for young women growing up with perinatally acquired HIV and the impact of the current HIV related and SRH services.

- To identify the psychosocial and SRH challenges of the young women as they are growing up to adulthood.
- To identify the issues and challenges encountered by caregivers as they look after the young women growing up with HIV.
- To identify the issues and challenges encountered by service providers as they provide health care to the young women growing up with HIV.
- To assess the impact of the existing health services on the needs of the young women as they grow up to adulthood.
- To identify the most important and realistic strategies in meeting needs of perinatally HIV infected young women as they grow up to adulthood in Malawi.

CHAPTER THREE

RESEARCH METHODOLOGY AND METHODS

'…the consequences of powerlessness that ensues will have an impact upon their capacity to find words to talk about their experiences and therefore upon their own sense of identity' (Hoggett, 2001: 48).

3.1 Introduction

This chapter describes the research strategy that was utilised to explore the life experiences and needs of young women growing up with HIV. The chapter is divided into six sections. Firstly, the research design is outlined in order to familiarise the reader with the nature of the research, then the philosophical position that informed the research design is discussed. This section also describes the methodological approach. Secondly, the access and the recruitment process and sampling procedure undertaken are outlined. Thirdly, the procedure and methods of data collection are described and include: familiarisation phase, individual in-depth interviews and use of 'my story' book to facilitate interviews with young women. Fourthly, data management and methods of data analysis are described to demonstrate how data was constructed and interpreted. Fifthly, the relevant ethical considerations are outlined. Finally, the chapter concludes with sections on strategies used to enhance worthiness of the methodological approach and reflections on the research process.

3.2 Study design

3.2.1 Qualitative case study approach

The study adopted a qualitative case study approach to explore the young women's experiences of growing up with HIV.

> "Qualitative case study is highly personal research. Persons are studied in depth…….. The quality and utility of the research is not based on its reproducibility but on whether or not the meanings generated, by the researcher or the reader, are valued."
>
> (Stake, 1995:135)

This section therefore discusses qualitative approach and use of case studies in qualitative research.

3.2.1.1 Qualitative approach

For the purpose of this thesis, research is delineated as a form of inquiry that is systematic as it is carried out following basic principles and procedures that ask questions about social realities encountered, known about or participated in by the researcher in a variety of ways (Freeman, 1998). The term 'qualitative' is described as an approach that seeks to understand the ways in which young women make sense of their social world including their experiences that take into account the contexts in which the women live. This includes their actions, thoughts, feelings, relationships and unique perspectives (Merriam, 1998). This research sets out to describe, understand and explain the study phenomenon which is 'experiences and needs of living with HIV' and also aims to interpret meanings, patterns and inconsistencies in the young women's lives (Britten et al., 1995 , Elder and Miller, 1995). The strength of qualitative research lies in researching human beings in their usual social environment (Gantley et al., 1999). Bryman asserts that fundamental to the qualitative research approach is the concept of "viewing events and the social world through the eyes of the people that are researched" (Bryman, 2008:385). Bowling (2009) concludes that the hallmarks of qualitative inquiry include collection of in-depth data, emphasis on participants' worldviews and the move from description to explanation. However, social researchers argue that in order to understand human behaviour reference is made to the meanings and purposes attached to activities (Bowling, 2009 , Bryman, 2008 , Murphy et al., 1998) hence qualitative research is acknowledged for providing such rich insight into human behaviour (Guba and Lincoln, 1994). Therefore, a qualitative research approach was chosen for this study as it was deemed the best method of enabling young women to express their own views about issues they consider to be important and which affect their lives. This hence provided a rich in-depth understanding of a social phenomenon understudy in a natural setting.

Qualitative research helps to "probe into the participants' thought processes to elicit reasons for and gain an understanding of each response. It addresses 'what?' 'how?' 'why?' and 'why not?' rather than 'how many?' or how frequently?" (Gantley et al.,

1999:7). These key characteristics of qualitative research made it the methodology of choice for the current study and helped explore the questions,

- What does growing up with HIV mean to young women?
- What are the issues that impact upon their lives as young women?
- How and why do the existing social, cultural and structural systems impact on their lives as they grow up with HIV?

Bowling suggests that qualitative methods have an advantage over quantitative methods in situations where maximum opportunity to pursue an exploratory approach is desired and when the issues are sensitive or complex (Bowling, 2009). A qualitative approach was selected for its ability to explore such issues in-depth to allow the young women to express their complex, sensitive and personal experiences of growing up with perinatal HIV (Wainwright and Forbes, 2000). In order to understand the complexity of young women's experiences and needs as they grow up with HIV, case studies were used to build a comprehensive picture of the life experiences and needs of young women and to produce in-depth explanations from different perspectives as illustrated in section 3.2.1.2.

3.2.1.2 Use of case studies in qualitative research

Case studies are an approach to research that enables exploration of a phenomenon utilising a variety of data sources to gain differing perspectives (Kendall et al., 2009) in order to create a contextual understanding. This ensures that the phenomenon which is 'experiences and needs of living with HIV' in this study was explored through a variety of lenses which enabled understanding of multiple facets of the phenomenon. Only when research is performed in context, where all the different factors affecting the lives of these young women are explored simultaneously is it possible to identify the most important and realistic strategies to meet their needs as they grow up with HIV. The case studies used were designed to pursue a linkage of key individuals involved in the young woman's care provision. This ensured that multiple sources of data could be obtained in order to achieve in-depth data for each 'case'. Particular emphasis was placed on the interactions of young women with their caregivers and healthcare providers. In this context, case studies allowed the researcher to consider the voice and perspectives of the young women including the pertinent groups of actors in their social worlds and the interactions between them. This provided an in-depth understanding of

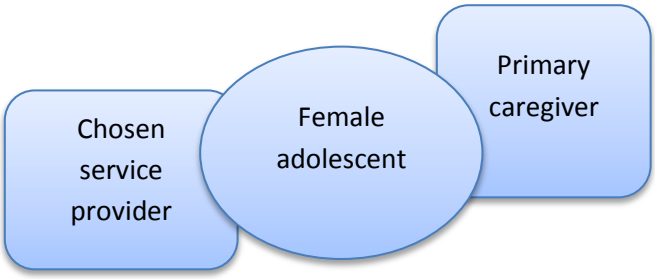
the illness trajectory of the young women along with their life experiences and needs of growing up with HIV in different contexts.

Stake (1995, 2005) describes the three kinds of case study which include intrinsic, instrumental and collective/multiple case studies. With intrinsic studies, the researcher has an interest in a particular case in order to gain a better understanding of that case and not building a theory. Instrumental case study uses the case to understand a broader issue, thus the case is of secondary interest in understanding something else. The multiple case study approach extends this idea to several cases to facilitate the researcher's understanding of the phenomenon (Stake, 2005). For the current study, the researcher sought to understand the experiences and needs of young women as they grow up with HIV and as such, the multiple case approach was considered preferable particularly because this enabled exploration of a wide-range of different situations (Creswell, 2007). Similarly, multiple cases could allow within and cross-case analysis, comparison and investigation of growing up with HIV in diverse settings (Stake, 1995).

This study adopted embedded multiple-case study methodology as described by Yin (2009). The embedded multiple case study refers to 'cases containing more than one unit of analysis[10]' (Yin, 2009:57). In this study, individual case included a perinatally HIV infected adolescent, her primary caregiver and a chosen service provider. The benefits of embedded case design include illuminating the case through analysis "within the subunits separately (within case analysis), between the different subunits (between case analysis) and across all of the sub-units (cross-case analysis)" (Baxter and Jack, 2008:550). It further facilitated holistic and in-depth understanding of the issues impacting on perinatally HIV infected adolescents, the situation and its meaning for individual uniqueness and complexity within a real-life context (Gosling et al., 2004, Tellis, 1997). This study comprised of fourteen (14) cases. Central to the case was a perinatally HIV infected female adolescent as the main 'unit' with her caregiver and the service provider as 'sub-units' making up an individual case. Figure 1 illustrates a typical case in this study.

[10] See Figure 1 for 'unit of analysis' in adopted case study method.

Figure 1 The individual case



The primary caregiver was typically a relative of the adolescent, such as an aunt (usually a sister to the adolescents' deceased mother), biological parent/s (mother/father), older sibling (a sister), a husband or an uncle (a brother to the deceased father). The service provider chosen was typically a registered or an enrolled nurse, a clinical officer, a counsellor or a paediatrician, who had been in constant contact with the adolescent for the minimum of six months. The caregivers and the service providers that participated in this study were specifically chosen by the adolescents to make up a complete case. Involvement of young women in the choice of other participants as 'sub-units' demonstrated commitment to relinquishing the researcher's power and enabling young women to determine whose voice and whose version of their story they wanted to be heard.

In conclusion, a qualitative case study design has the potential to produce highly sensitive and detailed accounts of individual and multiple cases from different perspectives (Hammersley, 1992). However, the design may be criticised for lack of objectivity, therefore the next section discusses the philosophical standpoints that informed the research design hence reinforcing the understanding of the chosen approach in this study. The two contrasting philosophical approaches to health service research: positivist and interpretive (Bowling, 2009) are discussed in the next section.

3.3 Methodology: Understanding the approach

3.3.1 Positivism and interpretivism

Positivists' and interpretivists' approaches are based on different epistemologies and different philosophical positions regarding types of knowledge that are possible and claims about how what is assumed to exist can be known (Benton and Craib, 2001). The

positivists assume that there is an objective reality, which can be measured and studied predominantly through research. Throughout early health research, positivism has been the dominant approach underpinning medical and scientific achievements (Benton and Craib, 2001). However, positivists place less value on the role of participant subjectivity or social factors (Pope and Mays, 2006). Pope and Mays (2006) argue that health service research can also benefit from the knowledge engendered through interpretive approaches. Interpretivists hold differing epistemological assumptions to positivists as they believe that study of a social phenomena requires an understanding of the social world and how participants construct meaning attached to it (Benton and Craib, 2001).

While epistemiological perspectives are concerned with the way human beings comprehend knowledge about what is perceived to exist or what can be known (Benton and Craib, 2001), ontological perspectives are concerned with the nature of what exists and the experience of being (Benton and Craib, 2001). The current study is shaped by a realist ontological perspective which acknowledges that the world is real. This signifies that the world exists independent of the conceptions that human beings have about it (Archer, 2003). The world does not need empirical evidence to prove its existence. But human beings' representations of that world are the constructions which they create and apply in attempt to relate to it and manipulate it through knowledge and acts. For example, HIV is real for a young woman but how the society or people understand and treat them is socially constructed. Archer (2000:2) argues that "being is not anthropocentrically reduced to knowing but rather human beings have real powers of acting – agency". This implies that human beings are agentic subjects – reflective and decision making individuals. In this context, the current study regarded young women perinatally infected with HIV as having agency i.e. the ability to speak about their social realities from different perspectives and capable of constructing meaning of their complex social worlds that involved other social actors. However, it was acknowledged that both individual and collective agency is always influenced by contextual factors which include gender and socio-economic status (Clegg, 2006). Thus, recognising that to some extent the social contexts shape the human beings (Elder-Vass, 2012). The section below discusses how this qualitative case study design was guided by critical realist and feminist perspectives.

3.3.1.1 Critical realist perspectives

Critical realist ontology assumes that there is a real world which is socially constructed, but critical realists would argue that ideologies construe than deterministically construct the world (Easton, 2010). Thus, critical realism acknowledges that:

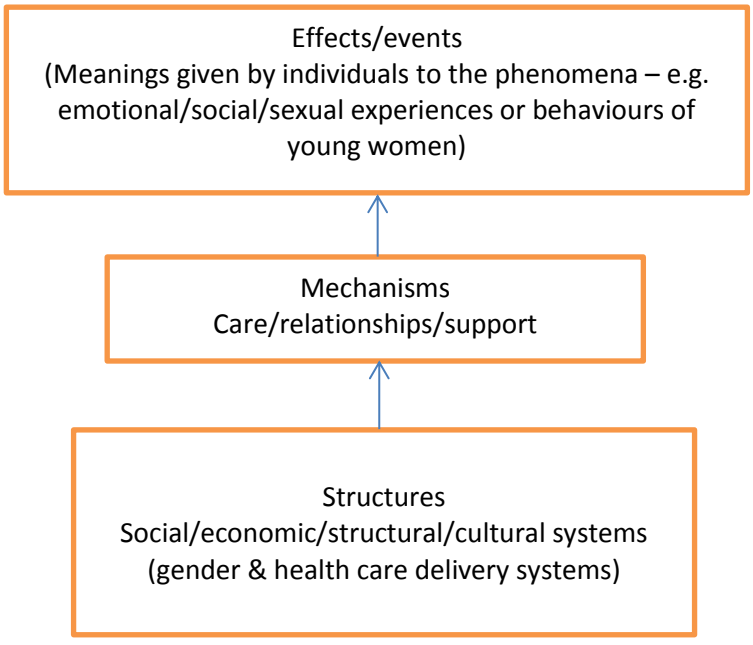
> "social phenomena are intrinsically meaningful and hence that meaning is not only externally descriptive of them but constitutive of them……..meaning has to be understood, it cannot be measured or counted and hence there is always an interpretive or hermeneutic element in social science" (Sayer, 2000:17).

In this context, the understanding of young women's experiences and their distinctive needs are shaped by a number of factors. These include the social settings inhabited by the researcher, the adolescents, the caregivers and service providers, their mode of interaction, prior experiences and the way all understood the expectations of the research relationship (Freeman and Mathison, 2009). Though each human being understands and interprets an event in an individual way, there is a likelihood that they will also integrate shared understandings held by members of social group to which that individual belongs such as peers, family, caregivers or service providers. This enables an individual to draw on shared meanings of the phenomenon 'needs and experiences of living with HIV.' However, critical realists argue that "in both everyday life and social science, individuals frequently explain things by reference to causal powers" (Sayer, 2000:14).

In critical realist ontology, phenomena are considered as stratified in the sense that it is always possible at least in principle to study deeper level structures and mechanisms of a phenomenon which in turn explains their more superficial actions (Sayer, 2000). Bhaskar, in his pioneering work, stratified the ontology of critical realism in order to differentiate the levels of social reality (Easton, 2010). The levels include the actual, the empirical and the real incorporating events, mechanisms and experiences respectively. Each of these levels relates to the embodiment of a difference between surface appearances and depth reality, necessitating expansion of the data beyond a descriptive account to one where the researcher offers her own explanation of the data. Easton describes the domains as follows: 'the actual domain is the level at which events occur

and focuses on what is visible. However, the events may be understood rather differently by observers or may be not observed at all. The empirical domain is that part of the actual domain which is experienced or observed through the fallible faculties of senses and interpretation, and is the part that is recorded' (Easton, 2010:120). Finally, the real domain is not observable in itself but through its effect. It is that domain which is not visible but causes the actual through generative mechanisms and structures. In other words, when researchers engage in social research, "they are interested in mechanisms, understanding what produces the cluttered outcomes" (Clegg, 2006:316), such as understanding why young women cope positively or negatively with positive HIV status. This helps to explain which structures or powers and mechanisms are producing the effects. Easton suggests that critical realism is well suited to case study research to respond to questions such as "what caused the events associated with the phenomenon to occur" (2010:123). Thus, the case studies explore the empirical domain through various data sources in order to comprehend the actual domain and discover, ultimately, the mechanisms operating in the real domain. Figure 2 illustrates how case study approach enables deep explanations, which is in line with critical realism.

Figure 2 Critical realist's view of deep explanations in case study approach



Note: Modified from Sayer, 2000

From the above explanation, the most fundamental aim of critical realism is to produce deep explanations in addition to an understanding of the phenomenon. Hence, the emphasis lies on events, which are described as "the external and visible behaviours of people, systems and things as they occur, or as they have happened" (Easton, 2010:120), and the mechanisms, which are described as "ways in which structured entities by means of their powers and liabilities act and cause particular events") (Easton, 2010:122) that cause the events. Critical realism therefore offers an approach that confronts the complexity and acknowledges the importance of meaning, agency and structural factors. A critical realist approach, focuses on 'how' and 'why' questions and meaning-making processes. In this context, the critical realism is compatible with case study research. The case study approach utilised in this research facilitated in-depth and comprehensive understanding of the phenomenon 'experiences and needs of young women living with HIV'. However, critical realists assert that there are structures that shape individual agency and one of the key social structures is gender providing a methodological link to feminist philosophies. Therefore the section below considers how gender can be taken into account in this study, as a key structure influencing young women's experiences and needs.

3.3.1.2 Including the feminist perspective within a critical realist approach

Feminists acknowledge how culturally a person's position in the society is sanctioned by attributes such as social roles, gender and family relationships, which are shaped into a social identity that gives an individual power and status (van Loon and Kralik, 2005). Allen and Baker indicate that the "feminist goal is to do research for women rather than about women" (Allen and Baker, 1992:9). Globally, males dominate in accessing resources, have hegemonic authority and often exercise repressive power over females. As a result, in several parts of the world, (including Malawi) females as a social group are marginalized and assume an inferior socio-economic position (Mkandawire-Valhmu and Stevens, 2009). Gender is a social construct which proclaims that the expectations, capabilities and responsibility of men and women are not always biologically determined (Ramazanoglu, 2002). Roles played by males in most cultures tend to be assigned higher values as compared to those played by females. These roles tend to create situations whereby males dominate structures and use their powers to maintain social and economic dominance hence paralysing the agency and assertiveness of their

female counterparts. Early feminists were therefore inspired to utilise research approaches that were based on the direct sharing of women's accounts of their experiences which would illuminate the structures that lie behind women's oppression and the type of the mechanisms which worked powerfully to produce imbalances within the society (Clegg, 2006).

Much of the feminists argument on subjectivity has been drawn from the critical realist ontological perspective that recognises human beings as having agency to make decisions (Elder-Vass, 2012). In his argument, Elder-Vass asserts that:

> "the kind of people we are accepted as, and the kinds of actions, whether discursive or practical, that we are authorised to perform, depend upon performative acts that enact social norms – norms of gender, class and social role……." (Elder-Vass, 2012:18).

The feminist perspective therefore sensitizes researchers to consider the voice of those who are being heard and those who are being excluded in the society. It also emphasises power relationships to examine and comprehend the context and lives of individuals taking part in research (Crotty, 1998). In this context, Crotty (1998) affirms that the feminist perspectives desists from continuing the understanding of women as victims of their situations but instead develops insights that allow researchers to understand women's struggles, restrictions and see their opportunities and challenges as similar to any human being. Additionally, Choby and Clark (2014) state that the feminist approach emphasises the concept of intersectionality. It is a concept that emphasises the complexity of types of marginalization and their construction through power relations and therefore it complements the critical realist approach. Intersectionality inquires how structures contribute to oppression and presumes that individuals undergo oppression in different ways based on their different characteristics (Choby and Clark, 2014). As such, the feminist view was adopted in the current study not only to give voice to young women regarding their experiences but also because of its emphasis on examining larger societal structures or mechanisms, gender and power relations to understand how they may pose danger to the young women.

Globally, (including in Malawi) women as a social group assume an inferior socio-economic position leading to feelings of being oppressed and marginalised in the society (Mkandawire-Valhmu and Stevens, 2009, Comack, 1999). This increases their vulnerability to social problems, sexual abuse and makes them have limited control to make decisions about their sexual and reproductive issues. It is in this context that a feminist perspective became relevant in the current study. Acknowledging that gender and social power relations constitute key structures influencing young women's experiences and agency (Mkandawire-Valhmu, 2009), the methods and analytical lens used in the current study attempted to take these structures into account.

In postulating women's experiences as 'epistemologically privileged' feminists emphasise the need to "account for diversity and difference, of women's multiple realities and fractured identities" (Comack, 1999:290). In this context, feminists acknowledge that women as the disempowered (living in a given reality) have the capability to know and understand what the socially, economically and culturally priviledged individuals cannot. Furthermore, they have progressively criticised the ways in which knowledge is constructed that it often omits women's perspectives and experiences (Oakley, 1993). Therefore, feminists highlight 'trust, empathy, non-exploitative relationships and empowerment as key factors in carrying out research' (Grbich, 1999:61). In this study, this necessitated the use of methods to minimise any imbalance of power dynamics within the relationship between the researched and the researcher. This was one of the reasons for the development of the participant-owned 'my story' book which was given to young women to complete (see Sections 3.3.2.2 and 3.5.3.1 for full explanation of this method). The use of 'my story' book was intended to minimise any possible exploitative power imbalances between herself and the participants. 'My story' book aimed to empower young women to actively construct the story of their experiences and to illuminate the inconsistencies in their lives. The young women were highly articulate and confident during interviews, as they explained their experiences in relation to the images they had chosen and were ready to discuss with the researcher.

Another important issue that feminists have discussed in depth relates to the interview setting. Feminist researchers have written extensively about different levels of reciprocity in the interview setting as the strategy in terms of considering how to reduce

exploitive power imbalances between the researcher and the researched (Oakley, 1993, Gelsthorpe, 1992, Ribbens 1989). For example, Ribbens (1989:584) argues that to talk about oneself as a researcher during interviews can be regarded as 'breaking the research contract' and can significantly impact on what the participants can reveal during interviews. However, Oakley (1993:235) in her work with women indicates that, 'an attitude of refusing to answer questions or to offer any kind of personal feedback was not helpful in terms of the traditional goal of promoting rapport' – 'no intimacy without reciprocity'. As such, the researcher answered all personal and research questions as fully as it was required. On the emotive issue of whether I experienced being rejected by a parent/caregiver/sexual partner as agonizing (common issues with the young women), I told them I was not rejected per se but I was raised up by my grandmother in the village while my parents were living in the city. As such, I regarded it important to utilise the resources that were available in the village to achieve my academic and vocational goals. Advice questions I also answered fully and referred them to health professionals when necessary. I felt that if participants were willing to tell me their personal and sensitive stories, it was fair enough to respond to relevant questions they wanted to ask. This was considered more important in this study because the topic was very sensitive, and most young women and their caregivers were more curious to know more about the researcher hence were offered the opportunity to ask questions and relevant responses were given.

Several feminists have also debated the advantages and disadvantages of the researcher having a shared identity with the group being studied in terms of gender (Maynard, 1994, Oakley, 1981, 1993, Merton, 1972). Oakley (1981, 1993) argued that female researchers enjoy the advantages of having an 'insider' status when interviewing female participants. This influenced the researcher to conduct all the interviews herself as opposed to recruiting interviewers. Changing the role of a clinician to a researcher has been a challenge particularly during the process of analysing and synthesising the data. Looking through a health professional lenses, risk was seen as something that needed to be prevented rather than to be understood. In addition, the researcher's personal experience shaped the age of the young women recruited in the study. As a female, a mature lady and a mother, the researcher felt older adolescents had wide experience than younger adolescents (10-14 years). Therefore, the researcher decided

to select older participants particularly ages 15-19 based on the age she felt the young women could have broader experiences and be open on sensitive issues like sexual behaviours. On the other hand, some feminists argue that shared identity is not necessarily adequate to build easy rapport (Reay, 1995, Riessman, 1991), and/or the participants may feel judged by the researcher's 'insider' knowledge hence limiting disclosures (Kelly et al. 1994). In this context, the researcher felt that use of 'my story' book encouraged young women's openness on sexual issues, hence yielded powerful and rich data on their sexual experiences.

3.3.2 Research methods

A variety of qualitative data collection methods exist which would be suitable for the current study. However, when determining the most appropriate method, it is important to consider the aim of the study, as it is recommended to adapt methods and procedures of analysis basing on research focus (Miles and Huberman, 1994). Silverman affirms that research methods should aim to collect data that is most appropriate to facilitate answering the research aims and objectives (Silverman, 1993). The method that can yield thoroughness and clarity of the data collected and make sure that the evidence generated is based upon rationality and credibility of methods (Miles and Huberman, 1994) could help facilitate objective analysis of qualitative data (Silverman, 1993). Since qualitative interviews allow the individual voices of participants to be heard (France, 2004:177), this was considered the most appropriate method to use in the current study.

3.3.2.1 Qualitative interviews

Rubin and Rubin (2012) describe qualitative interviews as a technique that aims to generate an in-depth understanding of a particular social phenomenon. Blaikie (2007) further adds that qualitative interviews allow women's voices to be heard and the worlds in which they live to be revealed. It allows for the possibility of non-hierarchical, non-manipulative and non-exploitative relationships between the researcher and the researched. The qualitative interview method recognises research participants as competent social actors situated in distinctive environments where their personal stories unfold, and enables expression of issues affecting their own lives and opinions in a meaningful way, thus providing an opportunity for young women to reflect. As such,

during a qualitative interview, some of the questions asked may depend on the responses of an individual subject or can emerge during researcher-participant interaction (Rubin and Rubin, 2012).

There are three types of interviews: unstructured, structured and semi-structured (Holloway and Wheeler, 2010). With unstructured interviews, the researcher starts with a general question in the extensive area of the study and often has minimal direction and control of the interview. When the respondent goes off track it can be difficult to get them back. As such, the interviews often generate data with different patterns and structures from one interviewee to another (Patton, 1990), which makes the data analysis very time-consuming and exhaustive. Thus, the unstructured interviews 'do not all deal with the same topics so their contents cannot easily be collated' (Robson, 1993:229). Patton sums it up that unstructured interviews are not appropriate when research goals are well-defined (Patton, 1990) hence could not be adopted for the current study. Structured interviews involve the researcher guiding the informants' responses or the direction of the interview and thus were not considered appropriate for this study. A semi-structured interview may be described as having "capacity of interviews to elicit data on perspectives of salience to the respondents rather than the researcher strictly dictating the direction of the encounter, as is the case with structured interviews" (Barbour, 2008:119). This approach was considered particularly relevant for the current study. The researcher guided the interviews by having a specific topic to learn about, prepared a limited number of questions in advance and planned to ask follow-up questions depending on the participants' responses (Rubin and Rubin, 2012). Basing on the critical realist approach, open-ended questions were used during interviews to explore the young women's experiences and meanings regarding growing up with HIV, and caring or providing care to young women growing up with HIV. An open ended approach provided the latitude needed for the participants to narrate their subjective experiences of rendering care to young women growing up with HIV (Conrad, 1990).

Alderson suggests that a key question in research about young people is: 'how can adults get beyond the power constraints and expose the complexities of power in dealings between adults and young people?' (Alderson, 2000:254). Christensen and James respond by stating that:

> "Only through listening and hearing what young people say and paying attention to the ways in which they communicate with researchers will progress be made towards conducting research with, rather than simply on, young people" (Christensen and James, 2000:7).

In the current study, the semi-structured interviews were conducted with caregivers and service providers, and visual based interviews with the young women as discussed in Sections 3.5.3 and 3.5.3.1. The semi-structured interview approach sought to discover what young women thought of their social world, to uncover their experiences and gain explanations why they behave the way they do as they grow up with HIV. This is in line with Murphy and colleagues, who state:

> "If you want to understand what people do, believe and think, ask them" (Murphy et al., 1998:112).

In this context, the interviews enabled the researcher to investigate the subjective experiences and attitudes of young women through their contextual presentation of meaning and experiences of growing up with HIV. Individual interviews were viewed as social events that enabled the young women, their caregivers and service providers to express their interpretations of their experiences (Freeman and Mathison, 2009). Through interviews, the young women were given voice to express their experiences of living with a perinatal HIV. This promoted their capacity building and facilitated understanding of how they interpreted their own social situations, both as individuals and a social group with distinctive needs. It also enhanced awareness of how they construct their social realities as young women.

As Murphy et al and Britten sum up, interviews allow the researcher to follow up fascinating ideas and to get to new dimensions which may not have been foreseen at the outset of the interviews (Murphy et al., 1998 , Britten et al., 1995). Similarly, in the current study with the use of a single, open-ended question to initiate the interviews, new and fascinating issues/ideas which were not foreseen at the beginning of the research were uncovered as young women raised issues of personal relevance and concerns about growing up with HIV. As such, additional questions were asked by the researcher to probe or follow up the leads mentioned by the participants. The approach

made young women feel more comfortable disclosing sensitive issues affecting their lives, thus revealing the complex realities influencing their real world which were comprised of individual, socio-cultural, relational and structural factors. This promoted in-depth understanding of their experiences within their social worlds which is consistent with the critical realist's approach that embodies the real underlying mechanisms of social reality i.e. the difference between surface appearances and depth reality, necessitating expansion of data analysis beyond the descriptive account to one where the investigator offers an explanation of the data.

However, Kellett and Robinson indicate that it can be methodologically difficult for an adult researcher to find techniques to listen to the young people's voices in research (Kellett and Robinson, 2004). They argued that the gap in generations between the adults and young people creates differences in viewpoints, experiences and power that becomes difficult to be completely bridged. In response to this concern, Samuels stressed the value of techniques for "bridging the culturally distinct worlds of the researcher and the researched" (Samuels, 2007:199). In the current study, the worlds to be bridged were those of the young women and the mature female researcher, and also the worlds of young women who were accustomed with the experiences or challenges of growing up with perinatal HIV and the world of the interviewer who had no experience or was not familiar with this. Chambers suggests that visual techniques offer new ways in which those who are marginalised can present their realities to those in power and perceive that what they say will be respected, influence policy and make a difference (Chambers, 1998). Therefore, use of visual techniques seemed relevant in the current study to enable and empower the young women, who face significant social disadvantage (Scheyvens and Leslie, 2000) to have their voices heard.

3.3.2.2 Visual techniques

A visual approach to interviews involves images generated by the researcher or participants to promote depth of information by broadening the established method of in-depth interviewing (Reavey and Johnson, 2008). Proponents of social studies for young people suggest that visual research methods are appropriate, stimulating and effective ways of connecting young people to research, and enable insight to be gained into their social worlds (Tunstall et al., 2004, Christensen and James, 2000). Visual

approaches allow young people to express their views or concerns in ways that could not otherwise be possible. This helps young people to express their agency, thus giving voice to those who are less often heard in the research milieu (Reavey and Johnson, 2008). While there are different visual methods such as self-portraits, graphic elicitation methods (mapping techniques, and timelines) and arts-based technique (drawings), in the current study the researcher expanded the domain of investigation by designing 'my story' book as the basis for in-depth interviews with the young women. 'My story' book included a sentence completion exercise and researcher-generated images depicting different life experiences, events and issues affecting lives of young women as they are growing up with HIV (see Appendix N for 'my story' book - images and sentence completion exercise). Use of 'my story' book was correspondingly based on "assumptions about the role and utility of images in reflections that words alone cannot" (Clark-Ibanez, 2007:171). The insight and reflections of daily lives emerge through choosing images of issues assumed (Holliday, 2004), and through discussions held with the researcher surrounding the selected images. Creatively mixing the methods, as Mason suggests, encouraged young people to think 'outside the box', and generated innovative techniques of interviewing them and understanding their social worlds (Mason, 2002).

The images and sentence completion exercise in "my story" were evocative methods and enabled young women to express their own world views. This facilitated a more holistic method of communication and enabled the women's stories to be captured through metaphors, ensuring the researcher attended to social reality in diverse ways, making the ordinary become extraordinary. For instance, the use of images and the sentence completion exercise revealed that male relationships including the adolescent-male service provider relationship boosted young women's self-image, but threatened the provider's professional integrity. Thus, 'my story' book facilitated explanation and discussions with young women concerning their chosen images and helped to generate rich interview discussions with the adult researcher. 'My story' book, therefore was considered appropriate in exploring life experiences and needs of the young women including their sexual behaviours and experiences. In this context, the use of 'my story' book assisted young women to actively construct the story of their experiences, which communicated not only key events but also contexts, feelings, values, challenges and

opinions as they were explaining the experiences in reference to the chosen images. This gave primacy to the young women's own explanation of the images. It also resulted in a shift towards a more equitable power distribution and provided the autonomy needed for the young women to reveal personal stories about the course of their illness. This allowed their voices to be heard and by telling their stories influenced change in their social worlds (Conrad, 1990).

Whilst much has been argued on the significance of images in research, and its multiplicity, Reavey and Johnson (2008) stress on its value in support of research and the likelihood to generate findings and add on understanding. For example, in a similar study to this (but with young men and women), adolescents were reported to be reluctant to discuss sexual matters, and avoided direct questions on sexual issues during interviews (Busza et al., 2013:90). However, in several other studies (Reavey and Johnson, 2008) including the current research, use of images and sentence completion exercises yielded rich data on sexual behaviours and experiences. Images lessened the directness of the researcher's gaze, and reduced the risk of the young women feeling too shy to express their feelings and experiences, or being overwhelmed by the researcher's presence. For example, an image of 'having a sexual partner' enabled young women to explain to an adult researcher how sexual abstinence did not resonate with the reality of the shared social identity and how male relationships boosted their self-image as young women. The images and the exercise expanded the modes of expression available to the young women, rather than just being an adult or researcher driven approach. This enabled data to be collected using visual method in addition to the spoken words and Gibson's suggestion that visual methods help young people find the words they need to express themselves (Gibson, 2012). Thus, in combining the interviews with the 'my story' book approach, a richer and deeper comprehension of growing up with HIV was gained.

In conclusion, use of multiple sources of evidence in this qualitative case study reflects an attempt to secure in-depth understanding of growing up with HIV for young women. However, the qualitative case study approach is typically open to criticism on account of the researcher's influence on a small number of cases (Hammersley, 1992). As such, Section 3.9 outlines the strategies that enhanced the trustworthiness of the approach.

3.4 Access and recruitment process

The study involved several stages: process of approval, familiarisation phase, access to and recruitment of prospective participants and data collection process (see Figure 3).

3.4.1 Study settings

Central to all researchers is the choice of an appropriate study site. While Bryman argues that the researcher needs to select a study site reflexively and be managed according to the context specificity in order to access the reliable views of the researched (Bryman, 2008), the choice of the sites in the current study was typically purposive. This was based on Pope and May's idea that "it is not to choose a setting to generalise to a whole population but to select a setting that is likely to demonstrate salient features and events of behaviour relevant to the research question" (Pope and Mays, 2006). Three sites were selected for the research: Maziko and Chiyembekezo HIV Management Centres, both of which included provision of paediatric HIV care which included young people and Yankho District Hospital specifically the HIV clinic, as a rural facility affliated to Maziko Centre. Maziko Centre is a non-governmental and non-profitable organization working in partnership with the Ministry of Health and manages 10% of all children commenced on antiretrovirals (ARVs) in Malawi, including young people. Chiyembekezo Centre is affiliated to the Ministry of Health and is the first specialist centre in Malawi for the care and support of people living with HIV (World Health Organization, 2003).

3.4.2 Process of approvals

Ethical approval to conduct the study was received from the following research ethics committees: Medical School Ethics Committee, The University of Nottingham in UK in December 2011; College of Medicine Research and Ethics Committee (COMREC), a sub-committee of the Malawi National Health Sciences Research Committee in Malawi in November 2011, and The Institutional Review Board for Human Subject Research for Baylor College of Medicine and Affiliated Hospitals in March 2012. Additionally, approval to access perinatally HIV infected adolescents, their caregivers and the service providers in the centres was obtained from the institutional gatekeepers, the Clinical Director of Chiyembekezo Centre in January 2012 and the Executive Director of Maziko

Centre in March 2012 (see Appendix A for ethical approvals). Having received the approval from the Directors of the selected centres, potential subjects were approached to consider their participation in the study.

3.4.3 Approach of prospective participants

Posters were displayed in the waiting rooms of the centres inviting participants for the study. The posters precisely indicated the category of participants required for the study and that their participation was entirely voluntary (see Appendix B for the recruitment poster).

The next phase involved observations for the researcher to familiarize herself with the study settings and potential participants for in-depth study. Each member of staff that would potentially be observed was given an information pack containing an observer information sheet and an opt-out slip by the receptionist (see Appendices C and D). The receptionist then collected back to the researcher the opt-out slips from those staff who chose not to be observed. Healthcare professionals working in the centres gave young women the information packs containing the observer information sheet and an opt-out slip both in English and Chichewa (local language) depending on young woman's preferred language (see Appendices E and F). English is not the first language of communication in Malawi although it is the official language. Therefore, all young women were provided with adequate information both verbally and in written form to ensure they understood what participating in the research study entailed. Healthcare professionals gave the young women a verbal explanation about the study, and collected the opt-out slips during their following visit to the centre and returned them to the researcher. A full explanation of the study was given to prospective participants by the researcher to allow them think about whether they wished to participate, hence offering them an 'opportunity to hear their views of any kind of taken-for-granted issues regarding research with young people' (Freeman and Mathison, 2009:29). Healthcare professionals explained the study and read the information sheet in Chichewa to adolescents who were illiterate.

For the in-depth study, the healthcare professionals approached both young women who met the inclusion criteria and their primary caregivers to ask them to participate in the study. Both young women and their caregivers were approached on an individual

basis if they expressed an interest in participating in the study. This was undertaken in order to provide them with opportunity to discuss any concerns and ask questions. The study was explained to young women and their caregivers and potential participants were given information sheets (see Appendices G and H for the information sheets). The leaflet included information on the nature and purpose of the study, voluntary participation, benefits and risks, storage of information, anonymity and confidentiality. It also included a statement waiving confidentiality if the adolescent shared information suggestive of being abused or at risk of any harm. This was done in order to obtain full informed consent regarding the individual's participation in the study. Young women who visited the centres on their own were given information sheets for their caregivers. This invited the caregiver to participate in the study and bring feedback during the following visit to the centre. If the caregivers were unable to attend the centre, the researcher visited them to explain more about the study and followed this visit up with a phone call or another visit. The young woman and her caregiver were then given an opportunity to identify a service provider who had been in constant contact with the young woman for at least six months. This was done to attain a complete 'unit of analysis' comprising of an adolescent, her caregiver and a chosen service provider. The service providers were approached by the researcher to determine whether they were interested in participating in the study (see Appendix I for the information sheet). If a service provider declined, the young woman and her caregiver were asked to identify an alternative. For rural participants, a similar approach was followed during monthly mobile clinics.

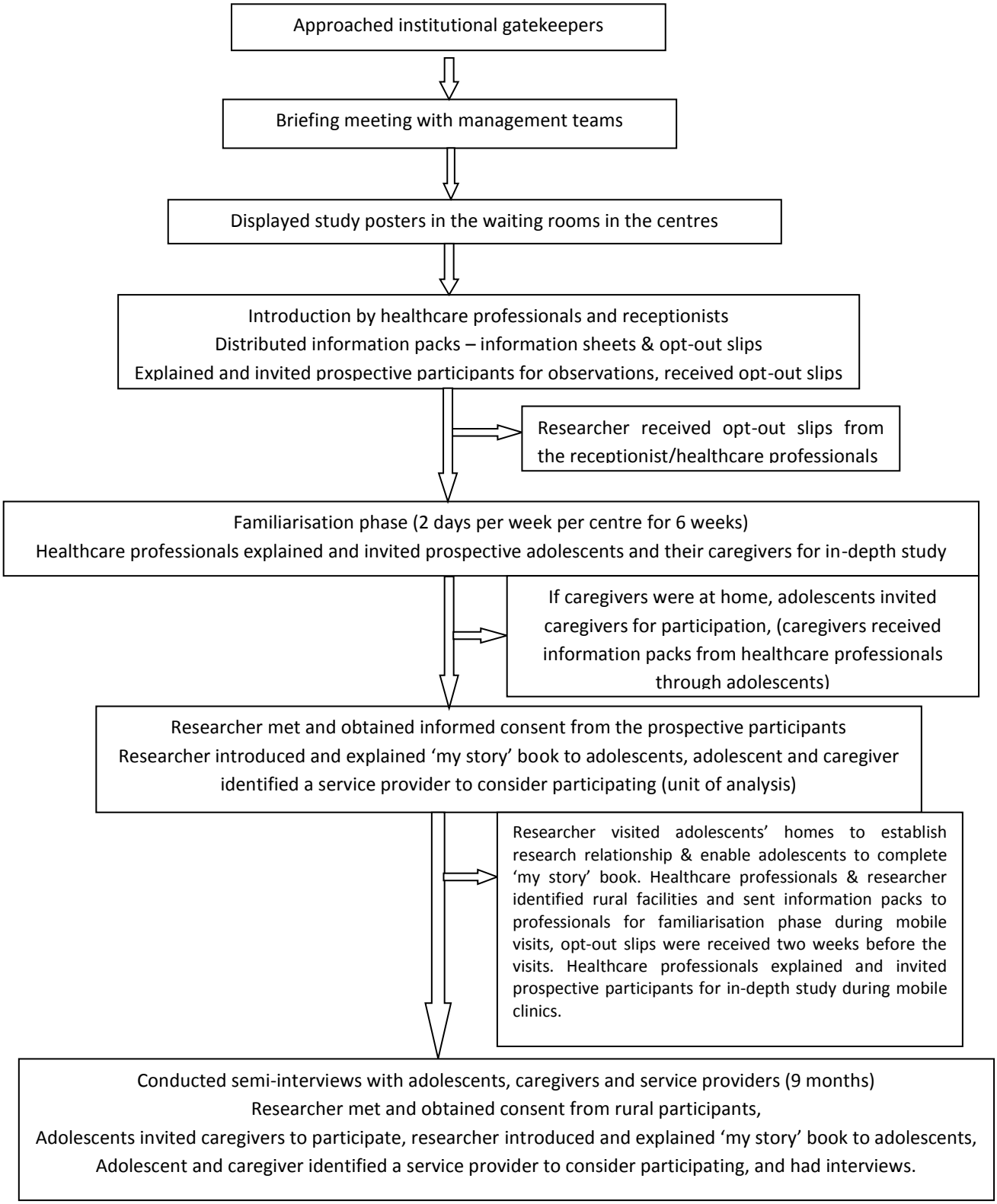
3.4.4 Recruitment

Only adolescents and healthcare professionals that had indicated a willingness to be observed were involved during the familiarisation phase. For the in-depth study, the young women and their caregivers who expressed an interest in participating in the study were invited to meet the researcher, who discussed in detail what the study involved. When the researcher was sure that potential participants understood what was involved and had given their consent, the pair was recruited into the study. Similarly, the chosen service providers who showed an interest in participation were recruited after being given a detailed explanation by the researcher. Eight young women were recruited from each HIV management centre, and four from the rural

facility, in order to achieve an adequate number of complete cases. However, out of the twenty recruited young women, only fourteen could be described as complete cases i.e. were comprised of a young woman, her caregiver and a service provider and were involved in in-depth study. Four were from Maziko Centre, six from Chiyembekezo Centre and four from Yankho District Hospital. Thus ten cases were recruited from the urban setting and four from rural location. Only young women whose caregivers also participated in the study were given a full explanation about the use of 'my story' books and took part in the sentence completion exercise (see Figure 3 for access and recruitment process).

Figure 3 Access and recruitment process

(Done concurrently at Maziko and Chiyembekezo HIV Management Centres)



3.4.5 Sampling

Since the focus of case study research is on depth of understanding, the researcher adopted Ritchie and Lewis's idea of "retaining depth of data collection rather than breadth in terms of sample size, even if this meant focusing the study on certain parts of the population" (Ritchie and Lewis, 2003:104). Therefore it became significant to explicitly state the criteria used to select each of the cases (Creswell, 2007).

A purposive selection of cases was considered in accordance with Stake's argument that "balance and variety are important; opportunity to learn is of primary importance" (Stake, 1995:6). According to Stake, selecting cases that researchers can learn the most from may be "superior criterion to representativeness" (Stake, 2005:451). However, a review of prior studies had identified variables known to influence the experiences and needs of perinatally HIV infected adolescents as well as those about which little was known or findings were contradictory. Few studies explored the needs of adolescents that acquire HIV perinatally and no published study had specifically focused on female adolescents. Therefore, the current study recruited young women with a wide range of variables in terms of age, parenthood, settings (rural/urban), literacy level, economic status, sexual behaviour, marital and child bearing status in order to compare and contrast their experiences, and identify commonalities and differences in their needs. This recruitment strategy provided a diverse and in-depth understanding of young women's experiences and needs in different contexts (see Table 2 for the characteristics of the young women).

As Ritchie and Lewis suggest, it was essential to prioritise the selection criteria as recruitment progressed to ensure that the sample size was manageable (Ritchie and Lewis, 2003). From this perspective, to help advance the richness and scope of the data, some young women were included in the current study because they differed from the other participants of their group in interesting ways, most notably in terms of academic progression, marital and child bearing status. Some young women were selected following the lead from service providers, as an example one service provider stated,

> "You will have to interview……she may be an interesting case, she is grown up and has gone through hard times in her life as a young woman" (researcher's field notes).

Table 2 Characteristics of the young women

Pseudo name	**Age**	**Setting**	**Parental status**	**Caregiver** *All aunts (sisters to their mothers*)	**Literacy level**	**Age on ARVs**	**Age Known status**	**Teen club**	**Sexual behaviour**					
									Age of initial relationship	*Current sexual relationships*	*First sex*	*No. of partners*	*Child bearing age*	*Marital status-married*
Ziliwe	18	Urban	Double orphan	Aunt	Form 4	15	15	√	15	x	15	unknown	17	x
Nane	19	Urban	Maternal orphan	Father	College	12	14	√	15	x	16	2	x	x
Penina	19	Urban	Maternal orphan	Aunt	Form 4	13	13 accidental	√	17	√	x	1	x	x
Ulemu	18	Urban	Double orphan	Sister	Form 3	11	17 accidental	√	x	x	x	x	x	x
Mwatitha	18	Urban	Double orphan	Aunt	Form 3	16	16 accidental	√	12	x	12	3	x	x
Gonjetso	16	Rural	Double orphan	School Headmaster	Form 3	13	13	√	x	x	x	x	x	x
Fatsani	17	Urban	Both alive	Mother	Form 2	13	15	√	14	√	14	4	x	x
Alindine	19	Rural	Double orphan	Aunt	Teacher' college	13	13	√	17	x	x	1	x	x
Chitsanzo	19	Rural	Double orphan	Sister	Form 2	11	11	x	14	√	15	3	17	√
Tawina	18	Rural	Maternal orphan	Uncle	Form 3	15	15	x	14	√	14	5	x	x
Zaiwo	19	Urban	Paternal orphan	Mother	Std 5	2	8	√	13	x	14	1	14	x
Tamando	17	Urban	Both alive	Husband	Form 1	10	10	√	11	√	12	1	15	√
Dalo	19	Urban	Both alive	Mother	Std 8	12	12	√	12	√	12	unknown	15	√
Tanyada	16	Urban	Both alive	Both (M&F)	Std 8	10	12	√	x	x	x	x	x	x

However, basing on the suggestion of Green and Thorogood, “the intention was to keep sampling and collecting data until nothing new was being generated, this strategy is known as sampling to saturation” (Green and Thorogood, 2004:103). The constant comparison of data helped the researcher to make the decision that data saturation had been reached (Glaser and Strauss, 1967). The keeping of a thematic log during in-depth interviews, keeping detailed researcher field notes, writing reflective remarks during data collection, ongoing reading of literature and transcript reading were also some of the research approaches that facilitated decision about data saturation and ongoing sampling (Tuckett and Stewart, 2004). These approaches allowed for comparison of experiences and needs of young women by comparing data from each participant against each other from different perspectives (Charmaz, 1990:1168). At this stage, increasing the sample size no longer contributed new evidence of significance for ongoing thematic development, which Ritchie et al. describes as “a point of diminishing return” (Ritchie and Lewis, 2003:83).

3.4.5.1 Inclusion and exclusion criteria

This study recruited participants who:

- Were female adolescents aged between 15-19 years.
- Had perinatal exposure to HIV and were aware of their HIV positive status.
- Were willing to participate in the study and had a cognitive capacity to complete ‘my story’ book.
- Were attending HIV Management Centres (Maziko and Chiyembekezo Centres or Yankho District Hospital) for a minimum of six months
- Were attending the centres during a 6-12 month data collection period.

Young women who were pregnant, already had children or were married were not excluded, but needed to fulfil the other criteria to be included. However, young women who were unaware of their exposure to HIV, and were either clinically unwell or too sick to complete ‘my story’ book were excluded from participating in the study. This was done to reduce any perceived additional stress to such individuals and to minimise the potential loss of informants due to critical illness prior to completion of the study.

The caregivers and service providers recruited in the current study were only those who were willing to voluntarily share their opinions and experiences of providing care or health services to a perinatally HIV infected young woman (see Table 3 for characteristic of caregivers and service providers).

Table 3 Characteristics of caregivers and service providers

Category of participants	Characteristics	Number
Caregivers	Age group (years)	
	20-30	4
	31-40	3
	> 40	7
	Relationship to adolescent	
	Mother	3
	Father	2
	Sister	2
	Husband	1
	Aunt	4
	Uncle	1
	School headmaster	1
	Marital status	
	Married	11
	Single	1
	Widow/widower	2
	Literacy level	
	Primary level	2
	Secondary level	10
	Professional	2
	No. of dependents	
	1-2	3
	3-5	4
	> 5	7
	Length of caregiving	
	1-5 years	5
	6-10 years	3
	>10 years	6
	HIV Status	
	Unknown	5
	Negative	1
	Positive	8
	Source of income	
	Not working	6
	Small business scale	3
	Working	5

Category of participants	Characteristics	Number
Service providers	Age range	
	20-30	2
	31-40	8
	> 40	4
	Gender	
	Female	8
	Male	6
	Marital status	
	Married	7
	Single	5
	Widow/widower	2
	Length of contact	
	1-5 years	11
	6-10 years	3
	>10 years	0
	Professional status	
	Nurses	7
	Clinical officers	3
	Counsellors	3
	Paediatrician	1

3.5 Process of data collection

3.5.1 Procedure for data collection

Data collection period spanned the period from January - November 2012. Table 4 indicates the activities taken to ensure that reliable data was collected on the experiences and needs of young women growing up with HIV.

Table 4 Timeline for data collection process

Period	Focus of Investigation	Activities	Purpose
November to December 2011	Adolescents Caregivers Service providers	Interviews for pilot study Transcribing interviews Capturing of definitive images in Malawian context	For feasibility, clarity and modification or adjustment of the data collection tools
January to February 2012	Data collection tools, centres & participants	Initial familiarization phase, two days per week per centre, recruitment of participants , Meeting the advisory committee, Follow up on completion of 'my story' books.	Familiarization with the study settings & research participants. Gaining background information of centres and participants
March to November 2012	Adolescents Caregivers Service providers Complete 'cases'	Interviews Follow up interviews Transcribing recorded interviews Initial analysis	Data for the analysis Determining consistency of data with research aims and objectives & issues for clarification

3.5.2 Initial familiarisation phase

This phase allowed the researcher to understand the settings in which services are delivered to adolescents. In all centres, observations were conducted for six weeks and continued informally during the data collection period, specifically during teen club meetings to validate some of the issues raised by young women through in-depth interviews. Club meetings are conducted once every month at Chiyembekezo and once every two months for older adolescents at the Maziko centre. The researcher observed details that participants did not consider relevant to mention such as consultation styles and issues that seemed key for the service providers versus young women's needs, hence providing rich insights of young women's experiences and needs in different settings (see Appendix M for guide for observations). The observations did not form part of the data set as such; however key issues observed were explored in subsequent data collection activities. Whilst the researcher intended to gain background information and became familiar with the research participants, she ably ventured into the social world of female adolescents in order to learn first-hand how they access services, behave and interact with the professionals and what captivated or distressed

them. This was crucial in determining the range and quality of information and services accessed by the adolescents, and their independence in making decisions and choices or asking questions. Additionally, this phase began to examine relevant issues which were carried forward through in-depth interviews with the research participants. During this phase the researcher kept detailed notes on consultation styles, provider-adolescent interactions, service provision approach and adolescents' independence in making decisions and choices. This data was not formally analysed but complemented the issues that emerged from the data collected through individual in-depth interviews.

3.5.3 Individual in-depth interviews

This study employed semi-structured interviews which were conducted by the researcher in the participant's language of choice. This mainly included Chichewa (Malawian vernacular language) and English particularly for service providers. The interviews were conducted according to the participant's schedule, availability and preferences in terms of venue to minimise distress and ensure that participants felt at ease, particularly the young women. Green and Thorogood suggest that participants' homes or familiar places be considered more suitable for these types of interviews, as most participants feel more empowered in their own environments hence offsetting the power imbalance (Green and Thorogood, 2004). Contrary to Green and Thorogood's suggestion, the majority of participants in the study preferred to have their interviews conducted at the centres than at home. Only four caregivers chose to have their interviews at home. With the increased workload at the centres, scheduled interviews with service providers were often postponed, but none of them wanted to be interviewed at home. The reasons given included: finding it difficult to create time for interviews at home, or because their participation in the study was dependent on being chosen by the adolescent who was accessing health services from the centre. However, critical reflection suggests that there may be fear of stigma associated with the nature of the illness on the part of the service providers especially since they were not the individuals who were infected. It could also be that the male service providers, whom some of the adolescents tried to be familiar with, did not want family members to know about their involvement. In situations, where interviews were conducted at participants' homes, other family members were asked to stay at a distance, or sit

outside of the house where possible, while the interview was in progress to ensure privacy and confidentiality.

Initially, forty-two semi-structured interviews were conducted with the three categories of participants; three interviews for each case comprising of an adolescent, a primary caregiver, and a service provider (see Appendices O and P for interview guides with caregivers and service providers). The single, open-ended question posed to initiate the interviews with the adolescents, caregivers and service providers was, "*can you tell me about your story of growing up with HIV?"* Or "*can you tell me your experience of caring for or providing care to this adolescent, who is growing up with the virus?"* A semi-structured interview with open-ended questions enabled the participants to recount details from any aspect of their life, and to discuss those cultural aspects of their social world and social relations that they considered relevant. It also created the setting in which the adolescents were allowed to sketch the big-picture issues such as living with HIV, growing up and being a young woman with HIV (identity formation), and revealed challenges encountered in coping with a positive HIV status. Prompts and probes developed as the interviews progressed to encourage the respondents to think more deeply and facilitate openness for the complexity and uniqueness of individual experiences, challenges and perceived needs for young women. Like other questions, the prompts were not leading, but sometimes used summary interpretation of the issue to encourage further discussion. Service providers were encouraged to focus their discussions more on the case they involved with.

Follow-up interviews were conducted with some of the participants regarding issues arising from initial interviews that required clarifications, but were not as structured or detailed as the initial interviews. A repeated interview was conducted with one caregiver (aged 21, a sister to an adolescent) who became distressed as she was narrating about the nature of the relationship with their aunt. Since the interview was being conducted within the centre, the distressed participant was referred for support services (see Table 5 for initial, repeated and follow-up interviews conducted).

Table 5 Summary of initial, repeated and follow-up interviews

Process	Category of Participants	Number of Participants
Initial interviews	Adolescents	14
	Caregivers	14
	Service providers	14
Follow-up interviews	Adolescents	4
	Caregivers	3
	Service providers	3
Repeated interviews	Caregivers	1

3.5.3.1 Use of 'my story' book to facilitate the interview process

The concept of 'my story' book loosely originated from the idea of 'memory books'[11] and was designed in English and Chichewa (Malawian vernacular language). It comprised of images and sentence completion exercises (see Appendix N). Young women were invited to put stickers on images that best suited their different experiences, major needs and issues that impacted upon their lives, future aspirations and priorities. For the sentence completion exercise, they indicated reflective relevance of the chosen images to their experiences, needs and challenges. In addition, the sentence completion exercise included different kinds of questions to provide multiple opportunities for young women to state their experiences or views and the meanings they ascribe to the chosen images (Freeman and Mathison, 2009). The chosen images and the exercise constituted the basis of their interview with the researcher. Since young women were viewed as competent social actors, during interviews they were asked to elaborate or explain about their chosen images, and the meaning(s) they attached to them in relation to growing up with HIV. The main themes of the 'my story' book and the interview topic guides were derived from the literature, empirical data, research objectives, consultations with experts on the research topic and the

[11] A memory book is a tool used in memory work with HIV infected individuals. It is a diary of a typical day and spaces for drawing (Evans & Becker, 2009).

assumption that it is not acceptable for adolescents to discuss sexual issues with adults such as caregivers and service providers.

The ‘my story’ book was carefully designed with sensitivity in mind of the research area, the young woman’s developmental stage and literacy level. The focus was on how ‘my story’ book could be used to evoke memories and enhance young women’s reflexivity, competencies, and capacities in expressing their feelings, values, perceptions, and aspirations. In addition, importance was placed on getting them to think holistically about their real life experiences, needs, challenges and identities. Furthermore, central to ‘my story’ book were the explanations, interpretations and meanings surrounding the chosen images. These images were used as a catalyst to guide their in-depth interviews with the researcher, as the young women were asked to explain their reasons for selecting the particular images and the meaning(s) attached to them. The ‘my story’ book gave young women more control over the representation of their own social realities as they were allowed to choose images that best matched their individual experiences.

While use of ‘my story’ book provided young women with the opportunity to bring in issues of personal concern and use a mode of dialogue that was familiar to them (Clark, 2011 , Freeman and Mathison, 2009 , Wengraf, 2001), it also made it easier for the researcher to explore in-depth experiences and issues with the young women resulting in candid discussion of sensitive topics. Thus, use of ‘my story’ book successfully allowed the researcher to overcome silences, and explore those aspects of young women’s lives that might be difficult or sensitive to express in words. It also enabled the researcher to gain insight into the young women’s visualizations about their own life with sensitivity to associations and meanings. Some of the young women’s visualizations were predominantly insightful and significantly facilitated the researcher’s own process of making sense of the collected data. For instance, Penina’s shared similar experiences with Tawina, as they both chose the image of having a sexual partner. Both had negative body images related to HIV and intake of ARVs which made both choose images on ‘depression and loss of hope’ as the initial state in their lives as young women. However, having sexual partners made them feel loved and accepted, despite their poor body images, which led to the choice of an image of ‘am happy’. During interviews, both elaborated on a change in their feelings and perceptions over time,

which signalled that male relationships boosted their self-esteem, social status and identity. They felt their changed body images did not hamper their physical attractiveness towards young men, and that they were seen like any other young woman as illuminated in Chapters Six and Seven. Therefore use of 'my story' book provided valuable data regarding how young women accounted for change in their social world, and how they were living, and were affected by HIV. As such, Section 3.6 focuses on how the collected data was constructed and interpreted.

3.5.3.1.1. Reflections on use of my story book

Use of 'my story' book posed a challenge. The plan was for adolescents to complete 'my story' book at their own time and pace within the scheduled period of data collection, in order to give them a better sense of control over the activity. However, some young women (three) in foster families took two to three months to complete 'my story' book as they were making every effort seeking for a safe place and to maintain privacy and confidentiality of the issues written in 'my story' book. This was very challenging and expensive for the researcher because more visits to adolescents and their families were conducted to establish a degree of trust in the research relationship and to enable adolescents to complete 'my story' book. The delay in completion of 'my story' book could also be attributed to the underestimation made by the researcher around the challenges encountered by adolescents to complete 'my story' book in foster families despite their commitment to undertake the exercise and underestimation of need for secrecy.

For future studies adopting use of 'my story' book with young people, plans are needed in advance on how adolescents could be assisted in terms of safe spaces and places, thus when and where to complete 'my story' book (taking into account their shorter attention spans) and where to store 'my story' book during the period of completing the exercise to ensure maximum privacy and confidentiality. This is because young people rarely have control over their environment and are reliant on adults to facilitate their engagement in research (e.g. storing their health related information including the research documents). Therefore 'my story' book, being a young person's story needs to be kept sensitively, in privacy with appropriate care to gain trust.

3.6 Data analysis

3.6.1 Data transformation and management

All the interviews with adolescents, caregivers and service providers were recorded using an audio digital recorder. Permission was gained from each of the participants to record the interview and no-one withheld permission. Digital recording is an increasingly significant data recording process used in qualitative research. Silverman points out that "transcript of such recording, based on standardised conventions, provide an excellent record of naturally occurring interactions, and can offer a highly reliable record to which researchers can return as they develop new hypothesis" (Silverman, 2006:20). For instance, Powney and Watts (1993) indicates that using an audio recorder liberates the participant to focus upon the assignment at hand. The effectiveness of the digital recorder therefore lessened the researcher's burden of recording activities in this complex data collection process. Audio recording provided a complete description of participants' responses and comments in the context with which they were made hence 'facilitating the interviewing process' (Kelly, 2010:313). Audio recording further allowed the researcher to return to the recorded data time and again with the guarantee of all information intact. In addition to recording the interviews, the researcher also took hand-written notes.

Since the research was aimed at investigating participants' own experiences, the researcher transcribed all the recorded interviews verbatim soon after each interview. This was done in order to add comments, particularly the emphasis on observations made, emotions expressed and facial expressions. In addition, any unclear sections in the recording were adequately recalled and could be included in the transcript. Interviews conducted in Chichewa were mostly transcribed straight into English by the researcher, herself a native speaker of Chichewa. Each transcript was then audited against the original audio recording by a lecturer in language and communication (bilingual expert), who is also an HIV and AIDS work place coordinator.

Reading of the transcripts was undertaken while listening to a recording of the original interviews, noting aspects of emphasis and tone, all of which were relevant in conveying meaning and could significantly alter the meaning of utterance. The main finding of this procedure was that although a few sentences were phrased differently from the original digital recording, there was no significant effect on the text's meaning. Transcribing the interviews enabled the researcher to ensure accuracy (Riessman, 1993), and gain "close contact and familiarity ……with the data" (Boyatzis, 1998:45). Transcribing each interview (that ranged from 40 to 80 minutes long) took between three to eight hours. The close attention required to transcribe the interviews enabled the researcher to develop a more thorough understanding of the data, and facilitated the close reading and interpretative skills required for on-going analysis of the data (Lapadat and Lindsay, 1999).

Field notes were made immediately following each interview for the researcher's understanding of the focus areas (Wengraf, 2001), and to provide an alternative record and memory trigger in case some parts of the recordings proved unintelligible. The notes consisted of a chronological diary kept throughout the duration of fieldwork and combined observational descriptions, records of informal discussions with the research participants, and personal experiences and responses. Though a comprehensive overview of the advantages and disadvantages of using qualitative software packages is provided (Bazeley, 2007), a point worthy to note here is that no software can fully perform qualitative data analysis which must still be done by the researcher and this process is described in the next section.

3.6.2 Retroductive analysis

Although Easton (2010:123) argues that "critical realism is highly compatible with the case study approach, he proposes that critical realism would require case studies to answer questions like, what caused the events associated with the phenomenon to occur?" As such, critical realists stresses on discovering the real mechanisms or structures which best explain the given events or the visible behaviours of people. This interplay between the behaviours, which are visible and influential mechanisms which are invisible (also referred to as structures) closely links to the concept of retroduction. It is the process of "moving backwards from an observed event and asking, what must

be true in order to make this event possible?" (Easton, 2010:123). Similarly, Yin (2009) states that to analyse data, the starting point must be a question, then techniques are identified to address the question, thereby enabling tentative conclusions to be drawn depending on the weight of the evidence. The current study moved beyond merely identifying which events co-existed, and penetrated to a deeper level of social reality by discovering the real mechanisms or structures that led to the practices of the young women. This is what Easton (2010:123) terms 'retroductive analysis, in which events are explained by identifying mechanisms which are capable of producing the events'. This iterative process of uncovering the underlying structures and mechanisms relevant to the topic under study helps explain why critical realism is a fitting approach to case studies. Thus, the retroductive analysis provides an alternative way of answering 'why' questions (Blaikie, 2007). Retroductive analysis relies on, or combines, elements from deductive and inductive processes facilitating understanding of how the underlying structures and influential mechanisms enable different events to occur (Easton, 2010 , Downward and Mearman, 2007). In this context, the current study employed the inductive process, which "embodies the shallow realist ontology that presumes that there is a reality out there with regularities that can be elucidated" (Blaikie, 2007 :105). However, the process of retroduction continued throughout the data analysis process.

The inductive process is an approach that is data-driven rather than by a pre-existing coding frame or the researcher's analytical preconceptions (Patton, 1990). Codes and themes are identified in the data. In addition, Yin indicated that to ensure methodological congruence, the analysed data should be in line with the philosophical underpinning of the study (Yin, 2009). Therefore drawing from a critical realist's perspective, the qualitative computer analysis programme QSR NVIvo 10, was used as a tool to systematically identify, sort, code and categorise data for the fine-grained, detailed analysis and comparison of cases (Gibbs, 2002). Using this approach, each participant's transcript was retrieved and coded while examining the reported events, the underlying mechanisms and participant's interpretations of what had happened, focusing on 'how', 'why' and 'why not'. The programme enabled flexibility to be maintained in the on-going analysis and facilitated the retroduction process. This allowed rethinking and reorganisation of codes in the light of other participants' transcripts, hence making the retroductive process central to the analytical phase. To

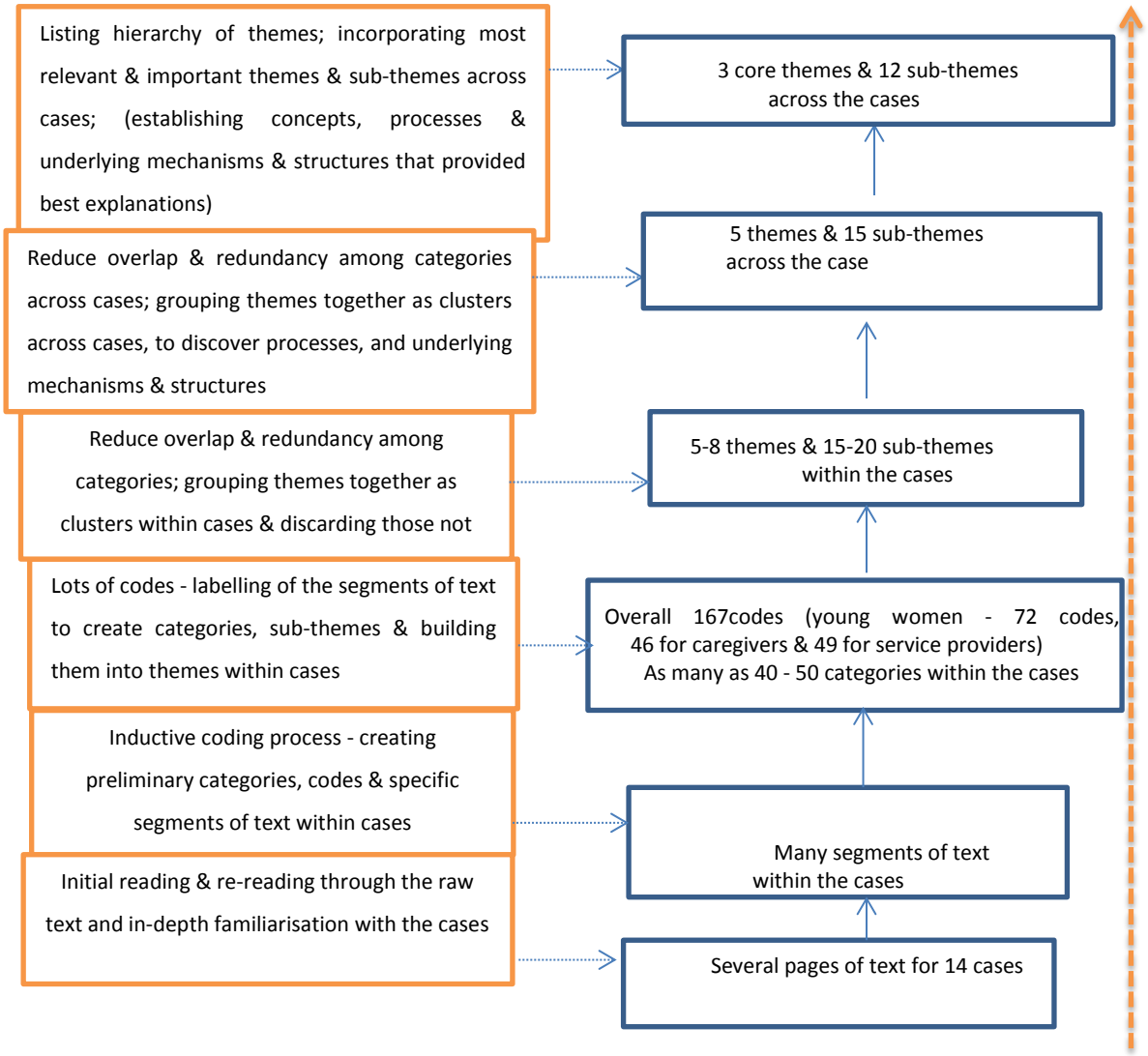
locate the real underlying structures and mechanisms that were responsible for producing the events (young women's experiences and practices), the inductive process involved:

- Close reading of the raw text to be familiar with the content and gain understanding. Notes of any observations and thoughts were made by the researcher during this phase.
- Initial coding of each transcript, all codes were labelled and given a description.
- Using both the 'free node' and 'tree node' functions to organise data in the computer software to sort and rank codes. Since it was clear how concepts related to each other, it was possible to build tree nodes and creating a hierarchy of codes.
- Identifying key concepts and linking them to underlying processes, mechanisms and structures
- Creating individual codes or groups of codes to promote engagement with the content of the code and to determine preliminary categories, sub-themes and themes.
- Overlapping coding and uncoded text. Themes were then grouped together as clusters with a view of creating a hierarchy of themes, and each sub-theme was checked for fitness by examining whether consistent with the remaining data. One segment of text could be coded under more than one sub-theme. Conversely, a considerable amount of text was not assigned to any category because it was not related to the aims of the study.

During the review and refining process, the themes were divided into two groups: 'free' and 'tree or grouped' themes to facilitate in-depth analysis of the social realities of the young women which is congruent with critical realism. 'Free' themes were considered as stand-alone and had no implicit association to any other themes, while 'tree/grouped' themes were constituent parts of the key theme or topic. Some categories or sub-themes were combined or linked when the meanings seemed similar. An example could be the two themes that labelled positive and negative influence on a young woman's self-image as she is growing up with HIV. While 'being in a sexual relationship' seemed to positively influence the young woman's self-image, 'change in body image' elicited stigma and discrimination from others hence resulting in a negative

influence on identity and self-image. This division helped in finding potential patterns within the coded themes. Coding was stopped when the themes were distinct, refinements were not adding anything substantial and all objectives of the study were addressed (Braun and Clarke, 2006). All the collated extracts relating to each theme were grouped together by source to facilitate ease of access and direct comparison (see Figure 4 for the modified coding procedure which was conducted for individual accounts, within the case and across the cases).

Figure 4 The modified coding procedure



Source: Modified from Creswell and Willig (Creswell, 2002:266, Willig, 2001)

The research reported in this thesis used a case study format based on the thematic analysis approach to analyse the data and report findings. This took into account the above retroductive process. The interviews were analysed thematically using a constant comparison approach of different data sets (Silverman, 2006). Through the process of constant comparison, structures, mechanisms and issues in the data were linked to relevant concepts about experiences, values and perceptions in an attempt to maintain a close link between the concepts and the data. This analysis allowed the voice of the participating young women to emerge from multiple constructed realities and to influence the choice of subsequent questions so that they reflected their priorities and experiences across time and different contexts (Denzin and Lincoln, 2008). General comparisons were made with underlying mechanisms, structures, incidents, assertions and events as they happened along with the process through which the actual events took place, which closely linked to the critical realist's standpoint. The approach was particularly significant in comparing the processes the young women passed through in their reactions and reflections. In order to be better able to distinguish between internal relations and contingent circumstances when employing retroductive process, a comparison of several cases was an important strategy (Easton, 2010). Ayres et al. assert that more contextually grounded, transferable findings combining within-case and cross-case approaches in the analysis of qualitative case study data produces (Ayres, 2003). Therefore, analysis of the data for the current study constituted within-case and cross-case analysis.

3.6.3 Within-case analysis

The thematic analytical approach provided a detailed description of individual interviews within each case. According to Stake this is referred to 'direct interpretation' (Stake, 1995). Thus, analysis of data within individual cases was undertaken to construct an in-depth understanding of each individual 'unit of analysis' comprising of an adolescent, her caregiver and the chosen service provider. The individual themes used in this analysis were given a naming convention by the researcher, which included a variety of ways that participants expressed an underlying concept. However, to ensure that there was no bias in the analysis of the data, some non-repetitive words, phrases or statements that appeared to bring in new dimensions to the understanding of young women's experiences and needs were also critically analysed for theme identification

(Ryan, 1999). Analysis continued with repeated play-back of each individual interview and repeated reading of the transcripts to gain familiarity with the content in terms of depth and breadth, thus searching for patterns and meanings in the data (Braun and Clarke, 2006). This continued re-reading of transcripts and individual case summaries (Ayres, 2003), revealed what individual cases communicated about feelings, perceptions, values, needs and challenges that affected them. In addition, insight was gained into how the social systems impacted upon the personal experiences of the participants, their reactions (compensatory behaviours) towards the experiences or challenges presented, and the consequences of their reactions (risks). During this phase, notes were taken and ideas marked for coding, thus a draft coding frame was developed whereby labels were set up.

Through coding, the researcher identified and developed more subtle and nuance sub-themes and themes, such as male relationships boosting self-image and coping with life challenges. This provided a deeper insight into the experiences and needs of young women, enabling more meaningful and less obvious conclusions to be drawn about the content than a more straightforward reading approach would suggest (see Chapters Five, Six and Seven). To concur with the inductive approach, as more information was added to the themes, a continual comparison to the original data source was performed to ensure the themes were still grounded in the data. As each new transcript was coded, new sub-themes and themes emerged and were added to the coding scheme. Each new transcript within a case incited potential reconsideration of the previously identified themes as commonalities and differences emerged. Attention was given to ambiguities within the case and possible links between the themes, in order to form the structure of the data chapters. The coded interview extracts were used as evidence to support the discussion of the findings. For example, how each caregiver and service provider (case sub-units) within the case described and interpreted the young woman's (case unit) illness trajectory or her needs and experiences of growing up with HIV and the distinctions drawn from them. This analysis led to the identification of general themes related to how each individual case described and interpreted the meaning of experiences related to growing up with HIV through commonalities across individual accounts within the case. This involved searching for commonalities, ambiguities and differences within the case among the ways participants described their personal

experiences, values, status quo and social realities for the young women growing up with HIV. The creation of thematic profiles of the sub-units (caregiver and service provider) and the case unit (the young woman), enabled comparison across individual accounts and helped to identify themes for each particular case. The individual accounts provided a clearer view of key elements in each case which included the nature of relationships, living situations, social and cultural influences and outcomes (see Figure 5 for within-case analysis).

The iterative process assisted the researcher with the next phase of developing relationships/links between themes, combining sub-themes to develop broader themes and critically comparing all the applicable coded data extracts within the identified themes (Braun and Clarke, 2006). Several questions guided the researcher during this process. The following were some of the questions: *what words and phrases in the data are indicative to how and why the young women perceive their particular social lives or realities? What are the experiences and why? What are the consequences and why? How are they describing the experiences or actions being observed? Why behaving in that way or why not the vice versa? How are they interpreting what they were passing through? Why facing those challenges or why not the vice versa?* When attempting to understand the social realities among the young women, the questions revealed that most young women perceived themselves as not being loved and accepted within the family and the society, which resulted in a loss of sense of belonging and adult support. For instance with loss of adult support networks, they engaged in male relationships to seek love, acceptance and support. This exposed them to gender power inequalities, increased their vulnerability to sexual exploitation and early child bearing as they succumbed to unsafe sexual practices to maintain their sources of support, social status and identity. Hence, these questions allowed a deeper understanding of the young women's experiences and needs, and generated explanatory frameworks as data was read interpretively and reflectively rather than literally and superficially (Mason, 2002 , Lacey and Luff, 2001 , Miles and Huberman, 1994).

Codes that had no connection with the aims of the study were discarded such as unintended/alternate uses of ARVs, success stories of paediatric HIV management and management of stolen ARVs. The complete coding scheme was gradually built up through repeated coding and active reading and re-reading of transcripts until all key

themes were identified and each clearly defined. Participants' voices and own words within the individual cases were used as evidence to support arguments developed in the current study. These concur with what Creswell posited that relevant meaning emerges when the researcher looks at each case and draws meaning from it, in addition to categorical aggregation from a collection of instances (Creswell, 2003). It was important to focus on individual accounts (adolescent, caregiver and service provider) within the case in order to be able to view each for its particular merits and remain true to the case study approach. This prevented individual cases from becoming inundated by the cross-case analysis and allowed the 'unique vitality' of each case to be displayed within its own context (Stake, 2006:39).

3.6.4 Cross-case analysis

Within-case analysis provided an in-depth understanding of the personal experiences and needs of young women as far as that situated case could provide (Stake, 2005). Cross-case analysis can be used to expand understanding of the experiences and needs of young women by comparing cases to identify commonalities and differences. The themes and sub-themes identified from the within-case analysis informed themes and sub-themes identified in the cross-case analysis. As per Creswell's observation, within-case analysis allow the researcher to become familiar with each of the participants' views (Creswell, 2003) about the needs and experiences of growing up with HIV. In turn this allowed the identification of unique patterns in the data and hastened the cross-case analysis process (Eisenhardt, 1989). This is what Stake describes as a 'categorical aggregation' of instances/incidents across the cases until something was said about them as a whole (Stake, 1995). Stake recommends that interpretation comprises of a search for patterns in the data and is often guided by a theory and this is referred to as a 'correspondence' (Stake, 1995:78). Similarly, Creswell and Yin recommend that analysis identifies themes within individual cases (within-case analysis) and is followed by a thematic analysis across cases (cross-case analysis[12]) (Creswell, 2007 , Yin, 2003). Cross case analysis in the current study took place in a number of different ways. Initially cases were divided by participant type: adolescents (case units), caregivers and service providers (sub-units), then by setting: urban and rural. Later when the data sets became more complete, spider diagrams were used to start to group codes into themes

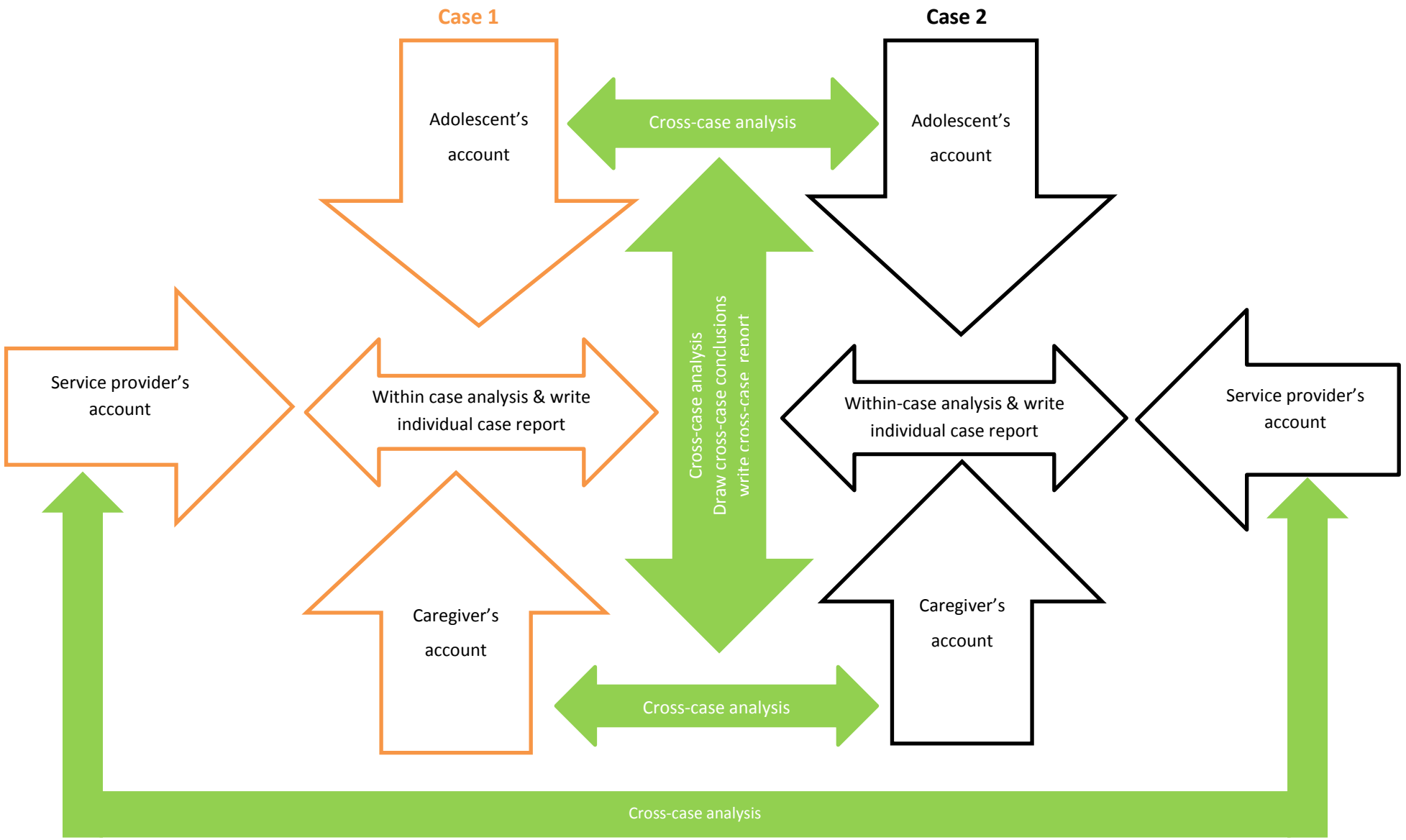
[12] See Figure 5 for within and cross-case analysis.

and identify similarities, differences, relationships and contradictions in themes for the cross-case analysis, which is in line with critical realism. The researcher used cross-case analysis to examine how issues systematically affected all cases.

As Moore et al. affirm, cross-case analysis enabled the researcher to significantly go beyond the first impressions gained from a within-case analysis. This influenced decisions within the current study as themes across the cases were being examined (Moore et al., 2003). As such, cross-case analysis in the current study involved examining for similarities, differences and ambiguities among participants in what they connected to their experiences, social status and values for young women growing up with HIV. Qualitative displays and diagrams were constructed, and story elements were plotted across participants. This enabled a comparison across all of the personal experiences described by all participants including sexual behaviours and access to sexual and reproductive health services, particularly those for young women. Comparison of these individual accounts with one another was done to identify distinct themes reflected in the data. Patterns were identified across the sample for a variety of factors related to young women including emotional responses, sexual events, values, and aspirations. In addition, patterns were also apparent in the young women's interpretations of their sexual partners' behaviours, values and perceptions of their own responsibility in male relationships and sexual matters. Following identification of these patterns cross-case conclusions were drawn (see Figure 5 for within-case and cross-case analysis). Finally, exemplar interview excerpts that best illustrated these patterns were selected.

In summary, the cross-case and within-case analytical formats allowed for broader themes to be developed without losing the context of each case. Chapter Four outlines the contexts and descriptions of the individual cases. Throughout the whole analytical process, there were constant reflections as well as conferring with supervisors which encouraged the application of an attitude of critical appraisal towards the findings. The analysis was enriched by going back to the literature to see where and how other research findings fitted in with current study and how it could further inform analysis of the findings.

Figure 5 Within-case and cross-case analysis



3.7 Writing the case study report

Though there is no single correct way of reporting a case study, it is significant that the context within which the phenomenon occurred is described, addressing, the 'how', 'why' and 'why not' questions. In addition, the report must remain focused and address the aims and objectives of the research in question. Since this particular study adopted retroductive analysis, the core themes that emerged from the analysis are used as chapters of the findings with specific sub-themes as subheadings. This assists in uncovering the underlying mechanisms or structures which best explain the experiences and practices of the young women in the current study. By using within-case and cross-case analysis the impact of HIV on the young women's sense of self, how they cope with the challenges of life and how they navigate the complex terrain of living with HIV were established and forms the write up for Chapters Five, Six and Seven. Relevant quotes from the transcripts are included to illustrate how the themes and sub-themes are labelled and described along with their meanings. Chapter Eight covers discussion of the key findings of the study. Gender, power and empowerment form the underlying theme in Chapter Eight as it pulls together many cross-cutting issues related to other themes. In addition, Chapter Nine will draw together the evidence presented in Chapters Five, Six and Seven including implications/recommendations for programme development, service provision and further research and the study strengths and weakness. Suggestions for the most important and realistic strategies in meeting needs of young women as they grow up with HIV will also be provided.

As this research involved young people, their participation in the study was informative and non-coercive taking into consideration ethical issues. The recruitment process involved negotiating the nature of the adolescent-researcher contact both with the adolescents and the adults responsible for them (Freeman and Mathison, 2009). Therefore the next section focuses on the relevant ethical considerations in the current study.

3.8 Ethical consideration

This section addresses the ethical issues in the current study which include institutional approvals (as discussed in section 3.4.2), mitigation of potential risks considering that young people are a vulnerable group, confidentiality and anonymity, and informed consent. Christensen and James considers these issues very useful in research, especially with young people, as they are subjected to subordinate and marginal positions in relation to adult researchers (Christensen and James, 2000).

3.8.1 Mitigating potential risks

The study posed no physical risks to young women, their caregivers and service providers who participated in this study. However, young people being a vulnerable group needed to be protected as discussed in the next section.

3.8.1.1 Vulnerable group

Young people[13] are considered 'persons with diminished autonomy hence vulnerable to coercion or undue influence', and are entitled to protection from unsafe and manipulative adults (Freeman and Mathison, 2009:24). Young women with perinatally acquired HIV are clients who have a chronic illness that is highly stigmatized and the researcher had to carefully consider her role in respect of young women's dignity and privacy. There is no Criminal Records Bureau (CRB) in Malawi as such, but the Child Protection Law offers statutory safeguarding to children and gives the police powers to investigate the criminal records of people or researchers who deal with children (Government of Malawi, 2010). However, there was no formal requirement for the researcher to be checked by the police. An ethics inspection team exists in Malawi which may be deployed during the study if issues arise that may impinge upon the ethical nature of the research.

3.8.1.2 Issues of power

Power relations of class and age may constrain the social relationship between the researcher and study participants and profoundly limit the data that can be collected particularly when the young people are involved (Thomson, 2008). From this

[13] Young people especially those below the age of 18 in Malawian context.

perspective, the use of visual and written methods in the current study aimed to give young women more control over the representation of their experiences and social realities. This further respected their individual autonomy and human dignity, thereby addressing some of the ethical issues about respect for the researched and unequal power relations between the researcher and the young women (Evans and Becker, 2009, Thomson, 2008). Young women were allowed to complete 'my story' book as experts of their own experiences, and this was done at their own time and pace within the scheduled period. This was communicated to them prior to the exercise so as to give them a better sense of control over the activity. Efforts were also made to ensure that interviews took place at convenient times and locations depending on participants' preferences. This was done in respect to participants' time and place.

During interviews, the researcher avoided giving the impression of expecting answers to all questions (Tisdall et al., 2009). When a young woman expressed feelings of sadness to a question, the researcher never forced her to continue or probe for more information. Instead, the researcher acknowledged it as a way of expressing distress, or remembering painful memories triggered by the issue, and asked the young woman whether they wanted to continue next time or move on to another question. For example, a caregiver (21 years old) to an adolescent became distressed during an interview and wished not to continue; the researcher recognised the need for a repeated interview and this was conducted a week later. Throughout the research process, the researcher checked that the young women were still willing to continue participating in the study, and they were informed that they could opt-out at any time.

3.8.2 Informed consent

According to Bryman, informed consent is described as a 'fundamental principle in social research ethics' (Bryman, 2008:694). It involves providing research information to prospective participants, for them to make an informed decision about their participation in the study and in respect to their human dignity and time. As Health et al. assert, when participants decide to participate in a study and give their consent, they should be empowered rather than protecting the researcher (Heath et al., 2004). In addition, the researcher should avoid coercion and causing harm upon participants alongside assurances of participants' protection (Heath et al., 2004). Heath et al. further

argue that, informed consent is "largely unworkable process because a researcher can rarely know the full extent of what participation may entail or predict in advance all the possible outcomes of participation" (Heath et al., 2004:406). In contrast, Alderson and Morrow emphasised the importance of retaining the principles of informed consent, especially when focusing on activities that are intertwined within qualitative enquiry (Alderson and Morrow, 2011) like sensitive and personal issues regarding HIV and sexual behaviours.

During the initial familiarisation phase of the current study, any healthcare professionals and the young women who did not want to be observed returned the opt-out slip to the researcher. The researcher explained the purpose, potential costs, benefits[14] and risks like psychological distress in the course of interviews to participants (young women and caregivers). In addition, the demands of the study such as depicting images, completion of 'my story' book and the need for follow up interview where necessary were discussed with prospective participants. The researcher answered questions and provided examples or further information where she felt it was needed. This allowed the young women to consider whether they were interested in participating in the study. The process took into account the young women's level of understanding, and by treating them with respect, gave them the right to choose whether or not to participate, hence avoiding exploitation. This is consistent with the feminist stance that young people be permitted to exercise control in deciding their participation in a research study and also to respect their human dignity and time. When the researcher had ensured that the potential participants understood what was involved, informed consent was obtained during their next monthly visit to the clinic. For any chosen service provider who showed an interest in participating in the study, consent was also obtained by the researcher (see Appendices J, K and L for consent forms). Thus, verbal and written consent to take part in the study was obtained from all participants. Consent given by young women allowed them to exercise autonomy in choosing whether or not to participate in the study. Participants who were illiterate marked the consent form with a right thumbprint and a healthcare professional signed the form as a witness. In situations where the young woman consented for participation

[14] Benefit in research context refers to 'something of positive value related to health or welfare' (Belmont Report, 1979 cited by Freeman et al. 2009). In this study it will be the evidence based advocacy for their needs at policy and program levels.

and the caregiver declined, or vice versa, the researcher opted for another adolescent/caregiver pair, both of whom did consent to participate in the study. Similarly, in situations where the service provider expressed no interest in participation or had limited knowledge about the young woman, the pair was asked to identify another service provider from whom consent was obtained until a sufficient number of cases were achieved.

While it was recognized that some of the adolescents were under the formal age of consent in the UK, informed consent in the current study was obtained from adolescents above 17 years and those that society regard as mature minors. In this context, mature minors were those under 17 years but who were legally married, university students or had given birth. However, adolescents aged 16-17 could assent for their participation in tandem with parental permission (Government of Malawi, 2007). For rural participants, a similar procedure was followed to obtain consent and was undertaken during monthly mobile clinics. All participants were informed that consent could be withdrawn at any time without any consequences.

3.8.3 Confidentiality and anonymity

Confidentiality, anonymity and respect for privacy were considered paramount as on-going issues at every stage of the current study, especially in view of the stigma and secrecy surrounding HIV (Evans and Becker, 2009). Confidentiality issues in the current study were dealt at two levels. Firstly, participants were assured that all the information they provided would be kept confidential, except an event of serious concern. While the information sheet included the statements on confidentiality, it also stipulated that there are limits to confidentiality in the event of serious concern (i.e. abuse/violence) being disclosed. This is because the researcher had a professional obligation to take appropriate action as part of her duty of care. The researcher therefore informed the young women prior to the study that in certain situations, with their permission the researcher would breach confidentiality by consulting the practitioner as an ethical necessity to prevent further harm from taking place (Evans and Becker, 2009). The situations included disclosure by the young woman of information that would require urgent attention of healthcare professionals, or details suggestive of abuse or risk of harm. As such, when abuse was disclosed, the researcher discussed with the young

woman as the individual participant affected as to the action to be taken, and where necessary, would seek advice from superiors specifically the Directors in the HIV management centres. All interview transcripts and photocopied 'my story' books[15] were kept in a locked filing cabinet to restrict unauthorised access to data. These documents were only used for the intended purpose of the research and were destroyed after data analysis. All electronic files were stored on a password-protected USB key to prevent loss of the collected data.

Secondly, regarding anonymity, all participants were guaranteed that when reporting and publishing the results of the study, reference would not be made to individual participants. If it was required to quote informants, pseudonyms would be used (Marshall and Rossman, 1999). In order to protect the research participants' identity and respect their dignity and privacy, all participants' responses were anonymous and pseudonyms invented by the young women themselves were used for their stories and 'my story' books to ensure maximum confidentiality and anonymity. Where participants' personal information was kept in computers, these were password protected.

3.9 Strategies to enhance trustworthiness of the approach

Trustworthiness described as the "methodological soundness and adequacy" (Holloway and Wheeler, 2010:302), is judged through the constructs of credibility, transferability and confirmability.

3.9.1 Credibility

Credibility refers to "the participants recognise the meaning that they themselves give to a situation and the 'truth' of the findings in their own social context" (Holloway and Wheeler, 2010:302). Therefore some of the strategies the researcher adopted to ensure credibility of the findings in this study can be summarised as follows. The researcher:

- Read and re-read the transcripts to understand young women's experiences.

[15] Some young women opted to keep the original 'my story' book for themselves.

- ❖ Kept memos about the analytic decision making which facilitated reflections on data collection, analysis and relevant reading as a means of deepening the reflective and critical nature of the research (Silverman, 2001).
- ❖ Engaged in inter-rater reliability activities such as sharing the emerging issues and themes with PhD supervisors and the research advisory committee during the data collection period, so that they could offer thoughts and insights into the higher level of analysis. The research advisory committee was instituted in Malawi and comprised of the five health personnel directly working with the young people in the HIV management centres – the medical officer (clinical coordinator), two clinical nurses, senior clinical officer and monitoring and evaluation officer (research coordinator). They provided guidance on data collection process particularly on meeting the expectations of the HIV management centres and the research participants.
    - ✓ The research advisor committee guided the researcher on how to approach the caregivers. The caregivers were supposed to be informed of the researcher's intention to meet them in advance in respect of their time. They were expected to suggest the venue and time of the meeting. If the meeting venue was away from their homes, the researcher was expected to make transport arrangements.
- ❖ Conducted participant validation exercise through meetings with the young women, caregivers and service providers (separately for each category of participants) after data collection. This enabled them to comment on whether the interpretations of the researcher related to their personal experiences and facilitated the discussion about the emerging issues and themes.
    - ✓ During participant validation exercise, all participants commented that the researcher's interpretation of the data was related to their personal experiences.

Furthermore, during follow up interviews, participants were informally asked to verify interpretations and data gathered during initial interviews. Involvement of multi-disciplinary members, in addition to participants meant that comparisons of the data from different perspectives were possible. This helped to improve the credibility of the

research findings as the themes and their descriptions were discussed and conclusions were drawn before endorsing them as suggested by Aronson (Aronson, 1994).

3.9.2 Transferability

This refers to the probability of applying the findings into a context other than the one in which they were generated (Lincoln and Guba, 1985). According to Green and Thorogood (2004:224) transferability refers to "the extent to which findings from a study apply to a wider population or to different context". In order to enhance the potential for transferability of the findings of the current study, a multiple case study approach was adopted. In addition, a diverse sample of young women, based on a range of demographic, socio-economic and HIV-related variables were selected to gain in-depth knowledge of a wider group. Furthermore, the comprehensive analysis of the whole data set from multiple sources of evidence coupled with the comparison of the findings within the individual 'case', across the 'cases' then with other findings in the existing literature likely allows transferability of the findings to young women growing up with perinatal HIV in a similar context.

3.9.3 Confirmability

Confirmability denotes the extent to which the research findings could be confirmed or verified by others (Lincoln and Guba, 1985). Lincoln and Guba demand confirmability, as an audit and decision trail where readers can trace the data to their sources. This includes transparency of how the sample was chosen (purposive sampling), the research methods used and explicitness on how the researcher arrived at the constructs, themes and their interpretations. As such, the researcher in the current study documented the procedures for checking and re-checking the data throughout the study. Similarly, in this thesis, the researcher has provided a clear account (step-by-step) of the actual procedures used for access and recruitment of research participants, data collection and analysis. Sections 3.4 to 3.6 provide the actual sequence of how participants were recruited, how data was collected, processed, transformed and the analytical strategies. This includes a description of how coding categories and themes were developed (inductive process, within-case and cross-case analysis), and how the extracts used to validate the findings were selected.

3.10 Reflecting on the research process

The researcher is from Malawi, a mature lady, a mother, a nurse, a lecturer and a Christian (see Section 3.3.1.2 on how much of this was revealed to participants). These are characteristics have influenced the research process in several ways. The researcher's social background, personality, position, values, culture and interests influenced the research process particularly data collection and analysis, and this is termed 'personal reflexivity' (Lipson, 1991). According to Ritchie and Lewis, personal reflexivity focuses on how the researcher's own values, experiences, social identities, and goals shape the research (Ritchie and Lewis, 2003). In this context, the researcher's personal experience shaped the age of adolescents selected for the current study. Based on her own experience as a female, a mature lady and a mother, the researcher felt older adolescents had wide experience than younger adolescents, as much of the literature was purporting. Therefore, the researcher decided to make her participants older, particularly ages 15-19 based on the age she felt the young women could have broader experiences and be open on sensitive issues like sexual behaviours. Furthermore, being of the same sex as the young research participants, it made the researcher more approachable to the young women and seeing the world through their eyes easier, as she could identify with the broader societal contexts of womanhood that they operated in.

As the researcher has almost a similar cultural background with the participants in the study settings (Malawi), also a social identity as a 'mature' lady, as a nurse and a mother to adolescents (a young woman and a young man), coupled with her own interests could also influence her data collection and analysis process. However, the use of literature, empirical data and research objectives to inform themes in data collection tools also assisted in reducing bias even during data analysis. In this case, the researcher critically reflected on how and what kind of knowledge to produce, and how to relate the new knowledge to be generated to that already in existence. This every day reflection was the way of thinking throughout the entire process of the current research.

The researcher had multiple identities (as health professional, lecturer, researcher) since she previously worked as a professional nurse/midwife at the central hospital which is affiliated and working in partnership with the HIV management centres. She also works at an adjacent nursing college as a University Lecturer, thereby interaction with the service providers in the study setting. These identities positively and negatively influenced the research process. Taylor, and Richards and Emslie recognised that the status of the researcher can influence the type of answers from the respondents, where the researcher is seen as a powerful figure (Taylor, 2005 , Richards and Emslie, 2000). The staff's remarkable assistance during recruitment of young women was likely a result of the shared identity and most service providers willingly accepted to participate in the study. However, there is a possibility that the socially desirable answers were given during the interviews or respondents especially the service providers stated what they felt would show them in a positive light or what they thought the researcher wanted to hear. In this regard, conducting interviews with three categories of participants – young women, caregivers and service providers and the responses being compared with the data collected during familiarisation phase enabled the researcher to assess whether their perceptions were a true reflection of how they communicated and behaved in the natural settings.

Familiarity and closeness with the study settings and ability to engage in regular conversation in the local dialect assisted the researcher to collect data using some informal interactions that occurred in daily conversation. The researcher's insiderness facilitated access to more 'in-group' activities, such as attending teen club meetings which could not be accessed by an outsider hence contributing to in-depth knowledge that enriched the data. There also appeared to be an immediate openness among young women and service providers in expressing their concerns about the social constraints of their daily lives, positive and/or negative experiences in the health system and some challenges regarding SRH services in the centres. This openness was due to a perceived shared understanding of the activities taking place in the centres. Young women's and service provider's accounts that are highlighted in Chapters Six and Seven affirm that this openness was created in the interviews and the researcher's role did not negatively impact on quality of data collected. It was therefore still important to adopt a more marginal role and being intellectually poised between familiarity and strangeness,

in order to minimise subjectivity, and bias and aim at more objective, critical and analytical perspectives.

The researcher also considered the nature of interviews she had with six participants (five young women and one caregiver – a 21 year old sister to an adolescent, both living with their aunt). All the young women were enthusiastic to tell their stories of growing up with HIV and the sister to tell her experience of providing care to a young woman growing up with HIV. However, some young women and the sister cried bitterly as they explained about their relationships with the caregivers especially the step-mothers. The researcher wondered whether there was a certain assumed level of trust and relationship that she had established with the young women that made them feel able to express about their traumatic experiences of feeling rejected and exploited after being diagnosed HIV positive or loss of their parents. The researcher was compelled to review and reflect on her interviewing technique. The replay of the audio recording of interviews revealed that the questions had been open and she was not asking questions in a manner that unconsciously distress the young women particularly with the use of 'my story' book. However, the researcher discovered that the young women had endured the long suffering and the hidden pain on their own until when they were given an opportunity to share their painful experiences with the researcher. This was as an important finding and is one of the sub-themes in the current study.

Finally, it is worth to point out the learning experiences that the researcher has gained through the three years of living in UK. The major lesson in conducting the current study, the researcher has learned to listen to the voice of others particularly the marginalised individuals including her own voice. Changing the role of a clinician to a researcher has been a challenge particularly during the process of analysing and synthesising the data. Looking through a health professional lenses, risk was seen as something that needed to be prevented rather than documenting it. Nevertheless, the researcher's initial feelings of uncertainty on her intellectual capacity have gradually worn out and paved way to the growing confidence and eagerness to share the findings and recommendations through publications and forums like national and international conferences. Upon return to Malawi, the researcher would hope to actively participate in further research in the area of HIV and AIDS among young people, influence practice and policies through dissemination of evidence-based publications.

3.11 Conclusion

This chapter has discussed how the research strategy for this study was developed and the methods used for data collection and analysis. The philosophical stance through a variety of ideological lenses such as critical realists and feminists justified the choice of approach and guided the whole research process in understanding the experiences and needs of young women growing up with HIV. It is evident that young people are a distinctive population, which has its own culture, norms and complexities. Therefore, if they are to be studied effectively, the researcher needs to acknowledge them as distinct from adults. Of late, emphasis has focused on increasing the participation of young people in health-related research. For this to be effective, studies must incorporate innovative visual methods that give researchers new insights that have been problematic to access using 'conventional' data collection techniques developed for adults (Driessnack, 2006). For instance, this chapter has discussed how effectively the 'my story' book approach facilitated interviews between adult researcher and the young participant and also empowered young women to actively convey personal stories to the adult researcher in the process (White et al., 2010). Finally this chapter has illuminated how within-case and cross-case analyses strengthened the findings around the experiences and needs of young women from multiple sources of evidence in different contexts.

CHAPTER FOUR

DEVELOPING CASES: CONTEXTS AND DESCRIPTIONS

4.1 Introduction

This chapter introduces the contexts in which this study was carried out. It includes an overview of the study settings, brief case profiles and contexts and descriptions of exemplar cases. The chapter is divided into two sections. The first section gives a brief outline of some of the main features of the two settings used in this study. The second section provides an essential background of the individual cases and describes the case profiles for each of the 14 cases. This chapter prepares the ground for a fuller presentation of the main findings in this thesis drawn from cross-case analysis and comparisons of coping strategies and themes in young women's responses to growing up with HIV. Pseudonyms are used to protect the anonymity of the study settings and the participants in accordance with the argument made by Bryman (2008) that the privacy of those who participate in research process needs to be respected.

4.2 Settings

4.2.1 Maziko HIV Management Centre (MHMC)

MHMC is a non-governmental and non-profitable organization providing specialised paediatric HIV care and operates in collaboration with the Ministry of Health. Prior to the establishment of the MHMC, confirmed HIV infected children were followed up in the Tachira Central Hospital (TCH) general paediatric clinic or were being seen in the adult focused Chiyembekezo Centre within the campus of TCH. TCH is a governmental referral hospital for the central region of Malawi and a critical entry point for care of HIV infected children. MHMC started as a paediatric HIV clinic within TCH in 2005, and moved into its flagship standalone clinic on the TCH campus in November 2006. By December 2006, the centre had registered 1370 patients including 1199 that were inherited from the TCH paediatric clinic. The median age of the active paediatric patients was 5.5 years and teenagers over 13 years old accounted for 8.2% of the total patient population. By 2012, the centre had a total of 2825 active patients, out of which 956 were young people: 635 were aged 10 to 14 years (325 females, 310 males), and

321 were aged 15 to 19 years (157 females, 164 males)[16]. Approximately 100 patients are reviewed every working day and 90 new patients are enrolled each month. Apart from the administrative staff, the centre is managed by both local and expatriate paediatric AIDS Corps (PAC) doctors who include paediatricians, clinical officers, nurses, pharmacy staff, counsellors, social workers and volunteers.

Apart from providing clinical care, MHMC also engages in several activities which include:

- Provider-initiated HIV testing counselling (PITC)
- Community outreach programs for paediatric HIV sensitization like grassroot soccer
- Tingathe – which involves community health workers conducting active case finding of HIV infected children and families in health centres or communities through door to door home based HIV testing.
- Teen club – which provides care and support of adolescents living with HIV.

By 2012, nearly 250 HIV positive young people between the ages 10 and 21 years were attending monthly teen club meetings. Many of these adolescents were primarily responsible for their own care. Activities during meetings include games, songs, dramas, role playing, and sports. In addition, the meetings facilitated discussions to address issues like career choices, high-risk behaviours, gender, stigma and relationships. The establishment of teen clubs had expanded to some of its fourteen mentorship sites in all three regions of Malawi, one of which was Yankho Clinic in the rural setting where children, adults and young people were accessing HIV care.

4.2.2 Chiyembekezo Trust (CT)

In Malawi CT was the first centre specialised in provision of HIV care and support to both young and adult patients living with HIV. Independent initiatives were instituted in September 1997 by health workers of the medical department at Tachira Central Hospital (TCH). They perceived the need for provision of HIV and AIDS support and care for patients both in hospital and at community level. The idea of integrating the existing services and the initiatives into one centre was conceived in 1998. In 2001 the concept

[16] Statistics from unpublished 2012 annual report made available to the researcher from the centre.

of improving the quality of life of people infected with, and affected by HIV was established through the provision of quality care and counselling. In order to secure independent funding and to operate as an essential partner in Malawi's public health system, Chiyembekezo Centre was registered as a Trust and was officially opened in July 2002. The centre is easily identified as an HIV/AIDS clinic serving patients of all ages and is situated within TCH campus. By 2012, CT excluding its sites had registered over 20,000 HIV positive patients; out of which 387 (192 females, 195 males) were young people aged 12 to 19 years[17].

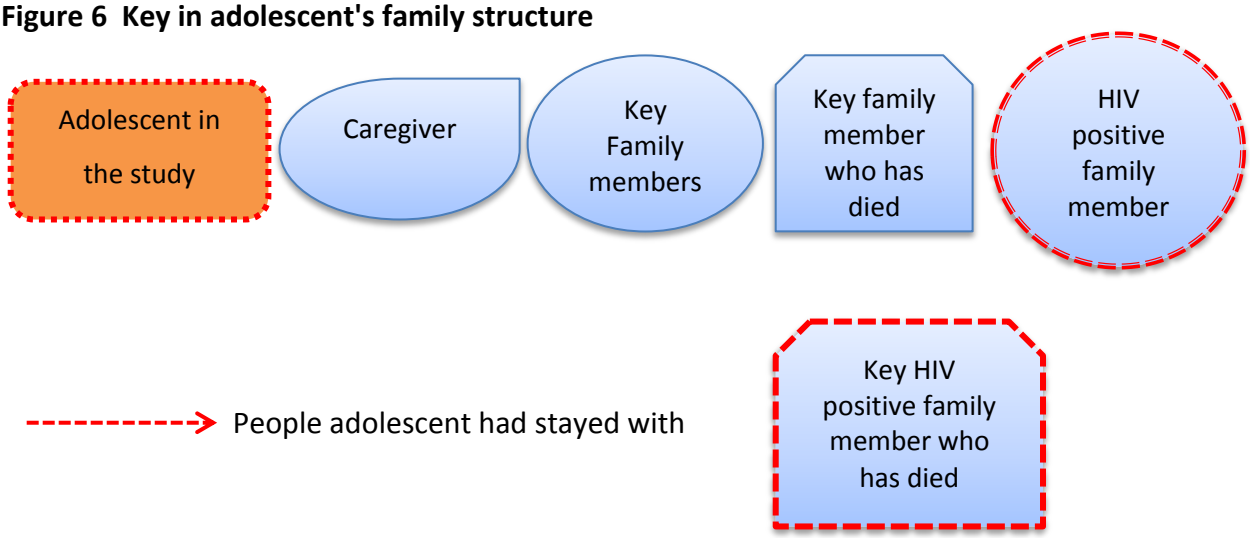
The CT offers three central services including: voluntary HIV testing and counselling, antiretroviral therapy and clinical care and community home based care. Additional services include counselling on family planning and contraceptives and teen club meetings for those aged 12 to 20 years. However, by 2012, only 37 young people were enrolled in the club due to lack of funds. The main activities of the teen club cover medical care, trainings in relationships, condom and contraceptive use, gender issues and indoor and outdoor games. The staff involved in provision of care includes medical/clinical officers, nurses, counsellors and community care supporters. Though Maziko Centre and Yankho Clinic focus mainly on children and Chiyembekezo Centre on adult patients, all centres serve young people.

4.3 Brief case profiles

This section outlines the case profiles for each of the 14 cases involved in this study, all of whom accessed services at the centres described above. These summaries comprise of members of the case, along with their family status, relationships and key information relevant to the young woman. The age, socio-economic status and number of dependants for each primary caregiver have also been included as that significantly impacted on the kind of care rendered to the young woman and hence influenced her behaviour and self-image. Different shapes have been used to link the central participant (the young woman) to the chosen caregiver and other family members. Dotted shapes signify any other family member who is also HIV positive and the dotted arrow indicates the number of people the adolescent stayed with (See Figure 6).

[17] Statistics from unpublished 2012 annual reports accessed at the centre.

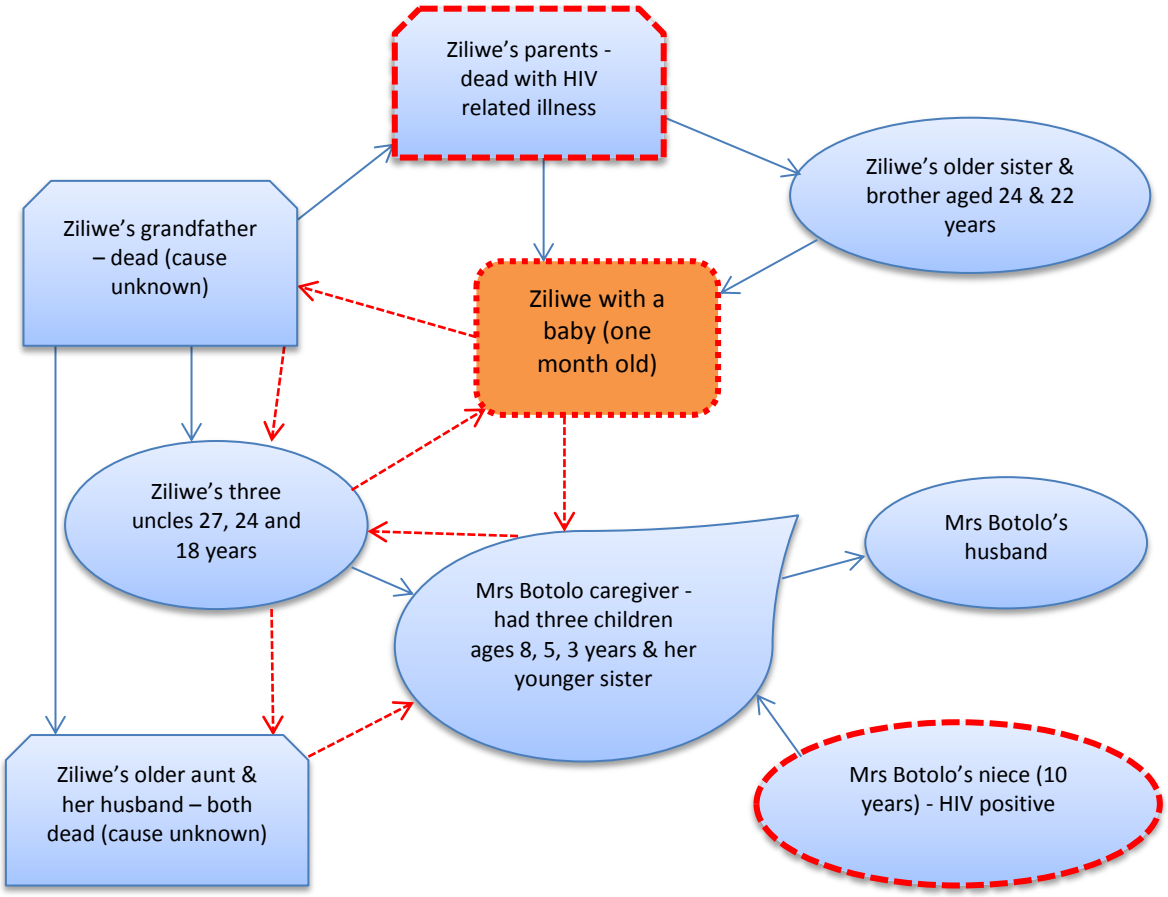
Figure 6 Key in adolescent's family structure



Ziliwe

Ziliwe is 18 years old, living alone in an urban setting. She is the last born in a family of three children. She lost contact with her older siblings after the death of her mother when Ziliwe was three years old. Soon after the death of her parents, she went to live with her grandfather for few months before he died. She was left with her three uncles, who were reportedly unmarried and consumed significant quantities of alcohol. After three years, she moved to stay with her older aunt and her husband, whom she perceived as being very loving, but they died when Ziliwe was 14 years. Then she moved to stay with her younger aunt, Mrs Botolo (a caregiver in this case), who by then was 26 years old. However, Ziliwe felt Mrs Botolo treated her differently to her own children and younger sister (Mrs Botolo's) and that negatively impacted on Ziliwe's self-image. Ziliwe's experiences of being discredited and neglected by her aunt contributed to her loss of sense of belonging to the family.

Ziliwe's family structure



Both Ziliwe and Mrs Botolo completed their Malawi School Leaving Certificate of Education level (MSCE) but were not working. Mrs Botolo acknowledged that she assumed an increased caring responsibility following the deaths of her two older sisters. She relied solely on her husband for material and financial support. Ziliwe lived with Mrs Botolo for over three years before she was sent away by her aunt's husband to live with her three uncles for breaking the household rules (for spending nights out with boys). Mrs Botolo reported that she was compelled to uphold her husband's decision of sending Ziliwe away because she was fully dependent on him for support, hence limiting her power in decision making.

Ziliwe reported finding it difficult to stay with her uncles because of the reversed role kind of relationship with them. She indicated that her uncles were consuming significant quantities of alcohol and they relied on her hard earned resources for survival. As such, Ziliwe secured her own accommodation and relied on piece works like washing clothes in homes to earn a living. Since she perceived diminished sense of belonging to the family, Ziliwe, a teen club participant, reported engaging in relationships with males at the age of 15 years for love and financial support. Both Mrs Botolo's and her

explanation on sexual relationships revealed that she engaged in multiple partnerships and experienced both protected and unprotected sex. Ziliwe perceived that life was becoming unbearable and she found a steady partner to live with and provide for her basic survival needs including rental payments. She did not disclose her HIV status to her partner for fear of losing her source of income, and therefore she was unable to negotiate condom use with her partner. Consequently, she became pregnant at the age of 17 years and her partner disappeared. Ziliwe struggled to earn a living during her pregnancy until she delivered her baby through caesarean section at the age of 18 years.

Ziliwe has been accessing HIV care from Chiyembekezo Centre for three years. Mr Hanuya is her service provider and is a 32 year old certified HIV counsellor specialising in youth friendly health services. Mr Hanuya indicated that Ziliwe had been in good health since she commenced ARVs and was an active member of the teen club before she became pregnant. He attributed Ziliwe's pregnancy to lack of parental affection, support and guidance. He reported that as Ziliwe struggled to earn a living, she engaged in sexual activities for financial gains resulting in her early child bearing.

All participants in this case had follow up interviews three months after the birth of Ziliwe's baby. Discussions with Ziliwe and Mrs Botolo were centred around challenges encountered in their relationship and how Ziliwe was coping with her baby. Follow-up interview with Mr Hanuya focused on how they managed Ziliwe with her baby.

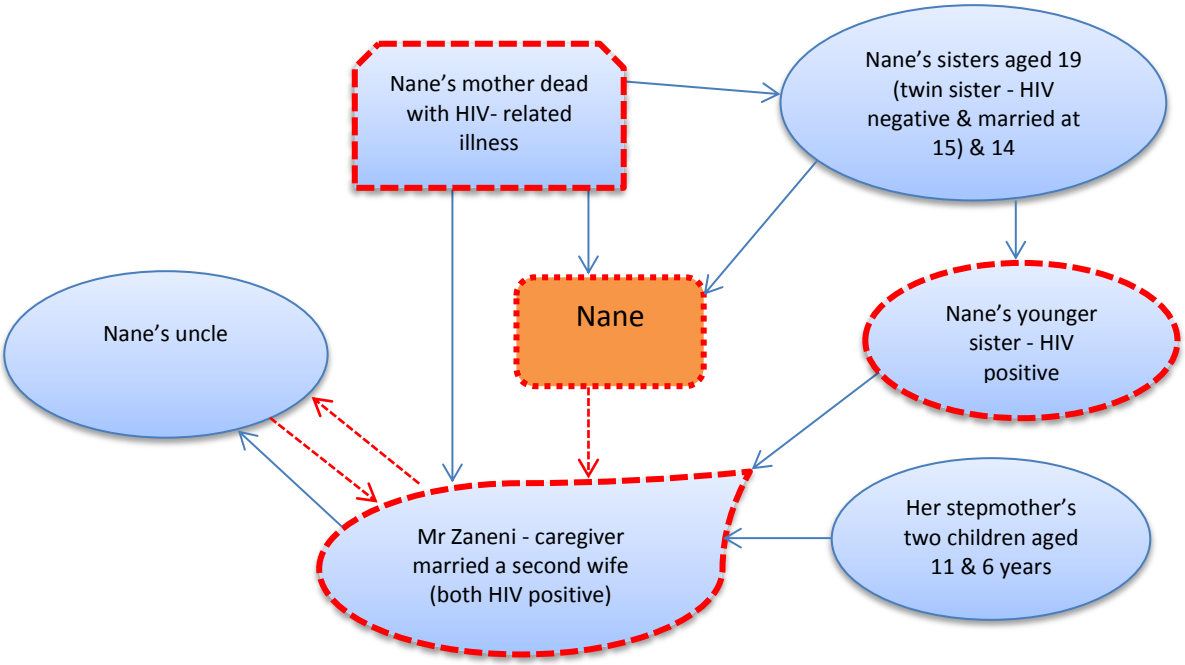
Nane

Nane is 19 years old, residing in an urban setting with her father, Mr Zaneni, her caregiver in this case and her stepmother. Nane is the first born (in a set of twins) in a family of three children. She reported that her mother died of HIV-related illness in 2004 when Nane was 11 years old. Her father married a second wife in 2006, who has her own two children. Nane completed her Malawi School Leaving Certificate of Education (MSCE) level and was pursuing a two year HIV and AIDS management course in college. Mr Zaneni aged 43 years, indicated that he has not worked since 2009 and that he along with his entire family rely on his younger brother for financial support. Nane described Mr Zaneni as a very loving and supportive father in contrast to her step-

mother, whom she perceived as favouring her biological children. Nane perceived being neglected by her step-mother which affected her sense of belonging to the family.

Nane reported initiating sex at the age of 16 as a source of happiness, to feel loved and for financial gains, hence promoting her social status as a young woman. Nane indicated that she did not disclose her HIV status to peers and her sexual partners for fear of being labelled promiscuous or having her sexual relationships terminated which would result in loss of her financial support. Mr Zaneni acknowledged that his failure to provide for Nane's basic needs was the likely cause of her seeking sexual activities for financial gains. In addition, Nane had to live with her uncle since Mr Zaneni was unable to support her, and this meant that Mr Zaneni had no control over Nane's sexual behaviour.

Nane's Family Structure



Nane has been accessing HIV care at Chiyembekezo Centre for five years. She reported knowing her HIV status at the age of 14 and expressed feelings of bitterness for having a stigmatised disease that is associated with immoral sexual behaviours. She felt that she had been cursed by God and was finding it difficult accepting her positive HIV status, especially with the delayed disclosure. Mr Zaneni, who was also HIV positive, attributed his delay in having Nane tested for HIV to his feelings of shame and guilt for passing on the virus to his family members. Nane's service provider, Ms Kando aged 39, was a

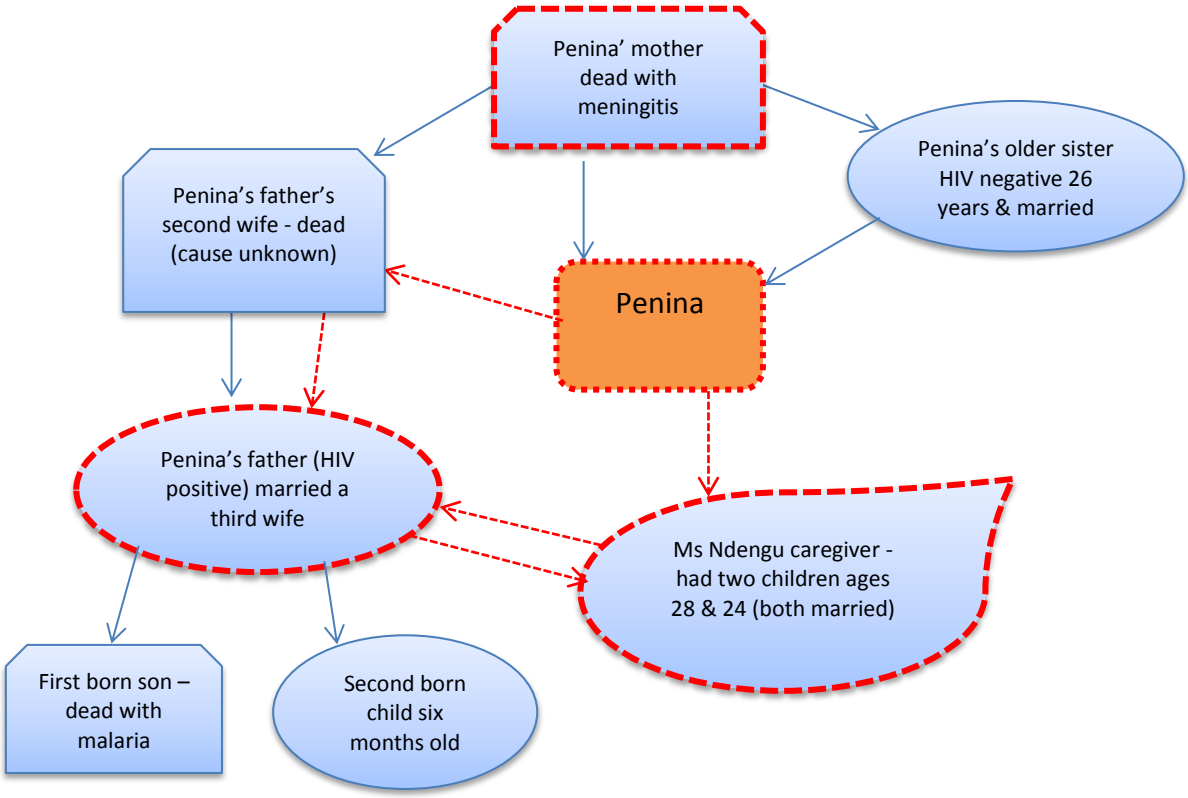
Nurse/Midwife Technician with a Diploma in Nursing and Midwifery and a certificate in child counselling. She indicated that after Nane joining the teen club and received several counselling sessions, coupled with a mutually supportive relationship with Mr Zaneni, she steadily accepted her positive status.

Penina

Penina is 19 years old, residing in an urban setting with her father and her second step-mother. She is the second born child in a family of two children. Her mother died in 2002 when Penina was nine years old. After death of her mother, Penina lived with her aunt, Ms Ndengu (older sister to her late mother, a caregiver in this case and is a widow) aged 45 years, for two years before her father took over the caring responsibility in 2004. Penina reported that the first stepmother loved her like her own child but she died in 2006. Penina has lived with her father and her second stepmother for six years. She described her father as her closest friend because he is so loving, supportive and always accepts the blame of passing on the virus to her mother and herself which reassured her. However, she perceives her second stepmother as uncaring and only interested in property inheritance.

Ms Ndengu has been providing care to Penina for 10 years in collaboration with Penina's father. Ms Ndengu has a Malawi Junior Certificate of Education and works as a messenger at the Ministry of Gender. Ms Ndengu reported that after her sister died of HIV-related illness (specifically meningitis), she struggled to meet Penina's basic needs due to her low economic status. Penina's father therefore had to take over the caring responsibility, although Ms Ndengu is more involved in caring for Penina whenever she is admitted to hospital and if there is need to make key decisions affecting her care. Penina's father has a managerial position at a tobacco company and financially supports Penina which provides security and helps to boost her self-image, despite having an altered physical appearance (lipodystrophy).

Penina's Family Structure



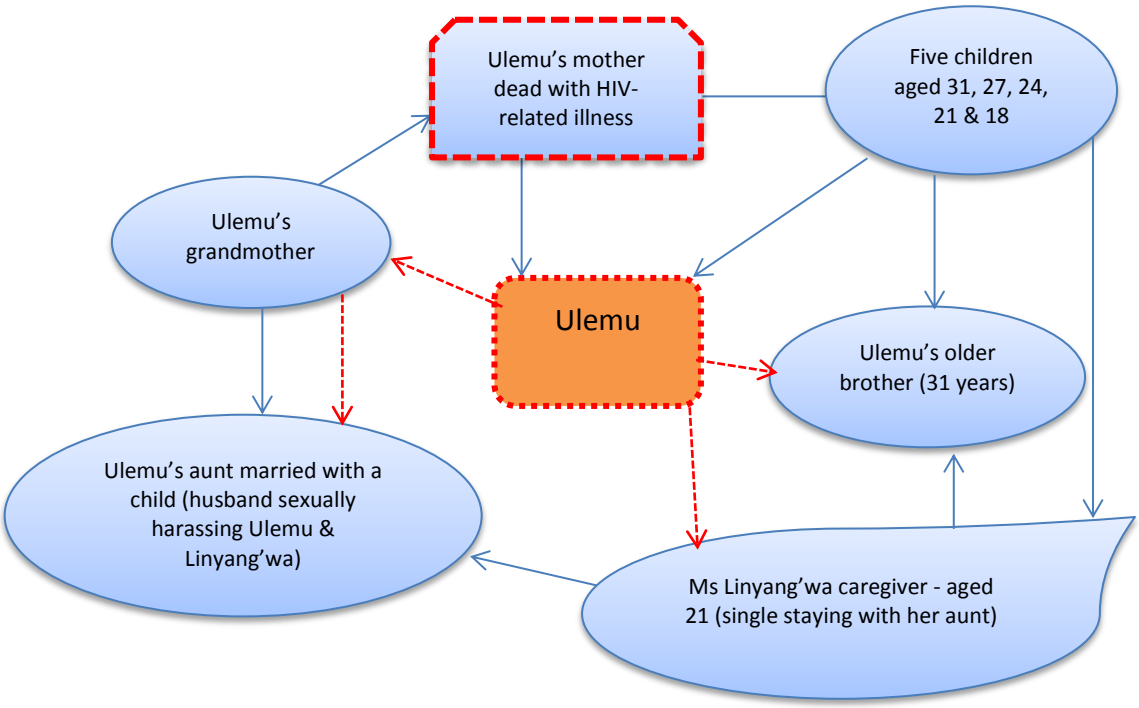
Penina was studying for her Malawi School Leaving Certificate at a day secondary school. She had previously attended a boarding school, but had left following situation that triggered suicidal ideas. Her friends had displayed her ARVs on the bed, in addition to publicising and posting her positive HIV status on Facebook. Penina reported becoming severely depressed as a result of these actions, with a reduced sense of belonging to her social group, and diminished self-image. These feelings emerged from the changed social identity that was made publicly known. However, Mrs Rwinu her service provider, a Paediatrician aged 33 years, who has been in contact with her for one year, indicated that with counselling and regular participation in the teen club, Penina coped positively with her situation. Penina has been accessing care from Maziko Centre for six years. Both Penina and Mrs Rwinu had two interviews. Penina's caregiver was out of reach on official duties and therefore had only one interview. Initial interviews were held during the time that Penina withdrew from the boarding school and follow-up interviews were done six months later to identify how Penina was coping with her situation at a day secondary school.

Ulemu

Ulemu is 18 years old, residing in an urban setting with her aunt, aged 26 years (young sister to her late mother). Ulemu is the last born in a family of five children. Her mother died when Ulemu was four years old. Ulemu (4 years) and her sister, Linyang'wa (7 years), were sent to stay with their grandmother aged 70+, in the village after death of their mother. She described her stay with her grandmother as very hard and often they could not afford a meal. Life became easier when they moved to live with their brother, aged 19 years, who was working as a sales representative in town. Four years later, their brother found another job in the Republic of South Africa and they had to move and live with their younger aunt, whom Ulemu described as very inconsiderate. Her aunt was unable to meet her academic costs or provide the food that Ulemu normally liked and often got furious whenever Ulemu could not eat foods like maize flour porridge, which made Ulemu sick and caused diarrhoea. Ulemu felt she was being disregarded by her aunt's attitude, which diminished her self-worth.

The aunt was young and financially challenged, due to her poorly paid job working in the civil service as a health surveillance assistant. She reported not being able to afford items for Ulemu's basic needs, or control her husband's sexual behaviours towards the young women as he was the source of financial support in the home. Nevertheless, both Ulemu and Linyang'wa (aged 21 years and Ulemu's caregiver in this case) reported being resistant to his sexual advances but that meant risking loss of financial support. Ulemu's description of her aunt and the treatment received from her foster family clearly signified her need for love, acceptance and a safe place to live.

Ulemu family structure



Mr Mbalame, her service provider (aged 38, Senior Clinical Officer with a Diploma in Clinical Medicine), felt that Ulemu had negative feelings about her life and a poor self-image due to her inability to comprehend the pressures of adolescence along with coping with a positive HIV status. Furthermore, Mr Mbalame indicated that Ulemu felt embarrassed about her altered physical appearance. These changes were related to HIV or intake of ARVs and included getting fat, bigger abdomen and breasts, poor sight and loss of memory, which he felt negatively affected her social interactions with peers as she tried to keep her HIV status a secret despite the visible marks. On the contrary, Linyang'wa believed that Ulemu had a negative attitude towards her HIV status and life because she felt unloved and was being treated differently from others in their aunt's home. Linyang'wa became distressed as she was describing the relationship with their aunt and a repeated interview was held at a later date.

Ulemu reported accessing care at Chiyembekezo Centre for seven years and had received a blood test for HIV at the age of 11. The results were not disclosed to her at the time because her aunt felt Ulemu was too young to comprehend the information and would not keep her HIV status a secret. The latter issue was clearly linked to the types of problems likely to be encountered when dealing with a stigmatised illness. Ulemu expressed suicidal ideas to her service provider and caregiver, when she had an

accidental status disclosure at the age of 17 during a teen club meeting. With the counselling and emotional support provided by Mr Mbalame plus regular participation in the teen club, Ulemu gradually accepted her situation and was able to focus her attention on what she wanted to achieve in life as she set her academic and vocational goals.

Ulemu was pursuing her Malawi School Leaving Certificate (form three) at a community day secondary school. She felt that being socially excluded by her aunt, sexually harassed by her aunt's husband and delayed academic progression due to lack of school fees triggered her negative attitudes towards her life. However, with continued counselling and emotional support, Ulemu reported a strong sense of determination to achieve the goals she had set for herself, helping to establish a better self-image. As such, when her older siblings sold their mother's house to earn a living, Ulemu invested her share in a small scale business. She was selling fried pan cakes at school and second hand clothes in her spare time to raise funds to cover basic survival needs like school fees and buying food which her aunt was unable to provide for her. Being financially self-reliant gave Ulemu the capacity to progress her education without interruptions and the position of power to desist being vulnerable to her uncle's sexual harassments. She also indicated that she was able to buy well-fitting outfits that completely changed her outlook and her perception of her body image as a young woman.

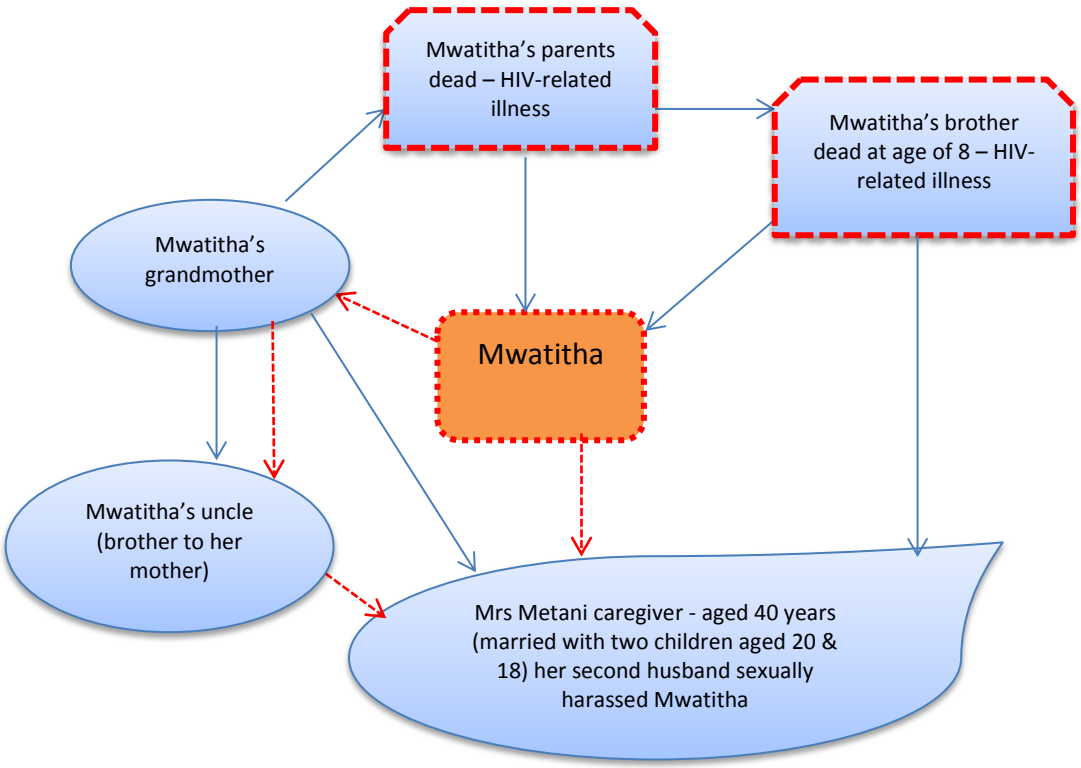
Mwatitha

Mwatitha is 18 years old, residing in an urban setting with her aunt, Mrs Metani (older sister to her late mother) aged 40 years and the caregiver in this case. Mwatitha is the first born in a family of two children. Her mother died when Mwatitha was three years old and her father died a year later. After the death of her mother, Mwatitha stayed with her grandmother in the village for few months before she was sent to live with her uncle in town. She lived with her uncle for five years and reported that she was stigmatised and suffered physical abuse for not adhering to tuberculosis (TB) treatment. Her uncle constantly reminded her that her parents had died of AIDS, which reduced her self-image despite the fact that she was not aware of her HIV status at that time. She experienced a diminished sense of belonging to the family and went to stay with Mrs Metani at the age of ten, whom she described as very loving and supportive.

However, the aunt's husband sexually harassed her and Mrs Metani was unable to intervene as the entire family were dependent on him for financial support. Simultaneously, Mwatitha reported losing her financial support, including school fees, from the aunt's husband for exposing his sexual advances. Mrs Metani has a Malawi School Leaving Certificate and was a housewife in a second marriage but did not have children with the second husband. She had been caring for Mwatitha for over eight years.

Mwatitha, a teen club participant, was studying for her Malawi School Leaving Certificate at a Community Day Secondary School. She had been attending a boarding school but had left after her cousin publicised her HIV status to peers. This created an agonising situation for Mwatitha as she felt socially isolated and that she did not have a safe place to stay. While she was sexually harassed by her aunt's husband at home, at school she was stigmatised by peers. This experience diminished Mwatitha's sense of self-worth and belonging to family and peers.

Mwatitha's family structure



Mwatitha's service provider in this case was Mrs Tayenda, a female HIV counsellor aged 39 years, with a Malawi School Leaving Certificate and a certificate in youth friendly services. She had been in contact with Mwatitha for six months and she asserted that Mwatitha's experience of sexual abuse in her aunt's home and the publicising of her HIV status to peers by her cousin diminished her sense of self-worth. This led to her feelings of suicidal ideas as she felt she had no safe place to stay. However, Mrs Tayenda perceived that constant counselling and participation in the teen club helped Mwatitha to accept her situation and unleashed her potential to achieve academic goals. Both Mwatitha and Mrs Metani had initial interviews and follow-up interviews six months later to determine whether Mwatitha was still expressing suicidal ideas and how she was coping in her aunt's house.

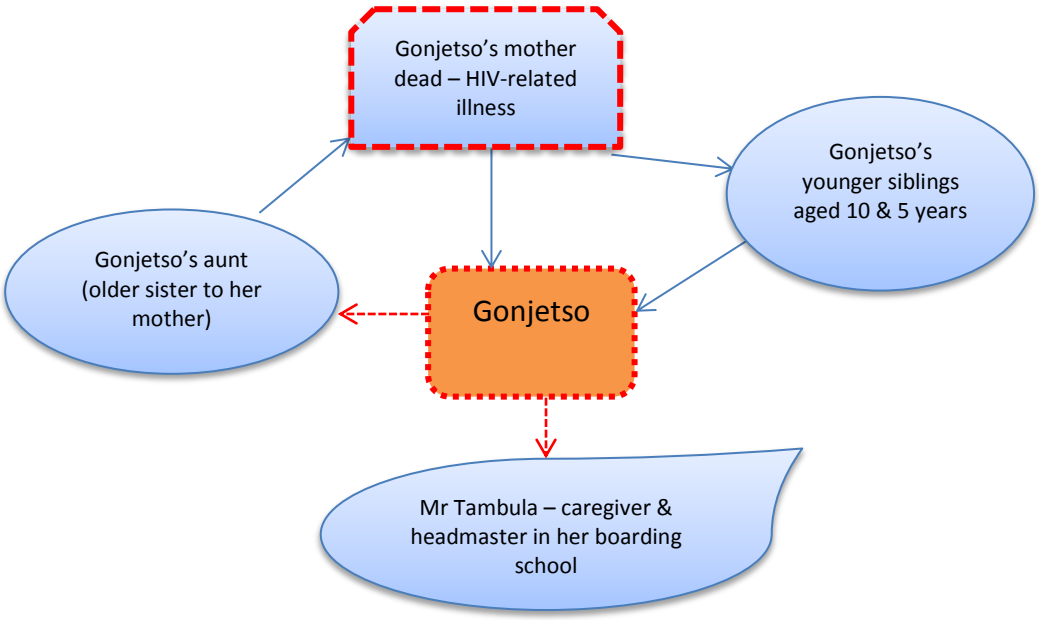
Gonjetso

Gonjetso is 16 years old, living in a rural setting with her aunt. She is the first born in a family of three children. Gonjetso, a regular teen club participant, knew her status at the age of 13 years through her mother who was still alive and taking ARVs. She reported missing classes because of frequent attacks of illness that severely affected her academic progression. She described her mother as very loving and they developed an intimate, supportive and trustworthy relationship, which was emotionally satisfying and increased her self-worth. Gonjetso lost her mother in 2009 at the age of 13, and six months after Gonjetso had tested positive for HIV. The death of her mother was extremely painful for Gonjetso as not only had she lost parental affection and support, but also her identity and sense of belonging to a family and society, which resulted in diminished self-image. Gonjetso reported that her mother, possibly anticipating her untimely death and being a teacher by profession, kept on motivating Gonjetso to work hard in school, to be self-reliant, responsible and look after her siblings. Her mother believed that if Gonjetso attached value to her life, she would have a meaningful mark in her clan like her mother who was the only educated woman in her village. This maternal inspiration enabled Gonjetso to look at life positively, to accept her HIV status, and provided a powerful influence on her self-determination to become goal oriented and excel academically.

Following the death of her mother, Gonjetso and her two siblings were sent to stay in the village with their aunt who had six children (three married with their own families, one school drop-out due to pregnancy and two in school). Gonjetso indicated that her aunt relied on subsistence farming and was finding it difficult providing for their basic survival needs. Gonjetso stated that despite her mother securing funds for the advancement of her studies, these were used within a year for home management as her aunt lacked resources. Although Gonjetso pursued her studies at a community day secondary school, she still dropped out of school as her aunt struggled to meet her academic costs.

Gonjetso has been accessing care at Chiyembekezo Centre for three years and Ms Mbenu, her service provider (aged 37, single, Enrolled Nurse/Midwife) has been in contact with Gonjetso for all of that time. When Ms Mbenu, took note of Gonjetso's need around her academic situation, the centre successfully secured her a place at Takulandirani Boarding Secondary School (mixed gender) supported by a government bursary through the District Education Office. Mr Tambula, the headmaster at the school (aged 49, and responsibly for 625 students – between the ages of 14 to 19) and the caregiver in this case, described Gonjetso as one of his form three needy students and acknowledged her struggles to earn a living.

Gonjetso's family structure



Mr Tambula indicated that although Gonjetso lacked financial resources, and had encountered delayed academic progression as a result of her illness and lack of school fees, she was determined to achieve academic excellence. She became one of the best students at her school and was made the library prefect. Gonjetso reported that though she encountered several challenges, she was determined to achieve her overarching goal of becoming a caretaker for her siblings in a meaningful way through her academic and vocational achievements as per her late mother's aspiration. In addition, Gonjetso indicated that the continuous support offered by Mr Tambula and Ms Mbenu were instrumental in facilitating her success both as the best (top ten) student and a library prefect in a gender mixed boarding secondary school.

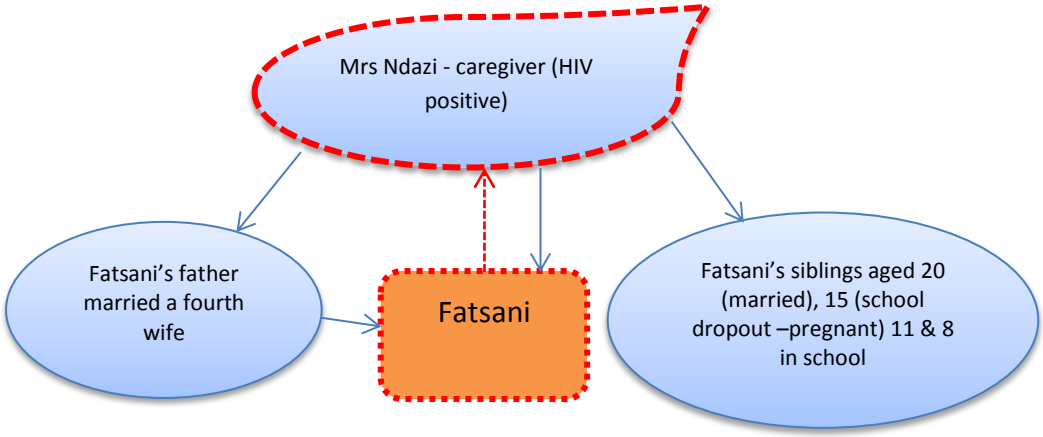
Fatsani

Fatsani is 17 years old, residing in an urban setting with her mother, Mrs Ndazi aged 41 years, the caregiver in this case. Mrs Ndazi holds a Junior Certificate of Education and is the third wife to Fatsani's father, a bus driver. Fatsani is the second born in a family of five children and the only child perinatally infected with HIV. Fatsani reported that she had failed her Junior Certificate Examination at a community day secondary school which she attributed to frequent bouts of illness requiring hospitalisation. Fatsani reported that she tested HIV positive at the age of 13, and she expressed finding it difficult to understand this when her siblings were not infected with HIV. She described being hospitalised for over two months, taking TB treatment and ARVs, being bedridden for over a year, having a body rash and losing all her hair, all of which was extremely distressing and reduced her self-image.

Fatsani indicated that when she was admitted to hospital, she expected her father to care about her illness, but instead her father seemed more interested in his fourth wife and ensuring financial stability for her. Fatsani perceived being discriminated by her father, who was the main breadwinner in the family. This greatly affected her sense of belonging to the family and self-image both financially and emotionally, as she reported feeling rejected and deemed unworthy of paternal support and care. Mrs Ndazi confirmed that Fatsani had lost interest in her surroundings and that her morale was very low since her father had switched his affections. She could not smile at any one which suggested that she might be severely depressed. Her father's behaviour was

likely to be attributable to him not wanting to share the stigma of Fatsani's HIV status as evidenced by her life-threatening illness. He anticipated that it could lead to exposure of his own HIV status, resulting in shame and social isolation. Mrs Ndazi had also been concerned about her husband's reaction to Fatsani's illness and the loss of his love at a time when Fatsani was critically ill and this resulted in her hesitation to disclose the HIV status to Fatsani.

Fatsani's family structure

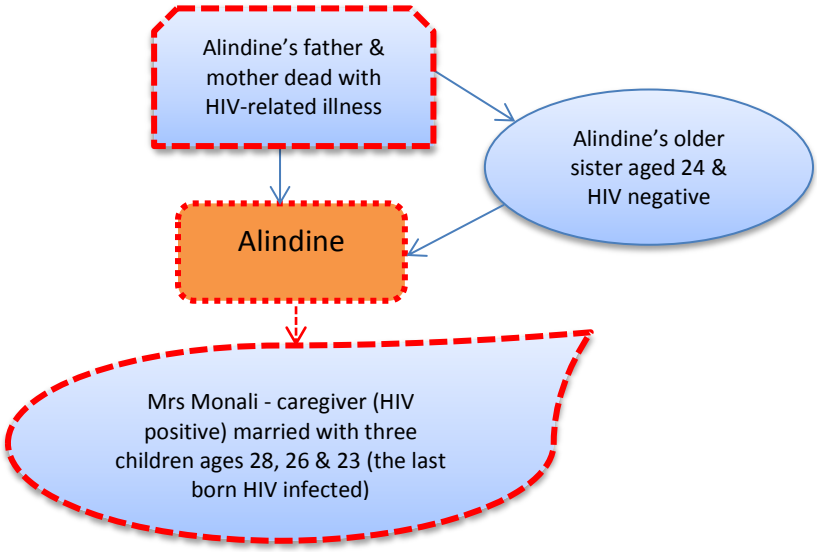


Fatsani was a teen club participant and has been accessing care at Chiyembekezo Centre for four years. Mr Zidelu, her service provider in this case (aged 26, a clinical officer with a Diploma in Clinical Medicine), indicated that several factors contributed to Fatsani's negative self-image. He pointed out her small stature, disrupted family and issues around being the only child infected with HIV. He suggested that the neglect Fatsani experienced from her father put her in jeopardy of forming unhealthy male relationships to boost her self-worth.

Alindine

Alindine is 19 years old, residing in rural setting with her aunt, Mrs Monali, who is the caregiver in this case (older sister to her mother, an Enrolled Community Health Nurse, aged 55, married with three children). Alindine is the last born in a family of two children. She reported that her father died in 2001 and her mother died in 2003, when Alindine was 10 years old, both from HIV-related illness. Since the death of her parents, Alindine has been living with Mrs Monali, whom she described as a very loving, supportive mother figure. She felt Mrs Monali was providing all of her basic survival needs in the same way as she did for her own child.

Alindine's family structure



Alindine, a teen club participant, has been accessing care at Maziko Centre for six years. She reported that she tested HIV positive at the age 13 and expressed feelings of bitterness at the result, particularly as HIV infection is associated with immoral behaviours. She indicated finding it difficult to understand her HIV status as she had never had any sexual contact and that it made her lose interest in many aspects of life including her education. Alindine reported missing classes because of severe, chronic illnesses such as TB, which made her fall behind in her studies as she was withdrawn from boarding school for one full academic year. This delay in academic progression made Alindine lose optimism for being able to achieve her goals in life.

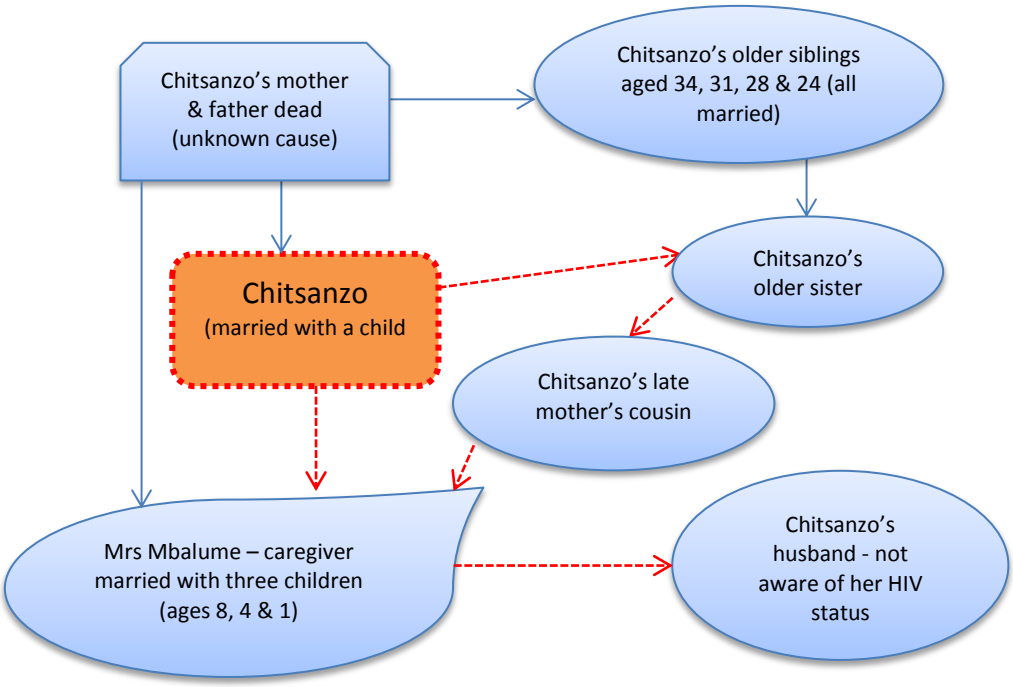
Throughout her interview, Alindine gave the impression that the stigma and discrimination she had encountered negatively impacted on her perception of self. The community members called her demeaning names like 'young woman using airtime', or 'ARV grinder' which negatively impacted on her emotional status and self-image. However, she felt that Mrs Yinde, her service provider in this case (aged 45, an Enrolled Nurse/Midwife and a counsellor with a Certificate in Youth Friendly Services), helped her accept her status and build confidence to identify and achieve her goals in life. Alindine believed that Mrs Monali's and Mrs Yinde's support assisted her to conquer the stigma and her academic challenges. She indicated that the psychosocial and financial support provided by Mrs Monali and supportive counselling provided by Mrs Yinde, helped her make appropriate choices and decisions. Alindine perceived that the support reduced her likelihood to succumb to paralysing feelings of self-doubt and incompetence, and helped to reinforce her confidence in thoughts and abilities around

positive choices, as she resisted peer pressures towards conformity. Alindine completed her Malawi School Leaving Certificate and a two year teaching course at Teachers' Training College which she said had completely changed her outlook in life and enabled her to become a primary school teacher.

Chitsanzo

Chitsanzo is 19 years old, married with a baby girl (three months old), and resides in a rural setting with her husband. Since Chitsanzo's husband was not aware of her HIV status, she asked her younger sister, Mrs Mbalume, to be a caregiver in this case. Mrs Mbalume aged 28, is married with three children and is a business lady with a Malawi School Certificate of Education. Chitsanzo is the last born child in a family of five children and she lost both parents at the age of nine years. She was brought up by her older sister, whom she perceived as having a demoralised outlook on Chitsanzo's ability to lead a meaningful life as reflected by her predictions of Chitsanzo's untimely death, possibly because she was often sick. Chitsanzo expressed feelings of distress for being marginalised by her older sister. Chitsanzo pointed out that her older sister struggled to conceal Chitsanzo's HIV status from neighbours and relations for fear of social rejection, including that of her family, but it was difficult because of Chitsanzo's visible HIV marks (stunted growth, negative facial outlook and recurrent infections). Chitsanzo, who was not involved with a teen club, expressed feelings of a loss of sense of belonging in her older sister's family. Five years later, her late mother's cousin suggested that Chitsanzo came to live with her which was a positive experience during which she felt loved. However, she failed her Junior Certificate Examination and according to the school rules, she could not repeat the exam at the same school and hence had to move to stay with her younger sister to repeat the class. Chitsanzo described her younger sister as very loving and supportive, though she was struggling financially as she only had a small scale business, selling second hand clothes.

Chitsanzo's family structure



Chitsanzo has been accessing care at Yankho Centre for four years. Mr Malido, her service provider in this case (aged 37 and an HIV counsellor with a Malawi School Certificate of Education), indicated that Chitsanzo reluctantly visited the clinic for doctor's appointments. He reported that Chitsanzo seemed to be embarrassed about her HIV status. Instead, Mrs Mbalume used to collect the ARVs on her behalf. However, Chitsanzo stated that the change in her facial appearance limited her social associations and interactions particularly with female peers who were teasing her. Hence, she reported engaging in three sexual relationships consecutively, including married men, for love, acceptance and financial support, which promoted her self-image. Chitsanzo indicated that male relationships had exposed her to unsafe sexual practices which resulted in a pregnancy with a married man. They agreed to terminate the pregnancy at a clinic in order to preserve his marriage. Six months after termination of the first pregnancy, Chitsanzo got pregnant again with another married man who refused to accept any responsibility. As such, she found a third partner, who married her and adopted the child she was carrying (pregnancy), which is unusual in Malawi.

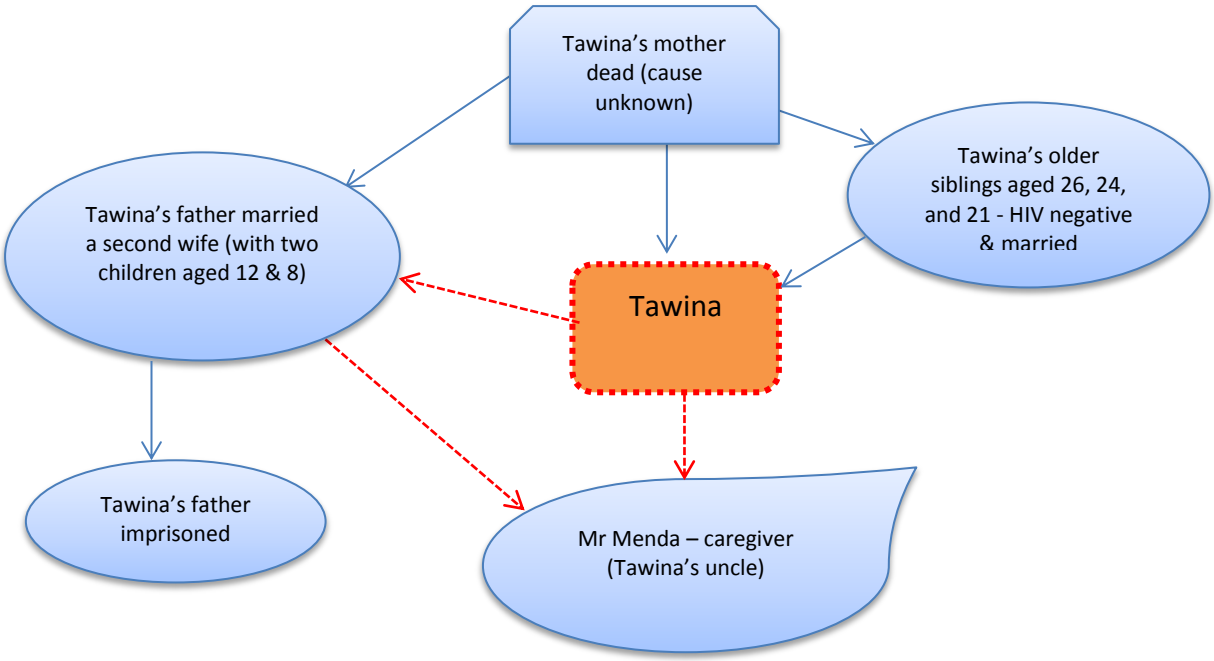
Chitsanzo indicated that fear of having the relationship terminated and loss of her source of financial support compelled her to keep her HIV status a secret to all her sexual partners, including the man that married her. Non-disclosure of her HIV status meant that her sexual partners were not inclined to use a condom. Chitsanzo's case is typical of the challenges young women face in disclosing their HIV status to significant others, including sexual partners, for fear of social exclusion and deprivation of the support they desperately need. All participants in this case had a follow-up interview three months after the baby was born to explore how Chitsanzo and the baby were managing and how they had dealt with disclosure of her HIV status to her husband.

Tawina

Tawina is 18 years old, living in a rural setting with her uncle, Mr Menda aged 39 years and a caregiver in this study. Tawina is the last born in a family of four children. Her mother died when Tawina was young, and since then she has been staying with her father and her stepmother, who brought her own two children to the family home. Tawina felt loved by her father but felt that her stepmother was ill-treating her. She reported facing hard times when her father was imprisoned after being implicated in money theft. She indicated that her stepmother treated her differently compared to her own two biological children and that she could not provide for Tawina's basic survival needs. This was attributed to the view that her stepmother did not want to share the stigma of Tawina's HIV status which was conspicuous by her skin condition (verruca vulgaris). This created a painful situation for Tawina as she experienced parental rejection and feelings of a diminished sense of belonging to the family. As such, Tawina, who was not involved with a teen club, reported having her first sexual relationship at the age of 14 in 2008, and by 2012 she had her fifth sexual partner consecutively. In this context, Tawina's experience strongly denotes that seeking love and acceptance is one of the factors that influenced Tawina to engage in male relationships as she coped with her difficult situation. Tawina reported that at the age of 15, her uncle took over her caring responsibility after getting reports that she was being ill-treated by her stepmother. Tawina perceived that her uncle was very loving despite her visible physical marks.

However, despite pursuing her studies at a community day secondary school, Tawina dropped out of school in form three because her uncle struggled to afford her academic and essential clothing costs. While both Mr Menda and Mr Pamba, her service provider (a male Nurse/Midwife Technician aged 25) at Yankho Centre, concurred that Tawina came from a poor family with limited support systems, Mr Pamba also perceived that Tawina dropped out of school due to social exclusion by peers as a result of her visible skin condition.

Tawina's family structure

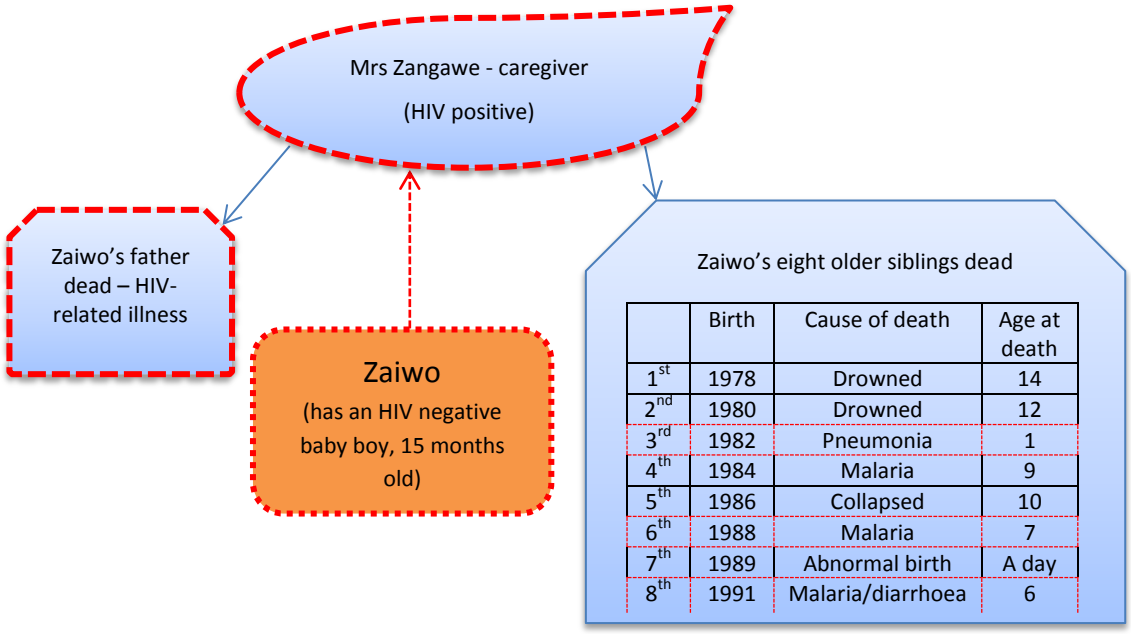


Within the community, Tawina reported receiving discriminatory remarks like being called 'an ARVs grinder' by peers. This caused emotional trauma and negatively impacted on her schooling. Tawina gave the impression of feeling devalued in the eyes of others and began to experience emotional isolation. Feelings of rejection resulted in Tawina developing a coping mechanism of secrecy and she maintained social interactions only with those individuals whom she considered to be safe and trustworthy. In this context, Tawina downplayed the dangers of male relationships to boost her self-image.

Zaiwo

Zaiwo is 19 years old with a baby and resides in an urban setting with her mother, Mrs Zangawe aged 48 (a widow and a businesswoman running a restaurant) who is a caregiver in this case. Zaiwo is the ninth born and only surviving child in her family. Mrs Zangawe reported that Zaiwo's father died of malaria, TB and herpes zoster when Zaiwo was four years old. Mrs Zangawe indicated that Zaiwo had stunted growth and at the age of three years was commenced on combination ARV and TB therapy to which she responded positively.

Zaiwo's family structure



	Birth	Cause of death	Age at death
1st	1978	Drowned	14
2nd	1980	Drowned	12
3rd	1982	Pneumonia	1
4th	1984	Malaria	9
5th	1986	Collapsed	10
6th	1988	Malaria	7
7th	1989	Abnormal birth	A day
8th	1991	Malaria/diarrhoea	6

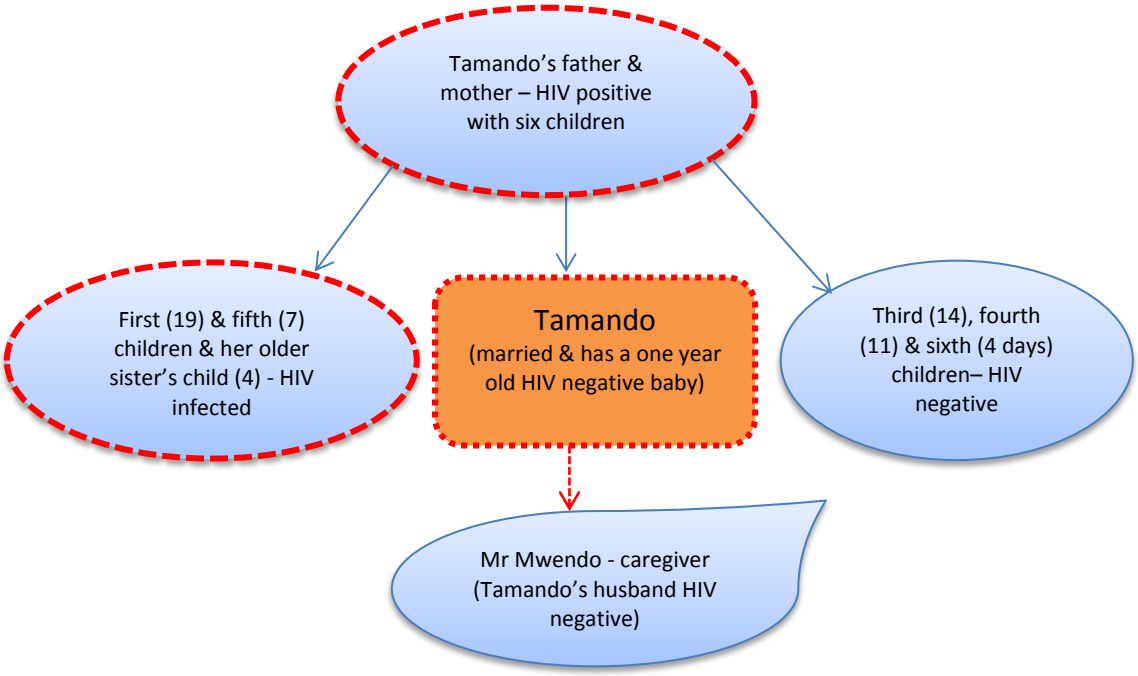
Zaiwo, a teen club participant has been accessing care at Maziko centre for 11 years. She reported knowing her HIV status at the age of eight years. She felt that being counselled together with her mother helped her to accept her HIV status and look at life positively as they mutually supported each other. However, Mrs Zangawe reported that Zaiwo became pregnant at the age of 14 years, but because of her HIV status and small stature, the service providers suggested termination of the pregnancy, which was done successfully. They opted for the termination in order to avoid complications associated with early child bearing in small stature. A year later, Zaiwo conceived again but this time Mrs Zangawe refused to give consent for termination of the pregnancy. She perceived that allowing Zaiwo to have a baby would possibly reduce the occurrence of successive pregnancies. However, Ms Benga, her service provider (a Nurse/Midwife

Technician aged 33), who had been in contact with Zaiwo for two years, perceived that Zaiwo became pregnant twice possibly because the young man was taking advantage of her learning difficulties. From Zaiwo's perspective, as she felt that she was not responsible for her HIV infection, that in turn her HIV status did not stop her from engaging in unhealthy sexual relationships. Mrs Zangawe had turned a blind eye to Zaiwo's relationships with men because she felt she was being blamed by Zaiwo for passing the virus on to her.

Tamando

Tamando is 17 years old, married with a one year old child and resides in an urban setting with her husband, Mr Mwendo aged 28, a businessman with a Diploma in Marketing and a caregiver in this case. Tamando is the second born in a family of six children. Tamando, a teen club participant, has been accessing care at Maziko Centre for seven years. She reported having tested HIV positive at the age of 10 years. She believed that counselling and participating in a teen club helped her to cope with her HIV status. However, Tamando reported dropping out of school in form one due to becoming pregnant and got married at the age of 15 years to Mr Mwendo, who was the father of her child. Tamando did not breast feed her child to reduce HIV transmission.

Tamando's family structure



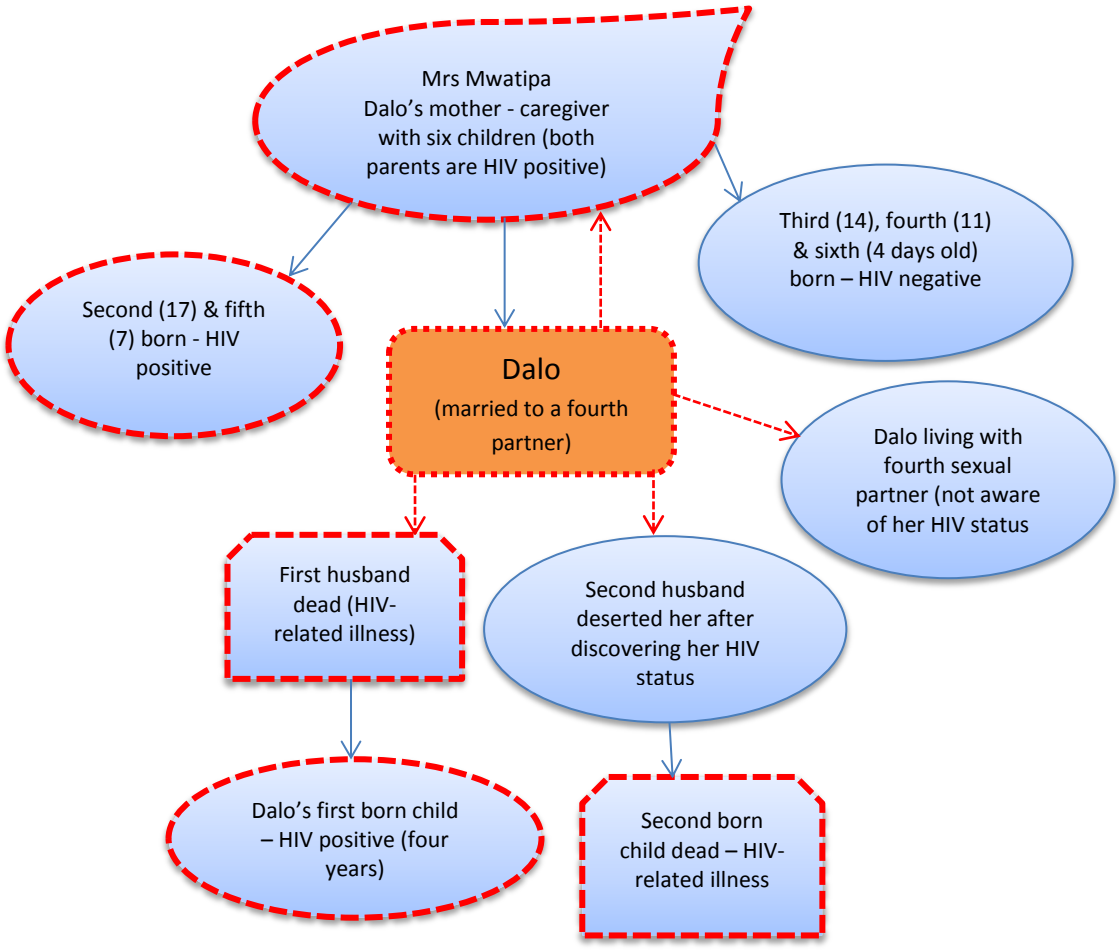
Tamando reported being born into an impoverished family. Her father works as a guard and being the sole bread winner for the family, survival becomes a major issue. As such, Tamando and her older sister (Dalo in this study) were selling cooked fresh groundnuts at the market to earn a living, which they were supplementing with money gained from sexual partners. Mr Mwendo indicated that he became trapped in the situation as he rendered financial assistance to Tamando. Mr Mwendo reported that he was supporting Tamando so that she could progress with her studies instead of having to earn a living from the age of ten. Since his plans to help keep Tamando in school did not succeed, Mr Mwendo decided to marry her, which Tamando was in agreement with. As Tamando's parents were living in poverty and had to provide nutritional and medical expenses for the six HIV infected family members, they turned a blind eye to Tamando's risky sexual activities. Her parents became powerless to control Tamando's early sexual behaviours since Mr Mwendo took over the caring responsibility as he provided financial support to entire family. Mr Mwendo reported having a barber shop, two benches for selling goat meat and was lending money to contractors, which made him capable of financially supporting Tamando and her family. Mrs Khambi was Tamando's service provider in this case, (an Enrolled Nurse/Midwife, aged 53 years), who had been in contact with Tamando for three years. She believed that Tamando's early marriage and child bearing (at the age of 15) was attributed to her dependence on Mr Mwendo for personal and financial security.

Dalo

Dalo is 19 years old, living in an urban setting with her husband, and is an older sister to Tamando. She is the first born child in a family of six children. Dalo reported that she tested HIV positive at the age of 12 years at Maziko Centre. With counselling and participation in teen club, she accepted her HIV status. Dalo perceived that life had been difficult for her family particularly because finding enough to eat was a constant struggle, so she dropped out of school at primary education level to assist her parents earn a living through selling cooked fresh groundnuts. Dalo also reported doing other piecemeal works from the age of 12 years to raise capital for her groundnuts business. She became pregnant at the age of 15 years by a married man who took her as a second wife, but this husband died two years later. Dalo now has a four year old daughter who tested HIV positive at six months old. She reported getting married to another man with

whom she had a second child, but that child died of HIV-related illness at the age of ten months. Her second husband deserted her after discovering that she was HIV positive. Mrs Mwatipa, Dalo's mother and the caregiver in this case (a housewife, aged 38), asserted that they struggle to get food for the day. Mrs Mwatipa further reported that Dalo's father works as a guard and what he earns does not meet the family's financial needs.

Dalo's family structure



Dalo's service provider, Mrs Nganya (a nursing officer aged 62), had been in contact with her for over six years. She complained that Dalo, despite caring little about her first child, still wanted to bear children whenever she found a sexual partner. Mrs Mwatipa had taken over caring for Dalo's first child. This was due to lack of proper maternal care, exemplified by the fact that the child's ARV therapy had to be changed to regimen 2 – Zidovudine (AZT) 60mg/Lamivudine (3TC) 30mg/Nevirapine (NVP) 50mg following on

from resistance caused by poor adherence to regimen 1. The child also suffered from malnutrition and was successfully treated with vita-meal and plumpy nuts[18].

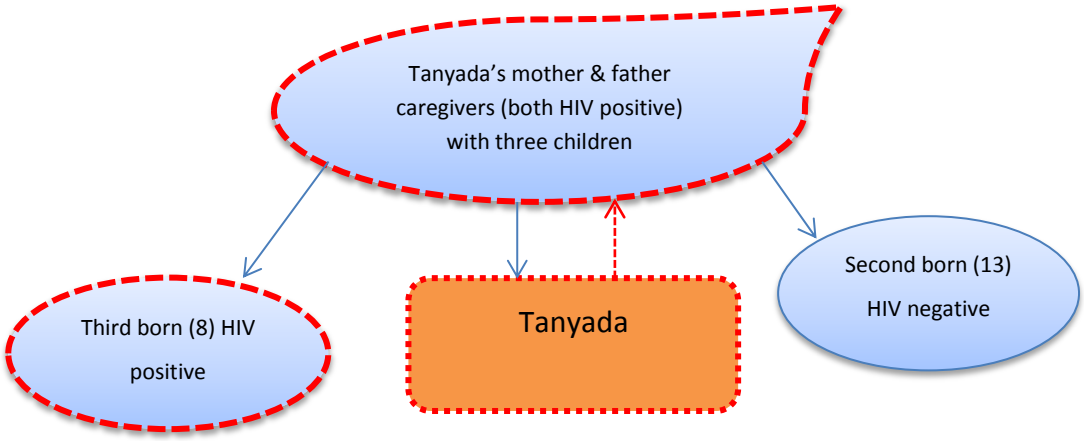
However, Dalo told a different story. She kept on complaining of being born into an impoverished family and finding it difficult to secure her basic survival needs. Hence, Dalo reported engaging in sexual relationships for love and financial support. Currently she was living with a fourth partner whom she had been married to for a month. Dalo's case illustrates a life full of hardships for a young woman, with multiple factors affecting her daily living and exposing her to risky sexual activities, particularly with older or married men, who symbolise power. Similarly, her parents seemed to turn a blind eye to her sexual behaviours, or were powerless to control her risky sexual behaviour, possibly because the family relied on her for financial support. Dalo's desire to have more children whenever she found a sexual partner could be based on many reasons. It is evident that Dalo was enduring hard times and possibly she just wanted to be loved or was using pregnancy as a strategy to maintain her sexual relationship thus securing her financial support.

Tanyada

Tanyada is 16 years old, residing in an urban setting with her parents, Mr and Mrs Mipando aged 48 and 40 respectively, who are both HIV positive and caregivers in this case. Mr Mipando works as a policeman and Tanyada is their first born in a family of three children. Tanyada has been accessing care at Chiyembekezo Centre and reported that she tested HIV positive at the age of 10 years but her parents and her service provider (Mr Nandi, aged 37, a clinical officer with a Diploma in Clinical Medicine) did not disclose the status to her because she was very sick.

[18] Plumpy nut is a peanut -based paste packed with calories and vitamins in a plastic wrapper for treatment of severe acute malnutrition or that is specially formulated to feed starving children.

Tanyada's family structure



Tanyada commenced ARV therapy, but developed TB and had to discontinue taking ARVs to start TB treatment. When she was able to recommence first-line ARVs, Tanyada responded negatively and both Mr Nandi and Mr Mipando reported that Tanyada's condition severely deteriorated as she developed body sores and wasting along with sight and hearing problems. Mr Nandi indicated that the initial treatment plan of stopping ARVs to start TB treatment likely contributed to Tanyada's resistance to first-line ARVs (Stavudine (d4T) 30mg/3TC 150mg/NVP 200mg). This resulted in deterioration of her mental capabilities and significantly derailed her academic progress and performance. However, after being shifted to second-line ARVs (Tenofovir (TDF) 300mg/3TC 300mg + Lopinavir/ritonavir (LPV/r) 200/50mg), Tanyada improved tremendously and returned to school, though visible marks on her skin remained, in addition to sight and hearing problems. Mr Nandi and her parents described Tanyada's recovery as a miracle and a success story in HIV management because she has not been subsequently been admitted to hospital.

Nevertheless, Tanyada reported encountering social exclusion in her neighbourhood and at school. Mr Mipando affirmed that his family was experiencing social rejection from friends and neighbours because the parents' HIV status was publicly known. This increased Tanyada's sense of alienation during a period when peer support in school was a particularly sensitive issue. However, Tanyada perceived that the mutually supportive relationship with her parents assisted her to accept her illness and to engage in and become involved with meaningful learning activities. Tanyada described her relationship with her parents as emotionally fulfilling. She also explained that her part-time teacher and a very close school friend were extremely understanding and

supportive. Both individuals helped her with some school work, especially mathematics and science despite the stigma and shame associated with Tanyada's HIV status. Tanyada reported that the support she received from her parents, her teacher and a friend gave her the capacity to engage in a meaningful role in her studies, resulting in a tremendous improvement in her academic performance.

4.4 Conclusion

In summary, this section has presented the participants' profiles in order to give an overview of the individual cases and illustrates some of the similarities and differences in the data collected as part of each case. Table 6 provides a summary of the cases and pseudonyms for each adolescent, her caregiver and her service provider as used in this thesis. The pseudonyms presented in Table 6 are used to represent cases in Chapters Five, Six, and Seven.

Table 6 Summary of cases and pseudonyms used

Adolescent	Caregiver	Relationship	Service provider	Profession of service providers
Ziliwe	Mrs Botolo	Aunt	Mr Hanuya	HIV Counsellor with Certificate in Youth Friendly Services
Nane	Mr Zaneni	Father	Ms Kando	Nurse/Midwife Technician; has Certificate in Child Counselling
Penina	Ms Ndengu	Aunt	Mrs Rwinu	Paediatrician
Ulemu	Ms Linyang'wa	Sister	Mr Mbalame	Senior Clinical Officer
Mwatitha	Mrs Metani	Aunt	Mrs Tayenda	HIV Counsellor with Certificate in Youth Friendly Services
Gonjetso	Mr Tambula	Headmaster	Ms Mbenu	Enrolled Nurse/Midwife
Fatsani	Mrs Ndazi	Mother	Mr Zidelu	Clinical Officer
Alindine	Mrs Monali	Aunt	Mrs Yinde	Enrolled Nurse/Midwife; HIV Counsellor with Certificate in Youth Friendly Services
Chitsanzo	Mrs Mbalume	Sister	Mr Malido	HIV Counsellor
Tawina	Mr Menda	Uncle	Mr Pamba	Nurse/Midwife Technician
Zaiwo	Mrs Zangawe	Mother	Ms Benga	Nurse/Midwife Technician
Tamando	Mr Mwendo	Husband	Mrs Khambi	Enrolled Nurse/Midwife
Dalo	Mrs Mwatipa	Mother	Mrs Nganya	Nursing Officer
Tanyada	Mr & Mrs Mipando	Parents	Mr Nandi	Clinical Officer

Out of the fourteen cases, six young women were living with their biological parent/s (father/mother), three were married and living with their husbands and five were double orphans living with either an aunt, an uncle or a sister. Five young women were still attending school (four in secondary school and one in primary school), one was in college, one had completed studies at a tertiary level, two dropped out of school (due to failed exams and lack of fees) and five have children. The service providers were from different health backgrounds such as nursing, medical and social welfare leading to acquisition of data from diverse health perspectives.

QUALITATIVE FINDINGS

CHAPTER FIVE

LOSS AND BELONGING: THE IMPACT OF HIV ON YOUNG WOMEN'S SENSE OF SELF

"I was used to go to private school, dad was very loving and was providing for all my needs, but now I cannot even go to a community day secondary school; my future is lost for I lack fees." (Tawina, 18)

"..If I (the dad) die today, who will take over her caring responsibility …my worry is who will stay with her, loving her as we do?"
(Mr Mipando, Tanyada's caregiver, 48)

5.1 Introduction

This chapter describes how HIV positive status disrupted the young women's development of 'self' and sense of belonging in different contexts. Many young women suffered loss of parental affection and support and disruptions in social networks which hindered their psychosocial adjustments and often threatened the development of 'self' and sense of belonging. The structural realities that shaped their experiences of loss are described. Death of a parent or siblings, family disruptions, low academic progression, low life satisfaction, negative sense of self-attractiveness, feelings of rejections and resentment disrupted young women's feelings of self-worth and their ability, which were fundamental to a young woman's identity. Relationship breakdowns also resulted in young women being cared for by foster carers, grandparents, or other family members or significant others, who could not satisfy the affection and support needs required by the young women. Since networks of social relationships ordinarily determine selves, social exclusion characteristically promoted loss of identity.

This chapter builds on three elements as illustrated by the participants regarding the impact of HIV on young women. The first section is constructed to outline the multiple losses affecting the young women as they grow up with HIV (see Table 7). The second section addresses the psychosocial impacts of a positive HIV status on young women's sense of belonging in their foster families and society. This section also illustrates how and why the perinatally HIV infected young women are treated differently at family,

community levels, and within the health services in different contexts from different perspectives. The third section highlights young women's experiences of sadness they endured as the result of multiple losses and HIV positive status. Cases are presented using pseudonyms and for their relationships with caregivers refer to Table 6 in chapter four. Findings are presented with quotes from the participants and some from their significant others.

Table 7 Cases to illustrate multiple losses

Name	Age at loss	Kind of loss	Living situation	Challenges
Ziliwe	3	Death of both parents	Lived with grandfather	Lacked maternal care & basic survival needs
	Few months later	Death of caregiver (grandfather)	Lived with three uncles for 3 years	Lacked proper care – uncles consuming a lot of alcohol
	14	Death of caregiver (older aunt & uncle)	Lived with younger aunt & had antagonistic kind of relationship before being chased by aunt's husband	Engaged in sexual activities for survival until she found a stable partner for financial security
	17	Disappearance of the stable partner when she became pregnant	Lived alone	Struggled to earn a living and financial security with the baby
Nane	11	Death of mother & paternal financial support	Living with her uncle (her father's brother); had antagonistic kind of relationship with her step-mother	Felt loss of sense of belonging to her family
	18	Sexual partner after disclosing her HIV status	Faced gender power imbalance as discussed in sections 7.3 and 7.4	Severely depressed
Penina	10	Death of mother	Living with father & step-mother with whom had antagonistic kind of relationship & was sent to a boarding school	Felt loss of sense of belonging to the family
		Friends	Friends rejected her	Peers posted her status on face book-withdrew from boarding to day secondary school
	17	Physical attractiveness (lipodystrophy)	Stopped associating with peers as they teased her of looking 'old'.	Lost sense of belonging to her social groups -felt no longer looking attractive to young men

Name	Age at loss	Kind of loss	Living situation	Challenges
Ulemu	4	Death of mother	Lived with grandmother then brother before she moved to live with aunt	Lacked financial support & sexually harassed by aunt's husband
	15	Physical attractiveness (big abdomen & breasts)	Living with aunt who teased her of eating too much, similarly was teased by female peers	Depressed with appearance & engaged in business to buy food she liked & well-fitting clothes; associated with boys than girls
		Loss of memory & deteriorating eye sight	Lived with aunt who discriminated & stigmatised her	Missed classes for weeks & used boys to assist her with maths & science subjects
Mwatitha	3	Death of mother & younger brother; Physical attractiveness	Lived with her uncle (physically abused) before moving to live with her aunt where she faced sexual harassment by her aunt's husband	Fully dependent on aunt's husband but neglected for whistle blowing his sexual advances.
Gonjetso	13	Death of mother, Reserved funds for her academic advancement	Lived with aunt, then in a boarding school	Dropped out of school due to lack of school fees
Fatsani	13	Paternal affection & support	Living with her mother, hospitalised & bed ridden for a year; father left for a fourth wife	Felt neglected by father, severely depressed & lacked paternal support
		Physical attractiveness (small stature, loss of hair) Mental capability & motivation	Lost interest in her surrounding including school when her father left Failed examinations leading to the need to repeat classes	Engaged in sexual relationships to boost her self-worth Dropped out of school
	15 16	First sexual partner after disclosing her HIV status Third sexual partner after collecting condoms from HIV centre	Faced gender power imbalance as discussed in sections 7.3 and 7.4	Severely depressed & found a second partner Found a fourth partner
Alindine	10 17	Death of mother Sexual partner for fear of being discovered HIV positive	Living with her aunt	Reduced number of peers

Name	Age at loss	Kind of loss	Living situation	Challenges
Chitsanzo	9	Death of both parents	Lived with older sister	Felt marginalised & sought acceptance & love through male relationships
		Mental capability & motivation	Failed examinations leading to the need to repeat classes	Dropped out of school
		Physical attractiveness ('face of AIDS'- negative facial outlook & stunted growth)	Her sister struggled to conceal her status from others as discussed in section 5.3.1	Reluctantly visited hospital & engaged sexual relationships to boost self-worth
Tawina	Very young	Death of her mother	Lived with father & step-mother with whom she had antagonistic kind of relationship	Felt loss of sense of belonging to the family
		Imprisonment of her father	Lived with step-mother who treated her differently to her biological children	Felt loss of sense of belonging to the family & sought acceptance outside the family unit
		Physical attractiveness (verruca vulgaris)	Stigmatised by step-mother & community members	Faced social isolation & lost friends hence loss of belonging to society
Zaiwo	4	Death of father and eight older siblings	Living with her mother	Felt lonely and loss of personal security
		Mental capability & motivation	Mother spending most of her time at restaurant (business)	Impregnated twice – first at age 14 then a year later
	14	Lost first pregnancy (therapeutic abortion)	Had a small stature which was perceived as risk factor by service providers	Conceived again at age 15 for she believed was her right to engage in sexual relationships
Tamando	10	Financial support Second pregnancy – aborted due to reduced pregnancy interval	Lived with her parents but unable to provide for her needs; living with her husband Faced gender power imbalance as discussed in sections 7.3 and 7.4	Early marriage & child bearing at the age of 15 years; became pregnant six months after delivery of her first child due to struggles on condom use; her child & husband are HIV negative

Name	Age at loss	Kind of loss	Living situation	Challenges
Dalo	11	Financial support Death of first husband & second child Second husband divorced her due to positive HIV status	Lived with her parents but unable to provide for her needs; lived with first husband as second wife (at the age of 15 years); back to parents; living with fourth sexual partner	Early child bearing (15 years); first child is HIV positive; lost first husband & second child to HIV related illness.
Tanyada	10	Mental capability & motivation; Deteriorating eye sight & sense of hearing	Living with her parents	Could not pass examinations but with involvement of part-time teacher & her best friend, her academic potential was unleashed.

5.2 Losses

All participants had suffered bereavement or diverse forms of loss. The experiences of loss were shaped by stigma, limited capacities and adult support networks in foster families. Stigma exacerbated the effects of bereavement and hindered psychosocial adjustments. The young women encountered both recurrent and cumulative losses. These included loss of parental affection and support, loss of physical attractiveness and disruptions in or loss of friendships and social support networks; they were thus left to endure these many types of loss and the associated agony on their own. This affected their functioning, social status and physical outlook, which often threatened the development of 'self' and sense of belonging to the family, peers and society.

5.2.1 Loss of parental affection and support

The loss of affection and support from parents or significant others created feelings of disconnectedness from family among the young women as they moved to foster families. This led to diminished sense of belonging to a family and greatly affected their functioning, as well as their personal and social identity as young women. Ziliwe, Ulemu, Mwatitha, Tawina and Chitsanzo lost either both parents or one parent when they were very young. All had moved on several occasions to foster families, which included living with extended family members (e.g. grandparents or step-parents) who were unable to

satisfy their affection and support needs. Loss of intimate parental relationships and support was reported as disrupting the young women's feelings of self-liking, self-acceptance, self-worth and diminishing their ability to participate in social groups.

> *"This illness is very depressing, I always ask, why did my parents die leaving me very young without their love and care? I'm suffering alone without anyone caring about me; I dislike this miserable life." (Ziliwe, 18)*

> *"My mother died while I was young and my father married another woman……I was living with my father and my stepmother until 2009, when I lost my father to imprisonment; it was difficult living with my stepmother; life became meaningless to me, she never loved me."* (Tawina, 18)

Some young women like Gonjetso and Tawina placed an overwhelming emphasis on their former self, a position which they viewed as 'normal' and more acceptable. This led them to desire a return to their former self. They acknowledged this was unrealistic as they experienced lack of adult support networks and social exclusion leading to loss of the happy times they used to enjoy with their parents before death and imprisonment (respectively).

> *"I was used to go to private school, dad was very loving and was providing for all my needs, but now I cannot even go to a community day secondary school; my future is lost for I lack fees."* (Tawina, 18)

> *"In town, mum was providing for all our needs, now mum is gone, we have to face it; it's not easy losing mum's love when I need her presence most. I believe if I do well in school, I will manage to give my sister and my brother the good time we used to have with mum."* (Gonjetso, 16)

Reflecting on their sentiments, both Gonjetso and Tawina described the death of their parents as loss of parental affection, support, financial security, personal and social identity leading to diminished self-worth. Similarly, Tanyada, whose parents were often sick, expressed fear of losing them to AIDS and raised concern that no-one would be left to care for her and her siblings. This fear of untimely death and succession plan for caring responsibility was also shared by her father, Mr Mipando.

> *"……if I (the dad) die today, who will take over her caring responsibility? Issues of visiting the clinic or taking drugs is not a problem but my worry is who will stay with her, loving her as we do?"* (Mr Mipando, Tanyada's caregiver, 48)

Both Mr Mipando and Mrs Zangawe (Zaiwo's caregiver) acknowledged that during the period of the terminal illness, their ability to provide for their children was diminished. They felt that while the young people are in need of care, the ill parents need support to live longer and affectionately support their HIV infected children. They expressed the view that lack of the support makes the young people prone to exacerbated stigma and vulnerability as they struggle to support their sick parents or earn a living. They shared concerns about what would happen if they died with no-one to take care of their surviving children. Mrs Zangawe described the loss of her husband and eight children to various illnesses and physical accidents as a catastrophe and wished if she could live longer despite her positive HIV status to take care of her only daughter (Zaiwo) and her grandchild.

> *"……am anxious about who would remain with my only child and my grandson if I die today; will they be accepted as I do? They need care, only if I had support or someone to take care of her; it was a disaster losing my husband and my eight children, I hope am still around to look after the two."* (Mrs Zangawe, Zaiwo's caregiver, 48)

However, Zaiwo and Fatsani expressed concern over the loss of parental affection and presence. Zaiwo's mother, Mrs Zangawe, indicated that her absence was linked to her low socio-economic status and lack of support networks as a single parent. As such, she had to spend much of her time doing business at the restaurant to earn a living, hence restricting her parental role. Fatsani's father married a fourth wife while Fatsani was hospitalised. These cases signified that the caring role was placed on women and created imbalances in the caring responsibilities, like in the case of Fatsani, in which her father was still alive. The feelings of parental neglect were strongly attached to the young women's sense of worth as they diminished their sense of belonging to the family. Loss of paternal affection was also reported to negatively affect Fatsani's

schooling, as she became severely depressed and lost morale for her academic endeavour.

> *"……her father left this house, when she was hospitalised and it was like he was not interested in taking part in the care of her illness. Since then she lost interest in most of the things and does not work hard in class; usually she spends so many days before she goes back to school. She felt ignored by her own father and I suspected thus why she was never interested in her surrounding, could not smile at anyone for over a year."* (Mrs Ndazi, Fatsani's caregiver, 41)

> *"Imagine while I was sick in hospital my father left mum alone, and married another wife; he never cared about me, it's painful seeing mum struggling alone, dad forsook us in hospital, without his support, poor me! Why dad doing that to me? It is painful when parents are alive and expected to be accountable, seem not to care, I couldn't understand for I did not choose to be HIV positive."* (Fatsani, 17)

5.2.2 Loss of physical attractiveness

Young women normally observed and shaped their physical outlook to enhance their attractiveness and increase their favourable attention of others, particularly the male partners. They perceived that young men when proposing young women for sexual relationships were driven by physical attractiveness. As such, though the visible marks of HIV infection elicited stigmatization by peers or the society, some young women felt insecure in themselves. They seemed to base their self-worth and physical attractiveness from others (particularly men) on their appearance. This signified how the young women upheld masculine dominance in evaluating or targeting feminine physical outlook for sexual advances. For instance, Penina, Ulemu, Fatsani, Chitsanzo, Zaiwo and Tawina were devastated with the change in their body image, especially upon reaching the age at which they are expected by society to look attractive to men as young women. Visible marks like stunted growth/small physique, big abdomen and breasts, lipodystrophy and facial hypodystrophy led to dissatisfaction with their appearance and hence diminished their self-image. They attributed their altered physical outlook to the type of ARVs they were taking. The emotional feelings of not

being accepted and fitting in their social groups, particularly among female peers were common among most of them and posed a threat to their valued identity as young women. It was not only loss of social identity that troubled them, but it was particularly traumatic to them that the illness threatened their valued feminine identity, as they reflected upon its consequences on their relationships with sexual partners, which affected their self-worth.

> *"Imagine when I get out of the house to escort my friends, people especially young men would ask me, 'why do you look like an old woman?' When I look at my face on the mirror am like an old lady, poor me! I have stopped moving with my friends because they tease me or young men single me out for looking like somebody's grandma, it's devastating; will I ever get a boyfriend?" (Penina, 19)*

> *"I've lost all that belongs to me; my skin condition prevents others from associating with me; I look different from other girls, the beauty of a young woman is not in me; this condition makes me sick, I feel am not attractive to young men." (*Tawina, 18)

Delay in development of physical features symbolic of womanhood (e.g. breasts and menarche) was also acknowledged as creating a developmental gap with peers and was devastating for Fatsani and Alindine, as it impacted on the development of their body image. However, Mrs Ndazi (Fatsani's mother) perceived that Fatsani's change in moral behaviours possibly signified that the menstrual period of a female-bodied individual is frequently a sexually defining point for many young women in many cultures. This was evidenced by Fatsani's irresponsible behaviours when she developed breasts and reached menarche.

> *"…….once she started taking the treatment, she improved; both of us were very excited to see breasts developing, she had her first monthly period…….surprisingly, her behaviour completely changed, mostly she was out and coming home late."* (Mrs Ndazi, Fatsani's caregiver, 41)

> *"….I had not had my period yet, I didn't even have breasts and I could not associate with my age mates; this was very frustrating, and the question remained but why me? Now am so excited, associating with friends."* (Fatsani, 17)

Similarly, caregivers (Mrs Mipando and Mrs Ndazi) shared young women's feelings of negative body-image. However, the majority of the concerned caregivers were females (biological parents), and this could possibly be attributed to a shared cultural understanding about the importance of physical attractiveness and sympathy for their loss. This could also signify that, being mothers, they were bombarded with images of an ideal face or physical appearance for women which in this case was distorted by the HIV infection, thus threatening the young women's valued identity.

> *"This illness is awful; my daughter's body has lots of scars, taking off all her beauty and she feels ashamed to mix with her friends. Am concerned as a mother; I feel responsible for her condition, especially failing to associate with her peers."* (Mrs Mipando, Tanyada's caregiver, 40)

During follow-up interviews, Mrs Metani also expressed concern that Mwatitha was very depressed with her changed body outlook (body sores) which she strongly linked to HIV infection and intake of ARVs. She perceived that she was no longer attractive to her peers and was withdrawn.

> *"She (Mwatitha) has now completely stopped taking ARVs despite several counselling sessions. She complains that HIV is a destroyer, her beauty as a young woman is gone, has lost peers because of her body sores and is no longer interested in life."* (Mrs Metani, Mwatitha's caregiver, 40)

Service providers also acknowledged that the visual scars of skin conditions, being shorter, big abdomen and breasts and lipodystrophy negatively impacted on young women's physical outlook. As such, they feared young women's intentional discontinuation of the treatment in order to alleviate their negative body image particularly the visible marks which they thought could easily attract social stigmatization.

> *"She (Fatsani) often complains that her abdomen looks big since she started taking ARVs. This may be the reason why she may not faithfully take ARVs because people in the community may start pointing at such changes in her physical appearance and easily associate it with intake of ARVs."* (Mr Zidelu, Fatsani's service provider, 26)

> *"The treatment she (Tawina) is currently getting caused a skin condition (**Verruca vulgaris**) and this is very pathetic for a young woman. I'm concerned that she may not adhere to her ARVs because it has completely changed her outlook; she doesn't look attractive and she complains of being isolated by peers."* (Mr Pamba, Tawina's service provider, 25)

Interestingly the service providers who pointed out loss of physical attractiveness in Fatsani and Tawina were both young men and single; this is symptomatic of how men value feminine physical outlook for sexual advances. It could be that, as young men, they were imbued with the same cultural expectations and behaviours that produced the very negative outcomes and insecurities among young women, despite being professional service providers.

5.2.3 Loss of mental capability and motivation

HIV diagnosis and its associated frequent attacks of physical ailments have had the most negative impact on young women's academic progression. The majority of the young women had lower academic achievements and consequently less chance of gaining economic independence. Recurrent infections and little financial support for school fees exacerbated the risks of interrupted school attendance and the existing learning disadvantages that they encountered through HIV-related cognitive impairment. For instance, Gonjetso, Ulemu, Fatsani, Alindine, Chitsanzo, Zaiwo, and Tanyada reported missing and repeating classes because of severe and prolonged illness requiring hospitalization and frequent hospital visitations, uncertainty of the prognosis and lack of school fees, all of which derailed their academic progress.

"…….while in form two, I became very sick and was in hospital for a month on TB treatment and ARVs. I withdrew from boarding school… I developed paralysis of both legs for three months. I was home for over nine months before I went back to school to complete my Malawi School Certificate of Education after I had improved……." (Alindine 19)

While Ulemu, Gonjetso and Alindine showed determination to excel academically despite their delay in their academic progression, Fatsani, Zaiwo, and Chitsanzo lost interest in schooling as they felt were out of sync with their peers, hence they felt a loss of belonging at that stage of education.

"…I started school late because of my illness; but my age was a mismatch with my classmates; though I wished to continue with my studies but my age, 14 years in standard five; I felt my situation was just humiliating; I lost interest in school." (Zaiwo, 19)

These views were in contrast to those of Mrs Mbalume, Chitsanzo's caregiver, and Ms Benga, Zaiwo's service provider, who felt that the young women's loss in interest in school was attributed to lack of inspiration by their caregivers. Gonjetso, who was inspired by her mother to achieve her academic goals despite her life challenges, justifies their argument.

"……her sickness affected her participation in school, but also my sister hasn't been supportive and mindful of her language - always predicting her untimely death; I feel that discouraged her from concentrating on her school." (Mrs Mbalume, Chitsanzo's caregiver, 41)

"My mum was the only educated woman in our village; I looked to her as my aspirer. As a teacher by profession, she used to encourage me to work hard in school, I admired her; she was independent and I know I will make it." (Gonjetso, 16)

Ziliwe and Tamando attributed their failure to achieve their academic goals to the lack of financial support from their parents/caregivers. For them, failure to advance with their education meant loss of their capability to make an independent future and to exert agency in their life. For instance, Tamando indicated that going to the market every day

to do business exposed her to initiate sexual activities early (aged 12 years), which resulted in teenage pregnancy at the age of 15 years. This led to termination of her academic journey hence her full dependence on her husband for survival.

> *"I wished I had advanced with my education to live a better life, going to the market daily made me lose my key, I lost the key to get my bright future. Only if my parents had resources for me to continue with my education than being at the market just to have something to eat, maybe I could have been talking of a different story today. Now I have to depend on my husband for everything; I lost my opportunity."* (Tamando, 17)

Each of the young women then went on to describe the social impacts their HIV positive status had had on their lives.

5.3 Stigma and discrimination

HIV status often exposed the young women to societal stigmatisation and discrimination and this was made worse by the shame, fear and rejection that often surrounds them. The stigma[19] negatively impacted on young women's decisions regarding status disclosure to others, as doing so led to rejection or physical abuse as reflected in section 6.5.1. Young women gave accounts of their everyday lives in which they experienced negative responses or reactions which likely distanced them from their normal (HIV negative) peers (enacted stigma). Stigma and discrimination was experienced differently by young women. It remained pervasive and negatively influenced young women's experiences at family, community and individual levels and within the health systems.

5.3.1 Stigma and discrimination at familial level

The stigma that surrounds HIV infection made a number of young women unable to access to the support and care they desperately needed from their foster families. The caregivers did not want to share the stigma of the young women's HIV positive status,

[19] Stigma is defined as a mark of discredit of shame, an identifying mark or characteristic, and as a mark of guilt or disgrace" (Merriam Webster, 2011), which disqualifies an individual from full social acceptance (Goffman, 1963). When an individual fails to meet expectations because of attributes that are different and/or undesirable, that person is reduced from an accepted person to a discounted one (i.e. they are stigmatized).

which was evidenced by visible physical marks and recurrent infections, as association could lead to their own social isolation. Ziliwe, Ulemu, Mwatitha, Fatsani, Tawina, Chitsanzo and Penina perceived that they were treated differently to uninfected or biological children in the foster families. This led to experiences of social isolation and hence a diminished sense of belonging to the families, which lowered their self-image. Stigma and discrimination manifested in different forms ranging from neglect and isolation to verbal and physical abuse. While Mwatitha was subjected to beating by her uncle, Ziliwe and Fatsani experienced separation and neglect from an aunt and a parent respectively. Fatsani perceived the pain of being neglected by her own father, who was the main breadwinner in the family, as he prioritised another woman with his resources, ignoring her in hospital failing to provide any financial support. The feelings of being neglected greatly affected the young women's sense of belonging to the family and self-image both financially and emotionally.

> *"……while on hospital bed for several weeks, I thought dad would be kind enough to be with me as the only child infected with HIV in our family, but he never cared; who then would accept me, if am being neglected by my own father? I could hardly believe it; I thought I deserved the support and care I required from my parents. This illness is not my fault, why should my father leave me in hospital without his support for another woman? I was traumatized……."* (Fatsani, 17)

Similarly, Chitsanzo perceived the pain of being rejected and marginalized by her own sister, whom she described as predicting her untimely death as reflected in her verbal expressions and efforts to conceal Chitsanzo's HIV positive status. This greatly affected Chitsanzo's sense of belonging to the family and self-image as she felt socially excluded.

> *"I wished mum was alive, my older sister used to insult me, keeping me indoors, she even had the courage to ask me, 'why didn't I follow my mother to the graveyard?' She could buy clothes only for her children and not for me. Her attitude worsened my distress; I did not choose to be HIV positive, I feel the pain of losing parents……."* (Chitsanzo, 19)

Mr Malido, Chitsanzo's service provider, indicated that in the rural setting where Chitsanzo was residing there was a high level of stigma and discrimination for individuals infected with HIV and the positive status was highly linked to immoral behaviours. It was not surprising therefore that Chitsanzo's older sister made every effort to conceal Chitsanzo's HIV status. It is possible that the older sister perceived personal insecurity about her own social isolation and loss of friends through sharing the stigma posed by Chitsanzo's HIV positive status which was evidenced by her chronic illness and stunted growth.

> *"….in this rural area, HIV positive women are highly stigmatised and discriminated by community members, as if they are the most promiscuous women; so most HIV infected young women do not easily associate with their peers."* (Mr Malido, Chitsanzo's service provider, 37)

5.3.2 Stigma and discrimination at community level

The social environment impacted on the young women's self-image and their identity differently when faced with daily problems, depending on the affection, acceptance and availability of essential resources for identity achievement. Friendships often waned as young women no longer shared the same social worlds. All participants expressed concerns over social isolation and verbal abuse. Name calling was particularly prevalent, and young women cited several derogatory epithets that people call them including: 'a person with AIDS', 'the sickly', 'ARVs grinders', 'individual with internal injuries', 'moving corpse', '*chiwole'* ('rotten person' who has no value in life), '*woyendera ma units'* ('people operating on use of airtime' - dependent on ARVs), and 'hybrid chicken' which refers to chicken that are given fattening feeds. Notably, many of these insults focus on ARVs, which infected individuals rely upon to maintain their health.

The popular association of HIV with sexual intercourse was surrounded by taboos and moral judgements, forcing the young women feel socially marginalised. Nane, Fatsani, Alindine and Chitsanzo all felt that they were being subjected to moral judgement, as their HIV positive status was perceived as the carrier's responsibility, especially considering that the primary modes of HIV transmission are intentional and preventable behaviours. Thus, they were stigmatised by the association of their HIV with promiscuity, prostitution or other forms of behaviour. They were called 'prostitutes' or

'bicycles' due to societal beliefs that their HIV status was correlated with sexual promiscuity, leading to further reduction of their social networks (as others did not wish to be associated with such behaviours).

> *"….though I have not engaged in sexual activity, to many HIV means you have been moving out with men; in this rural area people or boys regard you as 'a bicycle' or a 'prostitute;' this illness makes me feel bitter, for it keeps me away from my friends." (Alindine, 19)*

Notably, Tawina's service provider, Mr Pamba, and Chitsanzo's service provider and caregiver, Mr Malido and Mrs Mbalume respectively, having lived both in the rural and urban settings, perceived that there was higher level of stigma and discrimination for individuals infected with HIV in rural areas, where positive status was more strongly associated with immoral behaviours.

> *"……there is a difference on how HIV infected individuals are regarded in rural and urban areas. In urban areas, people are very knowledgeable and easily associate with the infected; the literacy levels differ and influence the way they react towards the HIV infected. In rural areas, the majority do not understand different ways of contracting HIV and the HIV infected are called names like 'ARV grinders' 'the already knocked off'; women are regarded as prostitutes and are highly stigmatised."* (Mr Pamba, Tawina's service provider, 25)

5.3.3 Self-stigma and self-discrimination (felt stigma)

Changes in physical appearance, low socio-economic status and low academic achievements shaped the young women's perceptions of self in relation to their peers. The majority perceived that they looked different from their peers and gave examples of anticipating potentially negative responses (felt stigma). A number of young women demonstrated feelings of insecure identity amongst their social groups. Nane, Penina, Ulemu, Chitsanzo and Tamando expressed fear of interacting with their peers and being discriminated against if their HIV positive status was known, which they felt could damage their self-image.

"I'm just uncomfortable being with my friends; will they not keep on talking about my changed outlook? I have stopped chatting and visiting them. If they know my status will they not isolate me? This is real life situation, I have seen people being discriminated and I feel bad whenever I think about it." (Penina, 19)

Furthermore, Ziliwe, Zaiwo, Tamando and Dalo also felt insecure about attending teen club meetings once they conceived. They feared stigma and discrimination among their peers and service providers for being pregnant while they had access to preventive information and services through teen club meetings. This deprived them of the support they desperately needed from the health services.

"Currently 'am no longer comfortable attending teen club, though am encouraged to attend I feel my peers and service providers would talk much about my pregnancy. I feel everyone would be asking why I am pregnant as if there were no condoms. I had a friend, who was also pregnant, everyone even service providers started pointing fingers at her; it is a bit difficult to find someone to support you as we used to do before I became pregnant. (Ziliwe, 18)

Interestingly, Ulemu, Fatsani, Tawina and Chitsanzo, who felt insecure themselves appeared to avoid social interactions with female peers and formed new social networks with male counterparts, in which they felt accepted, understood and safe, hence impacting on their self-worth. They attributed their growing isolation to experiences of being disgraced and devalued amongst the female social groups, who were more conscious of an ideal physical outlook for young women.

"I see it proper chatting with boys than girls because most girls tease me of getting too fat, having bigger abdomen; I no longer associate with them. I prefer chatting with boys, whom I feel they help me with school activities but they are not my sexual partners." (Ulemu, 18)

"……usually my friends tease me about my appearance, I do not associate with many except a few; I would rather chat with boys, who don't talk much about my appearance. I feel bad about it (HIV)." (Tawina, 18)

5.3.4 Stigma and discrimination within the health services

While service providers create an environment and prepare a situation wherein the young women can make decisions, or where their personal responsibility is called for, Ziliwe and Fatsani reported being denied access to sexual and reproductive health services particularly the use of injectable contraceptives. They encountered challenges with condom use with their sexual partners and opted for injectable contraceptives. However, they equated being restricted to access the injectable contraceptives to being punished because they were HIV positive or were expected to abstain from sexual relations.

> *"……I had problems with condom use so I wanted other contraceptives but so many restrictions; is it because we will pass on the virus to our sexual partners or they do not want us to have sex? Is it because this will make us relax, become pregnant? Why discouraging us? But those with challenges on condom use like me will still get pregnant and it's painful having a pregnancy that could have been prevented." (Ziliwe, 18)*

> *"….after we had a lesson on use of contraceptives to protect ourselves from pregnancy at teen club, I went to meet a nurse to access injectable contraceptives as my partner was refusing condoms; surprisingly she shouted at me for asking for contraceptives; it contradicted with what we learnt so I concluded that I cannot access contraceptives, may be because am HIV positive."* (Fatsani, 17)

Dalo reported being despised by some service providers for being pregnant as they thought she had access to preventive information and services like condoms. This interrupted her participation in teen club and access to the psychosocial support she desperately required.

> "*…though I got encouraged at the club; throughout my pregnancy I never attended teen club meeting because some service providers scorned me for getting pregnant. I resumed attending teen club when I had delivered my baby; likewise Tamando (her sister), she stopped attending teen club when*

her pregnancy became visible because some service providers were despising her." (Dalo, 19)

Service providers (Mr Pamba and Mr Mbalame) acknowledged that the stigma that young women encountered at the centres was attributed to service providers' lack of knowledge and skills in dealing with adolescent sexuality vis-à-vis HIV positive status. They perceived that providers' negative attitudes were affecting young women's self-image and access to sexual and reproductive health services.

"I feel stigma and discrimination she (Tawina) encounters affects her access to condoms; most providers know that she is HIV infected because of her skin condition. So if they see her collecting condoms it could be an issue; the negative attitudes - they would not expect her to be sexually active; they would think she is being suicidal to sexual partners. This makes young people prefer buying condoms from shops than collecting them from the centre; personally, I don't mind offering her condoms, but if she is seen by other service providers, will question her, why does she want to kill many? Reflecting on challenges with condom use in these rural areas, they would prefer she abstains - this discourages young women from using SRH services." (Mr Pamba, Tawina's service provider, 25)

Mrs Rwinu concurred with Mr Pamba that intense stigma was also attached to mental health problems presented by the young women in the centres. Mrs Rwinu felt lack of clarity surrounding their positive status experiences and changed social identities, rendering the majority of young women perplexed and unable to comprehend and share the challenges they encountered, compelling them endure the sadness on their own. This negatively impacted on their psychosocial and mental well-being as they felt service providers' absence.

"I feel like there is also stigma attached to mental health and it causes another huge barrier. She (Penina) even the others, have already stigma attached to their HIV status and if they are not supported to understand their situations it becomes confusing. If you diagnose them with mood disorders, that becomes an added stigma for them and are left on their own." (Mrs Rwinu, Penina's service provider, 33)

5.4 Enduring sadness

The majority of young women perceived that diagnosis of HIV created a raft of emotions including anger, depression, grief and other emotional pains, which they did not share with anyone until when they were given an opportunity to share their lived experiences with the researcher. The endured emotional pain stemmed from thoughts about negative impacts of a chronic illness, what people said about them, how their life styles had changed, traumatic experiences of neglect and being in an emotional desert[20] for years after being diagnosed as HIV positive or losing their parents. A number of young women living in foster families and with their sick parents endured long periods of suffering as they encountered antagonistic relationships with their caregivers and struggled to secure their basic survival needs. Tawina and Nane cried bitterly as they explained about their relationship with their step-mothers. For Tawina, living with her step-mother following the imprisonment of her father was acknowledged to have been an emotionally fraught experience leading to an urgent need for a safe place.

> *"I reached a point that I could no longer bear it; I felt it was better for me to leave my step-mother and stay with someone else. She was torturing my life for no apparent reason; I know I meant nobody to her, without my father in the house, I became a stranger; I wished I had a safe place of stay."* (Tawina, 18)

> *Tawina was heart-broken as she explained about her relationship with her step-mother; she sobbed continuously but when asked to continue next time, she insisted that she would continue narrating her story*. (Interviewer's observations)

Similarly, Tamando expressed feelings of long-suffering as she reflected upon her family's low socio-economic status, her parents' struggles to earn a living, the time she spent at the market in search of basic survival needs instead of going to school and how her pregnancy terminated her academic trajectory. She felt if she had achieved her academic goals, life could have been different for her parents and she could have been independent.

[20] 'Emotional desert' in this study is defined as a state in which young women were bombarded by a devastating level of distress for years with inadequate coping capacities (Murrell, 1999).

"It pains me that my parents have remained poor, I had to spend most of my time at the market; I missed my opportunity; I got pregnant. If I was educated, get employed, may be my parents could have been taken out of this indescribable poverty, asking everything from my husband until when? Poor me, born in a poor family!" (Tamando, 17)

Tamando started crying uncontrollably, her continuous sobbing for over ten to fifteen minutes demonstrated how painful she felt to see her parents struggling in life, yet if she was educated and employed possibly she could have been assisting her parents independently - without any restrictions; when asked to continue next time, she insisted that she would continue narrating her story. (Interviewer's observations)

Ulemu, Mwatitha and Penina reported suicidal ideations, following social isolation at home, to service providers at the centres. While Penina had antagonistic kind of relationship with her step-mother, Ulemu experienced stigma at a familial level, and with Mwatitha, they faced rejection by their aunts' husbands (who were bread winners in their foster families) after whistle-blowing their sexual advances. This kind of endured suffering led to suicidal ideas and attempts for these young women. Mwatitha and Penina further experienced social rejection in school, when their HIV positive status was discovered by peers. While Penina expressed suicidal ideas, Mwatitha attempted suicide, especially as she reflected on her long-suffering and lack of safe place to live.

"Aunt's husband touched my breast and my bums, though he stopped doing that, it still tortures my mind; he stopped providing for my basic needs including school fees yet I was determined to achieve my academic goals. At school my friends were calling me 'an HIV positive person' after discovering my ARVs. I felt I had suffered enough, I took ten tablets of different drugs and I was dying; but my best friend noted early that she reported immediately to our teachers who gave me first aid management (glass of milk) and rushed me to the hospital. (Mwatitha, 18)

Mrs Rwinu, Penina's service provider, perceived that young women with mental health problems like Penina lacked specialised attention and were viewed negatively by service providers and peers in the centres. She believed that such attitudes coupled with stigma already attached to HIV positive status created some barriers to thorough risk assessment and deprived the affected young women of appropriate mental health care.

> "*I feel there is also stigma attached to mental health in this centre and it causes another huge barrier to access appropriate care; if an adolescent is diagnosed with mental problem is not considered positively by most service providers or peers rather than a mad person and is talked to negatively. Currently, there is no mental health nurse for the centre and a lot of young people are missed out."* (Mrs Rwinu, Penina's service provider, 33)

The expressions of both Nane and Alindine on how they felt about being HIV positive signified the emotional pain they endured as they esteemed the clear association that exists in people's minds between HIV infection and morally incorrect behaviours. They attributed their intense emotional trauma to lack of explanations as to what happened to them to be HIV positive while their siblings are HIV negative, in order to comprehend their situations. Both expressed the emotional pain over their fate of being HIV positive despite their sexual innocence with uncontrollable shedding of tears.

> *"Why 'am I HIV positive? What happened to me? It pains me though I never told anyone; others may think that I have been so promiscuous, but I did not have any sexual contact before the HIV test; this illness is devastating." (Nane, 19)*

> *".....the pain of living with this shameful illness for a young woman like me is indescribable; I have never discussed it with anyone but I just feel like everyone looks at me as a prostitute, yet I have never had any sexual contact and my sister is HIV negative, what happened? Nobody tells me."* (Alindine, 19)

> *The continuous flow of tears down her cheeks demonstrated how difficult she (Alindine) felt expressing her feelings of having a shameful and stigmatised illness despite her innocence. After crying for five to ten minutes, when asked to continue next time, she insisted that she would continue narrating her story*. (Interviewer's observations)

The enduring sadness expressed by the young women was shared with their caregivers. Linyang'wa, Ulemu's caregiver, felt that in their aunt's home, Ulemu (her sister) was stigmatised, physically abused and they were struggling to earn a living, but she could not share her experiences with anyone for fear of negative consequences. Linyang'wa, burst into tears uncontrollably as she narrated the nature of relationship and the treatment of Ulemu in their aunt's home coupled with the sexual harassment by the aunt's husband.

> *"I feel the treatment she gets home makes Ulemu have negative attitude towards her life. She is not offered the food she likes, aunt treats her differently from anyone else, and her husband is fond of proposing us including Ulemu despite being aware that she is HIV positive. It pains me seeing her crying most of the times; I wished mum was alive; she deserves to be loved, cared for like any other child, she did not choose to be HIV positive."* (Ms Linyang'wa, Ulemu's caregiver, 21)

> *Linyang'wa became heartbroken and sobbed with tears unceasingly flowing down her cheeks and could not continue with the interview which was altered to another agreed date.* (Interviewer's observations)

It is clear from this section that some young women had endured traumatic experiences which were overlooked or no-one helped them to bear and handle them in a better way until they were asked to share their lived experiences with the researcher.

5.5 Conclusion

This chapter has presented findings related to impacts of HIV positive status on young women's development of 'self' and sense of belonging. The focus had been on physical, emotional and psychosocial impacts. The young women had endured multiple losses and HIV stigma that negatively impacted upon their sense of self and belonging. Many lived with an enduring sense of sadness that was rarely openly addressed. The multiple losses encountered by young women are highlighted in this chapter in order to gain in-depth understanding of the impacts of HIV in real-life contexts at individual, familial, community levels and within the health services. Taken together, such profound life challenges seriously threatened the young women's perceptions of 'self' and sense of belonging hence their mental health leading to suicidal ideas and attempts. Therefore, the next chapter focuses on how the young women coped with the various life challenges and constructed a new self-concept to boost their self-image.

CHAPTER SIX

MOVING FORWARD, SOMETIMES BACK: COPING WITH LIFE'S CHALLENGES

"……..it's like while you want to move forward, your life is kind of getting back again. ….When I moved to live with mum's cousin, she provided for all my needs, life became easier….. I failed exams, should I repeat the class but my age? I had to move and live with my young sister…how will she meet my needs? I found a partner…as my provider; but how do I pay back …..I became pregnant" (Chitsanzo, 19)

6.1 Introduction

The previous chapter addressed how HIV positive status impacts on young women's development of 'self' and sense of belonging to family, peer group and society. Generally, young women in this study encountered multiple losses which included loss of adult support networks, intimate and supportive relationships with parents or/and significant others; low academic progression, low life satisfaction, and social isolation with the majority enduring deep sadness. The multiple losses, self and social stigma and discrimination at family, community levels and within the health systems diminished young women's self-worth, compelling them to seek a safe place and personal and/or financial security. This chapter describes the agency and capacity of young women to deal with their multiple losses, challenges, limits and demands that make up their everyday lives, and stigma management though some of the strategies have consequences that pose risks for their health and well-being.

The chapter highlights different coping strategies that appear to play crucial roles in the development of young women's self-image. For instance, all young women experienced multiple losses and in each case they employed various coping strategies most of which exposed them to diverse negative impacts, including early child bearing. The risks to which the young women were exposed following the multiple losses are fully illustrated in Chapter Seven. Penina, Ulemu and Mwatitha experienced intense sadness that exposed them to suicidal ideas and attempts at ending their lives but different coping strategies at family, community levels and within the health services were employed which assisted them to cope in a more positive way. For example, while living with her

aunt, Ulemu encountered sexual harassment from her aunt's husband and she reduced her vulnerability through engaging in a small scale business, as exemplified in Section 6.4. In addition, Gonjetso and Tanyada, who had good support structures at all levels, coped optimistically leading to positive outcomes. Gonjetso became one of the best students in a mixed-gender boarding secondary school, and Tanyada unleashed her potential and gained fulfilment from a meaningful role in her studies. Therefore Ulemu, Gonjetso and Tanyada's stories are more prominent in this chapter. Table 8 shows the cases and the coping strategies that inform this chapter.

Table 8 Cases to illustrate coping strategies

Name	Age at loss	Kind of loss	Living situation	Means of survival	Consequences
Ziliwe	3	Death of both parents	Lived with grand-father, three uncles, aunts, sexual partner; then living alone	Doing piece work (washing clothes in homes); engaged in sexual activities for financial gains	Struggled on condom use leading to early child bearing
Nane	11	Death of mother & paternal financial support	Living with her uncle (her father's brother)	Dependent on her uncle; engaged in sexual activity to supplement finances offered by the uncle; relied on religious beliefs	Achieved her vocational goals but her father lost control of her sexual behaviour
Penina	10	Death of mother & physical attractiveness	Living with her father & step mother with whom had antagonistic kind of relationship	Fully dependent on her father for financial & emotional support	Despite being stigmatised & expressing suicidal ideas, excelled academically
Ulemu	4	Death of both parents	Lived with grand-mother, brother; now living with aunt & sexually abused by aunt's husband leading to suicidal ideas	Independent – relies on own business – sell fried pan cakes at school & second hand clothes	Self-reliant & reduced her vulnerability to sexual abuse

Name	Age at loss	Kind of loss	Living situation	Means of survival	Consequences
Mwatitha	3	Death of mother & physical attractiveness	Lived with her uncle (physically abused) before moving to live with her aunt where she faced sexual abuse by aunt's husband	Fully dependent on her uncle (her mother's brother) then fully dependent on aunt's husband but neglected for whistle blowing on sexual harassment	Lost support of aunt's husband leading to suicidal attempt; engaged in sexual relationships for emotional support
Gonjetso	13	Death of her mother	Living with aunt, then in a boarding school	Fully dependent on grandfather & aunt; her head teacher & service provider meet her academic needs; relied on religious beliefs	One of the best students in her school – always on top ten list
Fatsani	13	Paternal affection & support	Living with her mother, who sells second hand clothes	Dependent on her mother; engages in sexual activities for material & financial gains	Rebellious behaviour, had four partners serially in four years; failed her Junior Certificate examinations
Alindine	10	Death of her mother	Living with her aunt	Fully dependent on her aunt for material and financial support	Achieved her academic and vocational goals
Chitsanzo	9	Death of both parents	Lived with sisters, now living with a husband, who adopted her six month pregnancy (by a married man)	Fully dependent on her husband for personal & financial security	Concealed her status to the husband; takes ARVs & gives child Bactrim when husband is at work
Tawina	14	Imprisonment of her father	Lived with her step-mother who never loved her; now living with her uncle – unable to meet her needs	Sought acceptance outside family unit; & engages in sexual activities for material & financial gains	Had five sexual partners in five years serially; succumbs to partner's choices to keep relationships

Name	Age at loss	Kind of loss	Living situation	Means of survival	Consequences
Zaiwo	4 14	Death of father & eight siblings; mental capability & motivation First pregnancy to therapeutic abortion	Living with her mother who spends most of her time at restaurant (business)	Dependent on her mother; engaged in sexual relationships for companionship & emotional support	Impregnated twice – as influenced by peer pressure
Tamando	10	Financial support	Lived with her parents but unable to provide for her needs; now living with her husband	Selling groundnuts -got stable partner to supplement income & support her family; was impregnated & fully dependent on him as husband	Early marriage & child bearing at the age of 15 years; her child & husband are HIV negative
Dalo	11	Financial support Death of first husband & second child Second husband divorced her due to positive HIV status	Lived with her parents but unable to provide for her needs; lived with first husband as second wife (at 15 years); back to parents; now living with fourth sexual partner	Selling groundnuts -engaged in sexual activities with older & married men to supplement her income & to gain support for her family; fully dependent on her fourth partner	Early child bearing (15 years); first child is HIV positive; lost first husband & second child to HIV related illness.
Tanyada	10	Mental capability & motivation; deteriorating eye sight & sense of hearing	Living with her parents	Fully dependent on her father for material and financial support; her parents arranged for her supplementary classes; relied on religious belief	Her academic potential was unleashed as with involvement of part-time teacher & her best friend

The chapter is divided into five sections. The first section focuses on how young women coped with their multiple losses in different contexts. This section highlights how supportive and trustworthy relationships, counselling and psychosocial support, faith, prayer and meditation assisted young women to cope with their HIV positive status. The second section highlights how feelings of love, acceptance and recognition promoted self-worth among the young women. The third section focuses on the responsibilities young women took and the ways in which they attempted to earn a living and achieve some autonomy. However, not all young women struggled to earn their living as exemplified in section 6.4. The fourth section focuses on strategies young women employed to deal with stigma and discrimination in order to re-build their personal and social identity. Finally, the chapter concludes with caregivers' perspectives on their own struggles in enduring the young women's multiple losses and in dealing with practical psychosocial and financial challenges affecting the young women.

6.2 Coping with losses and adversity

After the loss of worthiness and identity which HIV positive status caused, a new self-concept was constructed by discovering new actions and relationships to boost their self- image and social identity. Hence, a young woman was an active agent, employing strategies which were both socially and economically empowering. In this regard, socio-economic status, support systems, nature of relationships, desire to be loved or liked by others, and their values, preferences and needs shaped the young women's coping capabilities and outcomes. The strategies employed by the young women to cope with their losses included building and using strategic relationships such as adolescent-caregiver/service provider support and trust; seeking love, acceptance and support; counselling and psychosocial support; faith, prayer and meditation. The supportive relationships yielded the social capital, the young women needed to cope positively. The extent of having effective support networks depended upon parental/caregiver connection and support, participation in teen clubs, school attendance and young women's ability to exercise their agency[21] in making decisions and choices. Young women who had large support networks or a wider range of resources (within the

[21] In this study, agency refers to young women's ability to reflect and act on issues affecting their lives including SRH related, make effective choices and transform the choices into desired outcomes.

family, society and the health systems) coped more positively than those with limited support networks.

6.2.1 Experiencing supportive and trustworthy relationships

After losing parents and significant others, the young women had a greater need for stability, care and protection. For a number of young women, family capacity represented the single most important factor in building a protective environment. Relationships with caregivers, aunts, uncles, step-parents, siblings, peers and significant others like service providers, teachers and sexual partners were a complex part of their personal and social lives and the glue that held their lives together. The relationships fundamentally influenced not only how one perceived one's self, but also perceptions of their value or worth to the social world, as they were fundamental in building economic/social capital. The strong attachment with a parent/caregiver or significant others was observed as an important ingredient to self-acceptance and positive self-image. For instance, Nane, Penina, Gonjetso and Tanyada reported that the steady, trustworthy, positive and mutually supportive relationships they experienced with their biological parents enhanced their self-perceptions, self-acceptance, academic competency and self-worth. The positive functional relationships, intertwined with their ability to make decisions confidently, reinforced development of a stronger sense of self-worth, which in turn enhanced their ability to accept their status, possess a clear sense of meaning in their lives, excel academically and function autonomously. Regardless of their age and the HIV positive status, the young women felt their parents/caregivers had seen them as worthy of trust, having potential and a sense of responsibility, which made them optimistic in life.

> *"Mum was very supportive, when my blood tested HIV positive I accepted my status; she encouraged me to work hard in school despite my positive status to change my fate. As a teacher, she valued education; always she said, 'work hard, to be employed, to be responsible for the young ones; I know you will make it, you have the potential'. Mum's trust and encouragements made me appreciate myself that early; and I always aim high to fulfil mum's dreams. My desire is to go to University to be self-reliant and care for my*

younger siblings. I don't need anyone to tell me that am capable; I have my goals in life. (Gonjetso, 16)

For Gonjetso, Alindine and Tanyada being trusted by their caregivers/parents was emotionally satisfying and increased their self-worth and validated their good character. It is clear in Gonjetso's account that she drew enormous strength from her mother and she indicated that she did not expect anyone to approve her potential as she was focused (see Panel 1). It appeared that Gonjetso attained her sense of achievement prior to puberty, which possibly assisted her to resist heavy social pressures toward conformity. Similarly, both Tanyada and her service provider, Mr Nandi, shared the views that being entrusted with the responsibility of taking care of the family and her younger sibling made Tanyada feel responsible and motivated to strive towards achieving the anticipated meaningful role of caring for her siblings if something happened to her parents.

"My dad and mum look to me as their hope to look after my siblings in the near future; they believe I will care for them, so I work hard in school to provide good support to my siblings and my parents." (Tanyada, 16)

"The parents entrust her with a lot of responsibilities so as to make her feel that she is like any other normal young woman. She brings the other infected child to the centre and that helps her feel responsible as she explains the child's condition to the service provider and provides feedback to her parents." (Mr Nandi, Tanyada's service provider, 37)

Nane and Penina also acknowledged the supportive and trustworthy relationships they experienced with their fathers as promoting their academic achievements hence self-worth as young women.

"I found it difficult to accept my status, but my father's support and encouragements to work hard in school despite my positive status, assisted me to accept my status, look at myself as worth of achieving my dreams in life – am pursuing a course in HIV Management. He has contributed so much to my academic achievements; I believe I will effectively support my younger siblings and my father in the future." (Nane, 19)

Reflecting on Nane's, Gonjetso's and Tanyada's accounts, it can be deduced that both male and female biological parents' support seemed to have an impact on young women's lives as they take an active role in supporting young women's development of 'self'. However, Fatsani had a different story; she perceived that paternal neglect (which ensued upon her father marrying a fourth wife while she was hospitalised) diminished her self-worth and sense of belonging to the family. This further diminished her morale for academic endeavour.

> *"Dad never cared about me when I was hospitalised……..he forsook me the time I needed him most, he left for another wife, it's very depressing to be treated like that by your own parent without his support; am I recognised? I wonder……I failed exams and am not interested to repeat."* (Fatsani, 17)

In contrast, Gonjetso's mother and Tanyada's parents were very optimistic that their children were capable to achieve their academic and vocational goals, and would grow up to adulthood. They invested in their children's education in the expectation that the young women could attain self-reliant future and meaningfully care for their younger siblings as the parents anticipated their untimely death. For instance, Gonjetso's mother (before her death) secured funds for the advancement of Gonjetso's education, although the funds were exhausted within a year on home management, as her aunt lacked resources. Similarly, Mr and Mrs Mipando arranged supplementary lessons for their daughter, Tanyada, by commissioning a part-time teacher to help Tanyada to release her potential to become a successful student and achieve self-reliance in the future.

> *"Our daughter was not performing well despite her efforts in school, but we realised that she had problems with sight and hearing. We thought of having a part-time teacher who is very closer to her and takes her through the lessons at her pace; she is now doing very well in school, we believe if she is well educated, she will assist her siblings with minimal challenges after we are gone."* (Mr Mipando, Tanyada's caregiver, 48)

Mr Nandi, Tanyada's service provider, commended Mr and Mrs Mipando's support and good relationship with their daughter, Tanyada which enabled her to feel worthy and capable academically, despite her hearing and sight problems. The parents' support had enriched Tanyada's intellectual capabilities hence assisting her to look at her life with a purpose.

> *"…….I salute her parents for being closer to her (Tanyada); they greatly assist her to add value to her life because they understand her situation better. They always monitor her condition with keen interest and intervene whenever necessary like the mental incapability they arranged for part-time lessons which have assisted her to perform well in school."* (Mr Nandi, Tanyada' service provider, 37)

Zaiwo also valued the parental care and support rendered by her mother, Mrs Zangawe to her and the child including the nutritional supplements. She demonstrated the significance of the biological parent upon her life in coping with her HIV positive status and early child bearing. Zaiwo believed that such support would likely be unattainable if she was in a foster family, as reflected in her change in attitude and constant reminder of her mother to take ARVs, thus maintaining her source of support.

> *"…though I had a child while young, mum has been of great help to me; I wouldn't have made it without her and no other person could do it for me. I entrusted her with my child's caring responsibility though it was too much for her but she was responsible for the provision of all our basic needs including special food for my baby; she is reliable for us."* (Zaiwo, 19)

Mrs Zangawe reported that since she assumed full caring responsibility of Zaiwo's child, Zaiwo demonstrated a change in behaviour particularly in relation to the 'blame game' regarding her positive status.

> *"Since she delivered her child, she stopped insulting me of passing on the virus to her but rather reminding me to faithfully take ARVs; she ensures that I adhere to ARVs."* (Mrs Zangawe, Zaiwo's caregiver, 48)

Ms Benga, Zaiwo's service provider, perceived that Mrs Zangawe was instrumental in promoting Zaiwo's mental and physical well-being as she had been there for Zaiwo, assuming the caring responsibility of her child. Ms Benga felt that their trustworthy and mutually supportive relationship seemed to promote Zaiwo's feelings of self-worth as a young woman, for she perceived increased sense of belonging to the family despite her early child bearing and being solely dependent on her mother for support.

> *"Since she was mentally retarded, it was very difficult for her to care for her baby, she entrusted the child's caring responsibility to her mother. Breast feeding was a challenge; and always the baby was with her mother, which meant she had nothing to do with the child and her mother ensured that both were properly cared for, she still looked smart as a young woman….."* (Ms Benga, Zaiwo's service provider, 33)

Nane, Penina, Fatsani, Zaiwo, Tamando, Dalo and Tanyada described their parents as being very affectionate and understanding which they also attributed to the familial HIV. The intimate relationships within the family positively impacted upon young women's self-acceptance, self-worth and motivated them to attach value to their lives, as they felt they were all in it together.

> *"My father is also HIV positive so he understands me better. He has been so friendly and he disclosed his positive status to me. I feel supported and loved especially the time I had suicidal ideas following the posting of my status on the face book by my friends at school. He reassures me that it was not my fault that I am HIV positive but his mistake for passing on the virus to my mother; accepting the blame lessens my anxieties."* (Penina, 19)

While having six family members infected with HIV, including Dalo's own child, could be considered as a burden to the family's limited or depleted resources, Dalo took it positively. She felt that familial HIV brought the family together and lessened their stress of being stigmatised and discriminated against, as they shared similar experiences within their family.

> *"It is six of us, who are HIV positive in our family including my sister, my mother, my father, brother and my daughter, and we encourage each other. We support and understand each other better; we don't isolate anyone than if it was only one or two of us."* (Dalo, 19)

Mwatitha concurred with Dalo that sharing similar HIV positive experiences and expectations within the family promotes affectionate, mutual and supportive relationships. She felt that familial HIV could reinforce the development of young women's stronger sense of belonging to their families hence their self-worth, as the members could realign their expectations and norms to the dynamics of the family to promote connection, care and acceptance, hence facilitating positive coping.

> *"…….the family that lives together, encouraging and sharing challenges with each other is a happy family despite the positive HIV status and life gets on easily without social exclusion. I wish my parents were alive, they could have been responsible and understand my experiences than living among those who look at you as a burden, who don't even understand what you are passing through."* (Mwatitha, 18)

Nane, Ulemu, Mwatitha, Gonjetso, Alindine and Tanyada also acknowledged the support rendered by significant others like aunts, uncles, grandparents, teachers and service providers as creating an opportunity for the young women to achieve their academic and vocational goals, hence coping positively.

> *"Initially I was not interested in my life and in progressing with my education, because I thought I would die anyway; but aunt's love and care and my service provider's time and support made me accept my status, attach value to my life and education. I made a decision not to mess up my life so as not to disappoint aunt, to achieve my dreams like be employed and live independently; now am almost finishing my studies and 'am the only one who has gone to college among aunt's children. Soon I will be teaching and supporting myself."* (Alindine, 19)

Equally, the role of Gonjetso's caregiver, Mr Tambula, her service provider, Ms Mbenu, and the family members, especially her mother (before she died) and her grandfather, was critical to Gonjetso's academic success (see Panel 1). Gonjetso reported that she

received material and monetary support from her grandfather, who looked to her as a potential granddaughter to continue the developments that her mother initiated. Gonjetso further reported establishing a mentoring relationship with Ms Mbenu in particular, who provided her with guidance and support which greatly seemed to boost her self-worth. Gonjetso described Ms Mbenu as her mentor and being very supportive; Ms Mbenu admired the support that Mr Tambula was offering to Gonjetso. Ms Mbenu believed that Gonjetso remained focused in her studies because she had a wider range of support/resources a needy student would require in a boarding school.

Panel 1: Gonjetso, 16 years old

Gonjetso was born in a family of three children and her mother died when Gonjetso was 13 years old. By the time she was diagnosed as HIV positive, she had an intimate supportive relationship with her mother, which enhanced her ability to accept her status, attach meaning to her life and excel academically. "Mum provided for all our needs and she saw potential in me to excel academically and care for my siblings." After death of her mother, Gonjetso with her siblings (two) were sent to live in the village with their aunt, who was finding it difficult to secure for their needs, instead her grandfather was providing for her school fees and other academic needs. "My grandpa prays for me before I leave for school, pays for my school fees, and gives me pocket money." However, Gonjetso still struggled to meet her academic needs and she dropped out of school.

Chiyembekezo Centre secured a place at Takulandira gender mixed boarding school and a government bursary through the District Education Office for her to continue with her studies. The news electrified Gonjetso and boosted her self-determination and self-confidence in academic achievements as she saw the green light to fulfilling her mother's dream of having her take over the caring responsibility of her siblings. "It was like a dream being offered a place at a boarding school; it was a miracle, mum's desire will be fulfilled" Gonjetso, a teen club participant acknowledged that the continuity of the support she received from Ms Mbenu, (service provider) and Mr Tambula, (caregiver) were instrumental in facilitating her academic success: "she assist me with money, clothes and soap…..being a young woman, she understands and assists me to achieve my academic goals. Her headmaster, Mr Tambula offered her an opportunity to store her ARVs in his office which made her feel self-worth. Her appointment as a library prefect responsible for control of books on loans in her school was a morale booster as she felt highly recognised by the school community. "I've trusted my headmaster with my status; he never disclosed my status to anyone. I store my drugs in his office and collect them without restrictions; it's an honour to me…….imagine 'am also the elected school library prefect, do I need to be told that am worth and capable?" Feeling supported at both familial and community levels and within the health system assisted Gonjetso to attain excellent academic achievements and she felt her identity completely changed to a successful student despite her status. The headmaster identified Gonjetso as one of the best top ten students in a class of over 100 students and potential student for university selection. Gonjetso was aspiring to become a medical doctor.

> *I commend her headmaster (Mr Tambula) who is very supportive since he knew her positive status. She is always given exit, the headmaster gives her*

money for groceries or to come for doctor's appointments and teen club meetings; he informed the boarding master not to restrict her from visiting the hospital. No wonder Gonjetso is doing extremely well in class; she has the support she needs." (Ms Mbenu, Gonjetso's service provider, 37)

Gonjetso had large support networks or wider range of resources (within the family, society and the health systems) and she coped optimistically with her HIV positive status (see Panel 1).

Furthermore Ziliwe and Gonjetso were beneficiaries of youth organisation and government bursaries respectively for their secondary school education. Gonjetso, had her grandfather, the head teacher and the service provider supporting her materially, financially and academically enabling her to become the best student in the boarding school, however Ziliwe lacked supplementary support and ended up establishing unhealthy relationships for support.

"Though the youth organisation paid for my school fees until I completed my secondary school level, but still I had to look for my meal for the day and my accommodation. How could I go to school on an empty stomach? I found a male partner to supply for my other needs including food; but I ended up being impregnated, and the organisation phased out, now I have no-one to pay for my further education." (Ziliwe, 18)

While a wide range of supportive structures at family and community levels and within the health services empowered the majority of young women to cope positively with their HIV positive status, Ziliwe, Chitsanzo and Dalo perceived that their situations particularly lack of good support structures often dragged them backwards from achieving their goals in life.

"……..it's like while you want to move forward, your life is kind of getting back again. ….When I moved to live with mum's cousin, she was very loving, and providing for all my needs, life became easier….. I failed exams, should I repeat the class but my age? I had to move and live with my young sister…how will she meet my needs? I found a partner….. as my provider; but how do I pay back…..I became pregnant." (Chitsanzo, 19)

It is clear from this section that young women who had a wider range of support networks coped positively (e.g. Gonjetso) as compared to those who struggled to access resources or had limited support networks (e.g. Tawina, Chitsanzo, Tamando and Dalo) as shown in Chapter Seven.

6.2.2 Valuing counselling and psychosocial support

Counselling[22] at the time of high emotional distress, HIV testing (before and after HIV testing and diagnosis), or on-going counselling was significant to young women because it provided them with critical information and continuous support. A number of the young women reported that counselling involved emotional support and information exchange between the counsellor, themselves and their significant others including family members or primary caregivers. It was directed at meeting the young women's optimal physical, mental and social health and functioning. The majority felt the counselling enabled them to cope with their emotional stresses of HIV positive status, consequent problems like bereavement and to take personal decisions regarding necessary lifestyle changes that facilitated preventive and therapeutic behaviours. Penina, Nane, Gonjetso, Zaiwo, Fatsani, Tamando, Dalo and Tanyada perceived that such counselling helped them to come to terms with the realities of HIV positive status and to act in a balanced way. The initial and on-going counselling sessions assisted them to accept the uncertainty of their future and objectively analyse feared issues such as life-long illness and treatment, untimely deaths, social exclusion, pain and separation from parents or significant others by death. They all indicated that the service providers' support and seeing others who had grown with the virus to young adulthood leading meaningful lives were instrumental in reinforcing their self-worth. They felt that the service providers' interest in their physical well-being facilitated their status acceptance and reinforced their positive self-image as both caregivers' and service providers' attitudes and actions portrayed high regard for their lives.

[22] In this study counselling is defined as a confidential dialogue between a young woman and the counsellor or service provider aimed at enabling the young woman to cope with the stress associated with her positive HIV status and to take personal decisions relating to living positively and achieving optimal physical, psychological and social well-being.

".....with several counselling sessions, their support, and seeing friends growing healthy, I felt it is possible to live like any other young woman who is HIV negative." (Penina, 19)

The young women further reported that having counselling sessions together with their parents/caregivers made them optimistic about living positively and longer. Penina, Nane, Gonjetso, Zaiwo, Fatsani, Tamando, Dalo and Tanyada attributed their parents/caregivers' efforts to assist them to comply with the guidance offered by service providers to their involvement in counselling sessions. Mrs Mwatipa, Dalo's mother, Mrs Zangawe, Zaiwo's mother and Tanyada's parents, Mr and Mrs Mipando also felt that family counselling was crucial as it assisted them to embrace HIV associated challenges as a family, accept parental responsibility and promote emotional support within the family unit.

"Initially we were having counselling sessions as a family and that helped us to understand HIV positive status, take up the challenges and support each other as a family. Later, my daughters were being counselled as individuals and they seem to benefit from the sessions as well." (Mrs Mwatipa, Dalo's caregiver, 38)

"Though I have challenges with my stepmother but dad is always very supportive to me; is it because we were together during initial counselling sessions? He consistently support and encourage me to live positively and achieve my dreams." (Nane, 19)

Mr Zidelu, Fatsani's service provider, believed that on-going counselling and emotional support were crucial to assist young women fully comprehend the HIV positive status and strategies that promote living positively to prolong their life span, enhance security of personal identity and look at life meaningfully despite being HIV positive.

"....continuous counselling was significant for her (Fatsani) particularly that she had several issues that she could not understand like why she is the only child infected with HIV out of five children in her family? So her counselling process was gradual from modes of HIV transmission, purposes of ARVs, need for adherence, living positively, *avoid self-stigma; consistent condom*

use to avoid *passing on the virus to her sexual partner, reinfections, and unplanned pregnancy."* (Mr Zidelu, Fatsani's service provider, 26)

Similarly, Nane, Ulemu, Gonjetso, Fatsani, Alindine and Tamando valued the continuous counselling offered at the centres as it assisted them to cope up with their positive status particularly when they were finding it difficulty understanding their HIV positive status or cope with their difficult situations. Upon diagnosis of their positive status, they felt distressed, but after having several sessions of counselling with their service providers, they became optimistic and felt better about their future and 'self'. The counselling was instrumental in the broader aspects of their lives, helping them to get through the world and attain their goals in life. For instance, Gonjetso indicated that the continuous counselling offered at the centre assisted her to cope with the bereavement phase (loss of her mother); which was a particularly acute time as she had just been commenced on ARVs. Alindine also indicated that continuous counselling assisted her to be self-determined, and value that which she felt was important for her, which was even reflected in her relationship and interactions with her sexual partner.

"I have valued the counselling I receive from my service provider and my aunt; it has helped me to attach value to my life and 'am determined to achieve my vocational goals. My partner insisted on having sex with me; I told him I could not do it, he suggested use of condoms instead; but I told him I do not trust condoms and I terminated the relationship because he insisted…… I was determined to progress academically than dropping out of school due to unplanned pregnancy." (Alindine, 19)

Mr Zaneni (Nane's father), Mrs Ndazi (Fatsani's mother), Mrs Mwatipa (Dalo's mother), and Ms Linyang'wa (Ulemu's sister) shared the young women's views that counselling and emotional support rendered by the service providers greatly assisted the young women to accept their positive status and look at life meaningfully.

"It was not easy for her to understand her positive status coupled with poor relationship with her step-mother but the counselling she got from the centre assisted her to accept her status and look at life positively, and now she is in college." (Mr Zaneni, Nane's caregiver, 43)

6.2.3 Trusting in God: faith, prayer and meditation

The young women's faith in God was a source of strength and courage as they dealt with the multiple difficulties and challenges of their personal journey, which was altered by the HIV infection. They regarded spiritual experiences and religious practices as potential resilience[23] factors for coping with their difficulties. Nane, Gonjetso and Tanyada and their parents identified faith, prayer and meditation as an important coping strategy in their hard times. Though the other young women and their caregivers did not show the same faith, but Nane, Gonjetso and Tanyada and their caregivers including Mr Tambula, Gonjetso's caregiver (the headmaster) believed that God had the capacity and power to intervene in their hard situations as long as they trusted in Him.

> *"Life has been so difficult for her, especially coming from a poor family; but I have always been encouraging her to trust in God, who hears our prayers, and grants the desires of our lives. He will see her through until she completes her studies to stand on her own; she performs well in class and always appreciates God's faithfulness upon her life."* (Mr Tambula, Gonjetso's caregiver, 49)

Gonjetso also reported that every time she was leaving for school, her grandfather offered a prayer for her success and that enabled her to develop more confidence in attaining higher education level. Faith in God made Gonjetso and her grandfather optimistic that God would help her meet her academic goals. They believed that God answered their prayers which positively impacted on Gonjetso's mental health status. She never allowed her low socio-economic status to hamper her potential to achieve her goals due to her belief that God would take her through, despite the delay in academic progression. Gonjetso's interest to attend college was also rooted in the need to repay her grandfather's support and prayers.

[23] In this study, resilience refers to young women's ability to bounce back from tough times, or capacity to overcome challenges or adversity (Ungar, 2004).

> *"My grandpa believes I will succeed in life; the prayers he offers to God every time before I leave for school have played a big role in my life. May God's grace be sufficient to take me through my studies, succeed and secure a good job to give back grandpa's prayer time and support including caring for my two siblings."* (Gonjetso, 16)

Tanyada indicated that her parents' illness in particular reinforced her faith in God, especially when she could focus on the future juxtaposed with the anticipated loss of her parents. She reported remembering prayers that the priests used to offer beside her sick bed as being very powerful to influence her recovery from her severe illness. Likewise, she believed that the prayers could do wonders for her parents' condition. Tanyada testified on how she felt God touched her mother, who was at a point of death. The concept that the touch of God had influenced her life and her mother's critical condition, fear of parental loss and anticipatory grief shaped Tanyada's spiritual experiences and faith in God.

> *"….I was once very sick, God touched me; mum got very sick, her legs were very swollen; she was told to discontinue ARVs, she was in a bad shape and I was afraid; I whispered a prayer to God, not now let her live oh! My God! With dad, we prayed every morning and evening, asking God to touch her, I was afraid, I still need mum, and slowly she recovered; now she is back on treatment. We always thank God that He hears our prayers."* (Tanyada, 16)

Similarly, Mr Mipando, Tanyada's father and Mr Zaneni, Nane's father expressed their strong faith in God with particular reflection on what they believed God had done upon their families. They both attributed their daughters' recovery from critical conditions to God's touch and faithfulness in answering their prayers.

> *"……..as a family we value time of prayer together because we are all alive to date by God's grace, it is a miracle that my daughter is alive today, she was dying; it worth praising Him all the time."* (Mr Mipando, Tanyada's caregiver, 48)

This section has revealed that faith in God, prayer and meditation contributed to physical and mental well-being particularly for those who trusted in God. On the other hand, the spiritual beliefs and religious norms acted as social controls to young women's sexual practices and access to sexual and reproductive health services in order to discourage them from becoming sexually immoral, as reflected in section 7.5.2.

6.3 Seeking love, acceptance and recognition

Young women experienced positive self-image when they engaged in affectionate, supportive relationships with parents, caregivers, peers and significant others, including sexual partners, with whom they felt loved, accepted and understood or who provided social, moral and financial support. This means that the social group provided the young women with stability, personal security, sense of belonging to the family or peer group, purpose, meaning and direction which typically had positive implications on their self-worth and social identity. This became the source of motivation for social interactions, which young women need on continuous basis to cope with their multiple losses and boost their feelings of self-worth. For example, Ziliwe, Penina, Mwatitha, Fatsani and Chitsanzo expressed their desire for others to see them as friends, young women worth recognition and love, and to recognise that being HIV positive is only one part of their personhood.

> *"What I wanted was to have someone, let it be a friend or a boyfriend, who would love me like any other young woman despite my positive HIV status. Aunt never loved me, you are kind of being forced to find someone who can love and accept you as a human being, as a girl; thus how my first boyfriend crossed my way……..…when I disclosed my status, he acknowledged that it was not my intention to be HIV positive and we were living happily." (Ziliwe, 18)*

Mr Zidelu, Fatsani' service provider, perceived that it was evident that male relationships boost young women's positive self-image as evidenced by Fatsani's low morale when her first sexual partner terminated the relationship upon disclosure of her status.

"….she (Fatsani) appears very excited with sexual relationships; she was down, very depressed when her first partner terminated the relationship after she had disclosed her positive status. She is dating another young man and now she is very happy about it." (Mr Zidelu, Fatsani' service provider, 26)

6.3.1 Benefitting from peer acceptance and support

The young women perceived benefiting from a supportive relationship they established with their female friends. Mwatitha, Fatsani and Tanyada reported disclosing their secrets to their best friends, who never publicised their positive status, encouraged them to live positively and that boosted their self-worth and motivated them to look at life purposefully.

"I get good support from my best friend; she has never disclosed my status to anyone. After I was discharged from the hospital following suicidal attempt, she reassured me of her support and shared with me her resources. Her support for me is beyond sharing resources because we even focus on our academic endeavours, future plans including sexual relationships." (Mwatitha, 18)

Likewise, Tanyada reported having a very close friend who was very understanding, supportive and who assisted her with some school work, especially mathematics and science subjects. With effective educational guidance of her part-time teacher and the close friend, Tanyada unleashed her academic potential as she was able to fulfil a meaningful role in her studies and perceive that life had a purpose.

"If it was not for my part-time teacher and my friend, I wouldn't have made it; if my friend did not understand me, assist me with maths and science, I could have been a failure; the two accepted me, I feel capable of achieving my academic goals now." (Tanyada, 16)

Furthermore, Ziliwe, Nane, Penina, Ulemu, Mwatitha, Gonjetso, Fatsani, Alindine, Zaiwo, Tamando, Dalo and Tanyada expressed feeling a sense of belonging to a peer group when they joined the teen club. They perceived that the club assisted them to associate with others, share experiences with peers, gain significant information necessary to reduce risks and live positively thus promoting their positive self-images.

For Nane, Gonjetso and Alindine, joining the club emerged as an important coping resource for the loss of their mothers, allowing them to deal with intrapersonal stresses and combat feelings of isolation. They described the teen club as a place where they could share their experiences with others, who could relate and help each other.

> *"I was very fortunate because I joined teen club immediately I was diagnosed HIV positive, so it was easy for me to cope up with my status and mum's death; learning from other people's experiences, seeking advices, getting involved in trainings, finding friends to share concerns assisted me to live positively."* (Gonjetso, 16)

Many young women, except for Chitsanzo and Tawina who had no access to teen clubs in the rural settings, felt that participating in the club provided them with strong friendships which contributed to their positive self-image. This clearly signifies that the sense of shared identity reinforces the young women's capabilities to share their experiences and views hence buffering themselves from the negative repercussions of their HIV positive status hence adding value to their lives.

> *"I like teen club meetings because have added value to my life. Service providers reassure us that a bright future is possible; their love and care assist us to value life and achieve our dreams. Associating with friends at teen club has greatly assisted us to share experiences, encourage each other, accept our status, and become motivated in achieving our dreams."* (Alindine, 19)

Fatsani and her mother, Mrs Ndazi, indicated that the club assisted Fatsani to attach value to her life as she interacted with peers after she had lost interest in her surrounding following loss of her paternal love. Fatsani's views were shared with Mr Zidelu, who felt that teen club provided Fatsani with the source of sense of belonging to peer group and society. This triggered her interest in others as she felt being accepted by her peers.

> *"Apart from medical care, she (Fatsani) has benefited more on socializing with peers as now she is fully involved in teen club activities. Initially she was completely withdrawn, could not talk to anyone especially after her father left their home for another woman. Now she is one of the active teen club members."* (Mr Zidelu, Fatsani's service provider, 26)

> *"I accepted my situation because at teen club I have seen others who don't have even a single parent but life continues for them. Hearing their sad stories, how they are treated and seeing them living positively like any other person, I have been strengthened."* (Fatsani, 17)

Caregivers like Mrs Monali (Alindine's aunt), Mrs Ndazi (Fatsani's mother), and Mrs Zangawe (Zaiwo's mother) believed that teen club was beneficial to young women as it assisted them to accept their positive status, live positively and influenced young women's association with peers and access to peer support and relationships.

> *".....she (Fatsani) could not smile at any one until when she started participating in teen club and having discussions with service providers thus when she started smiling at people, interacting with others in the community and accepted her status."* (Mrs Ndazi, Fatsani's caregiver, 41)

For Ziliwe, Zaiwo, Tamando and Dalo being discharged from teen club was perceived as a loss of their source of belonging to peer group and feelings of self-worth. Dalo's value for peer acceptance and support was reflected in her expression of feelings of distress when she was advised to discontinue participating in teen club because of having a child, without giving her an option. For the young women, being discharged from teen club meant being dumped out of their normal environment. They felt the two-day training conducted at Maziko Centre did not prepare them enough for adulthood and parenthood. They desired a club for young mothers to continue sharing their experiences and challenges of parenthood and to support each other.

> *"When I delivered my child, I felt the pain of being abruptly stopped from attending teen club, where I was sharing experiences and concerns with my friends and they never gave me an option as to where to go for such experiences. I wished we had a club for young women who have children. This would help us share experiences, learn from and support each other in dealing with challenges we encounter."* (Dalo, 19)

The service providers also indicated that young women's negative reactions to being discharged from teen club evidenced how much they benefited from participating in the club and the value they attached to peer support and relationships.

> *"When they were asked to stop participating in teen club following delivery of their babies, some (including Tamando and Dalo) cried bitterly. They expressed feelings of disappointment and felt have been dumped out of their peers. They felt that having a two day training did not fully prepare them for adulthood; despite being discharged, once in a while they still come to the club."* (Mrs Khambi, Tamando's service provider, 53)

Notably, peer support and relationships, and participating in teen club helped the young women to cope positively.

6.3.2 Male relationship boosting self-image

After loss of their parental affection and care, most young women experienced diminished sense of belonging to a family, peers and society. Since they felt different from their female peers due to low socio-economic status and negative body images or other differences, they attempted to regain that sense of belonging through sexually attaching themselves to male partners in order to defer loneliness and depression. These male relationships were used as their coping devices for the social isolation or challenges encountered with their female peers. For instance, Fatsani and Zaiwo had smaller statures than their age mates; Ulemu and Fatsani perceived that their breasts and abdomens were looking bigger. Penina and Chitsanzo had lipodystrophy, making them look older than their age mates; and Mwatitha and Tawina had skin conditions which they all perceived had changed their physical appearance hence loss of physical

attractiveness. Ziliwe, Fatsani, Tawina, Chitsanzo, Tamando and Dalo were negatively affected by their low social economic status. These changes in physical outlook and the low socio-economic status exposed the young women to male relationships in which they felt accepted and understood but at times they were exploited or sexually abused. The male relationships seemed to provide a powerful antidote to young women's feelings of unworthiness that otherwise pervaded their lives following loss of their parental financial support and physical attractiveness. They gained considerable sense of self-worth through male relationships which appeared to restore their value of femininity.

> *Initially I was so concerned that I was looking different from other girls; looking at my skin, I lost my beauty to this illness …….and I felt I was not looking attractive to young men; but now am proposed; like other girls I have had boyfriends including married men. Having a partner makes me feel happy; this is my fifth boyfriend consecutively from July 2008 to May 2012. It is good to have a sexual partner, because at least someone has accepted me as I am; I share with him my concerns, discuss issues freely and feel loved; he is very reassuring and providing for some of my basic needs."* (Tawina, *18)*

Nevertheless, Penina and Alindine reported that they had sexual partners just to feel loved and accepted and the relationship appeared to restore their femininity as well. While both enjoyed the companionship of their male partners, they perceived personal insecurity, and lacked mutual intimacy and understanding regarding sex. As such, although they gained considerable self-worth through the male relationships, they never succumbed to their partners' sexual decisions and desires; rather they terminated the relationships because their authentic selves allowed them not only to see their future but to have faith in their thoughts and opinions.

> *"I disliked my face for looking like an old lady. Despite having my treatment changed to second line ARVs, there has been slight improvement in my physical appearance; I thought I was not looking attractive to any young man. I thank God that he gave me my first boyfriend and even if I heard people calling me names like 'a person with AIDS' I was not worried because I had my closest friend, who accepted me as I am. But he wanted us to be*

engaging in sex that was not my priority; I want to go to University so I terminated the relationship until when I got my second partner who is also a teen club member and he accepts me and accommodates my future plans." (Penina, 19)

Similarly, although Ulemu engaged in male relationships as she felt safe, accepted and understood, she never succumbed to sexual activities but utilised the boys to achieve her academic goals.

"……..mostly girls tease me of having bigger breasts and abdomen; so I prefer chatting with boys, whom I feel they don't mind about my appearance but also they help me with school activities particularly maths and physical science; and am doing well in class these days." (Ulemu, 18)

In contrast, Ziliwe, Tawina, Fatsani, Zaiwo, Tamando and Dalo reported engaging in sexual relationships because they felt the partners understood their challenges and were very supportive, which boosted their self-image as young women. They perceived that their sexual partners were instrumental in promoting their mental and physical well-being as they provided for their basic survival needs.

"I was passing through hard life at home, he gave me his ears, he spared time to listen to my problems, and thus how I got connected to him; he (Mr Mwendo, her caregiver) used to give me money which I used to buy food for my family, and my necessities like body lotion, clothes which made me look like other girls…we became connected." (Tamando, 17)

Nane and Zaiwo expressed the delight of having a sexual partner as they felt loved and accepted, which promoted their self-image. While Zaiwo seemed excited about getting involved with male relationships, and succumbing to the partner's decisions and choices in order to maintain the relationship, Nane felt that achieving her academic goals was a priority and she could not yield to her partner's choices, which could terminate her opportunity to achieve her academic and professional goals. As such, she insisted on condom use with her partners and she achieved her academic goals.

"….it's nature to be in love with a young man despite being HIV positive, honestly I just need to be loved like any other young woman. But for me, sex without condoms, no! I would like to complete my studies and be working. Am in college now and am not ready to drop out of school due to unwanted pregnancy." (Nane, 19)

6.4 Struggling to earn a living and to achieve autonomy

When young women lost one or both of their parents, their experiences were shaped by their relative lack of autonomy. Where there was low socio-economic status in the family, with consistent provision lacking, young women experienced food insecurity and worried about their basic survival needs, they naturally became preoccupied with where their next meal was coming from. As such, they embraced activities that met their needs which included sexual relationships as a key economic strategy, which is fully highlighted in Chapter Seven, Section 7.3.1. The young women who had lost a parent/s like Ziliwe, Nane, Ulemu, Mwatitha, Gonjetso, Fatsani, Chitsanzo, Tawina, Zaiwo, and those whose parents were HIV infected like Tamando, Dalo and Tanyada were often deprived of not only parental care, but also basic necessities such as safe place, food, clothing, health, education and financial support. The majority of them continued to live in the care of the remaining parent or significant others, but often had to take on the responsibility of surviving independently far earlier than most of their non-foster counterparts. For example, Ulemu reported that when her older siblings sold their mother's house to earn a living, she invested her share in a business that provided for her basic survival needs (see Panel 2).

Panel 2: Ulemu, 18 years old

Ulemu is the last born child in the family of five children. She lost her mother when Ulemu was four years old. After death of their mother Ulemu (4 years) and her sister, Linyang'wa (7 years) were sent to stay with their grandmother (aged 70+) in the village. She described her stay with the grandmother as very hard and often they could not afford a meal. "It was hard to get food when we were living with our grandmother so our bother took us." They moved to live with their brother (19 years old) then moved again to live with their aunt because their brother had secured a good job in Republic of South Africa and by then Ulemu was 11 years old. She described her aunt as inconsiderate: "aunt could not provide for the food I liked; even when I was sick (headache) she told me to look for pain killers myself." Linyang'wa concurred with Ulemu in that she was treated differently from other children in their aunt's home. Her aunt was working as a health surveillance assistant hence was unable to afford items for Ulemu's basic needs or control her husband's sexual behaviours towards the young women, as he was the source of financial support in the home. Ulemu was usually reporting for classes late for the school semester. When her older siblings sold their parents' house, Ulemu, a teen club participant at Chiyembekezo Centre invested her share in a small business.

She was selling fried pan-cakes at school and second-hand clothes out of school hours to sustain the funds for her school fees and buy rice and Irish potatoes for her breakfast, which her aunt was unable to provide for her. She also indicated that with her small business, she was able to buy for herself well-fitting outfits that completely changed her outlook and her perception of her body image as a young woman. "I depend on my business for my fees and buy my clothes to look like other young women. Now I'm respected by aunt's husband, who used to sexually harass us with Linyang'wa because usually the money that aunt leaves at home for household use when she goes for field work is not enough so often we use my hard earned money to buy the food items like maize flour, sugar, relish [accompaniments to the staple food like beans, small fish and vegetables], and snacks for aunt's children to take to school." Being financially self-reliant gave Ulemu the capacity to advance with her education without interruptions and the position of power to desist being vulnerable to her uncle's sexual harassments as she was partially supporting the family with her finances.

However, in situations where the caregiver was elderly, not working, living below the poverty line and also a sole provider like for Nane, Gonjetso, Tawina, Chitsanzo, Tamando and Dalo, concerns about survival and financial support became major issues.

> *"……currently dad is not working, and he is struggling to meet our needs including food and my transport to school; I moved to live with my uncle during school blocks for financial and material support and to be closer to my college in order to continue my studies without interruptions." (Nane, 19)*

Tawina and Gonjetso also reported that their caregivers were finding it difficult to secure their basic survival needs. As such, despite pursuing their studies at a community day secondary school, both still dropped out of school as their caregivers struggled to

meet their academic costs. Both Gonjetso's service provider Ms Mbenu and caregiver, Mr Tambula, acknowledged her struggles in securing resources at school including meeting the doctor's appointment dates due to lack of transport to the HIV management centre.

> *"Her major challenges include lack of clothes, pocket money for simple things like soap, body lotion, writing materials, sanitary pads which are needed every month and where would she get the money? Her caregiver is elderly and the foster family is poverty-stricken; she cannot ask from friends all the four years she is in school, they cannot afford; lack of such basic items can affect her performance in school, if she is not supported."* (Ms Mbenu, Gonjetso's service provider, 37)

In the quest to help support their parents (who had lost productivity due to illness) and siblings, Nane, Tamando, Dalo and Tanyada indicated that they assumed adult roles within the family like securing finances and had to take on the daily household tasks like preparing meals, cleaning the house and caring for younger siblings or assisting their sick parents.

> *"I made a decision to wake up early in the morning do house work, make breakfast for my parents whenever they are not feeling alright and go to school; after classes I could do the rest of the work with my sister. My parents, my part-time teacher, my teacher-friend, all help me with my school work so that I can achieve my dreams. I want to be educated, get employed despite my sight and hearing problems and provide better care for my parents."* (Tanyada, 16)

The young women adopted different strategies of securing finances to support themselves and their families. Most of the strategies exposed them to early sexual debut, unsafe sexual practices and early child bearing (see Panel 3), as they sought economic support through sexual relationships (but not all young women).

Panel 3: Dalo, 19 years and Tamando, 17 years

Both Dalo and Tamando complained of being born to an impoverished family and finding it difficult to secure their basic needs. "Our family is poor; sleeping on an empty stomach has not been easy." Of Dalo's five siblings, aged 17 (Tamando), 14, 11, 7 years and 4 days (a neonate), three (the first, second [Tamando] and fifth) and both parents are living with HIV. Dalo perceived that life had been tough for her family and finding enough to eat was a constant struggle, so as an older child, she dropped out of school at primary education level (in standard eight) to assist her parents earn a living through a small business. At the age of 12, Dalo reported doing piece works like drawing water for brick moulding, and this assisted her to raise capital for her groundnuts business. She was selling cooked fresh groundnuts with her young sister, Tamando, who was by then 10 years old. "With my sister (Tamando), we had to go to the market every day to sell cooked raw groundnuts so as to have food for the day instead of going to school."

Both Dalo and Tamando, teen club participants at Maziko Centre, reported that the money they earned through sales of groundnuts were not enough instead they also used male relationships as an economic strategy to meet their family needs, so they supplemented their income from the sales of groundnuts with prostitution: "But the money we earned from the sales of groundnuts was not enough to meet the needs of the whole family so we found sexual partners, who were giving us money." Tamando engaged in a stable sexual relationship at the age of 12 to secure financial and material support for her family, leading to her early marriage and child bearing. However, Dalo engaged in multiple sexual partnerships at the age of 12 as well, and the consequences of Dalo's efforts to gain financial support through multiple sexual partnerships are highlighted in Panel 5 in Chapter Seven.

Conversely, Penina and Alindine whose caregivers demonstrated capacity to provide for their basic survival needs did not struggle to earn a living but rather they coped positively. As their basic survival needs were being provided for, they were optimistic about their future hence boosting their psychological and social well-being.

In this section, it is clear that young women who struggled with the hardships of poverty as they lacked adult support networks, food insecurity increased and household income decreased or was diverted to medical expenses, struggled to cope with their HIV positive status leading to negative outcomes.

6.5 Dealing with stigma and discrimination

6.5.1 Keeping HIV status a secret

The stigma associated with HIV made the majority of young women and their caregivers keep their status a secret. They used silence and secrecy as a coping strategy against the social stigma. However, secrets concerning the status interfered with optimal relationships and young women's subsequent emotional adjustments. The fear of loss of relationships and social exclusion resulting from status disclosure was a driving force to secrets in relationships. For a young woman, a decision to inform others of the diagnosis carried the risk of a double disclosure: it simultaneously revealed the positive status or previously hidden lifestyle of the parent. Therefore, the hurdle confronting many young women was deciding whom to disclose their status and when. Although, disclosure of HIV status usually took place in a setting where caregivers and service providers worked together, there were different reasons cited by young women or their caregivers for late status disclosure, keeping status a secret to other family members or significant others like teachers, neighbours and sexual partners. Although the young women hated having to lead a life of secrecy they still judged it to be necessary, given the public image of the young woman with HIV infection. The issues related to status disclosure to sexual partners are highlighted in Section 7.3.

6.5.1.1 Challenges of status disclosure

A number of young women reported having accidental or late disclosure of their HIV status because their families/caregivers did not want them to tell others and stigmatise the family. Nane, Penina, Ulemu, Mwatitha, Fatsani, Alindine and Tanyada indicated that their parents/caregivers hesitated to disclose their status because they were very sick or were not sure how to communicate to them, or they thought the young women would not keep the status a secret. However, unlike Gonjetso and Zaiwo who coped positively with early status disclosure, those who had late disclosure encountered several challenges which included denial, difficulties accepting their positive status, and suicidal attempts following accidental disclosure (as in the cases of Ulemu and Mwatitha).

> *"I tested HIV positive at age 11 but aunt and my sister didn't tell me that I was HIV positive until at the age of 17 when I started participating in teen club. The service provider said, 'since all of us are HIV positive, we should support each other; I was shocked because I didn't know that I was HIV positive despite taking ARVs. When I asked aunt, why she didn't tell me? She said, she was afraid of my reactions; I cried, at times I abandoned my ARVs; I wished I was dead; it was very difficult for me to accept my status, but with counselling I accepted……"* (Ulemu, 18)

While Penina had accidental disclosure of her status (through reading in her medical records), Nane and Alindine indicated that they had late status disclosure though it was done at the centres. Mr Zaneni, Nane's father, attributed his challenges of taking Nane to the hospital to have her blood tested for HIV to parental guilt and shame of passing on the virus to Nane through his first wife, who died of HIV related illness.

> *"It is not easy having a child who is HIV positive. She (Nane) had been sick since death of her mother. I took time to communicate the need for the test, thinking how she will react if she tested positive; what will she think about me, unacceptable behaviours? When her results came out positive, it took some time for her to come to terms with her positive status……..."* (Mr Zaneni, Nane's caregiver, 43)

For Nane, Penina, and Alindine, late disclosure of their status meant the disease was associated with shame, unacceptable behaviours or sexual immorality which they perceived their caregivers were not comfortable to discuss with them. Simultaneously, they felt the pain of being associated with such a shameful illness which did not give a true reflection of their sexual behaviours as young women and exposed them to social isolation.

> *"You may not understand the pain of having this disease; you feel like not associating with others. It seems even our parents are ashamed of this disease thus why it took long for dad to have me tested for HIV; it pains me; is it because he was not ready to discuss it with me? Is it because it's sexually related?"* (Nane, 19)

Nevertheless, after being aware of their status, all the young women followed their caregivers' lead in concealment that they kept the status a secret to their peers, relations and significant others including sexual partners.

Ulemu, and her sister, Linyang'wa, Zaiwo and her mother, Mrs Zangawe and Fatsani and her mother, Mrs Ndazi, reported keeping the status a secret to other siblings for fear that they would not keep the HIV positive status a secret within their family unit, and other family members including significant others for fear of social isolation or loss of support. However, Linyang'wa perceived that the concealment of the status deprived Ulemu of the needed social and financial support from her uncles or teachers whenever she was sick. In contrary, their aunt objected to disclosure of her status for fear of social isolation which included her own insecurity and loss of their sources of support.

> *"I wished our uncles and her teachers were aware of her status; when I asked aunt, why don't we disclose her (Ulemu's) status to uncles and her teachers? She says 'will they keep it a secret? Will the whole community not know that she is HIV positive? It is our secret; do not let others know about it, they may stop assisting us; even the young ones don't tell them.' I feel our uncles, who assist us whenever she gets sick, could have been informed of her status, so that they know her real problem, possibly they could provide assistance of some kind." (Linyang'wa, Ulemu's caregiver, 21)*

Interestingly, concealment of young women's status by caregivers in foster families was often extended to their spouses, as long as the female caregiver felt the young woman would be rejected or it would jeopardise the care being provided to her.

> *".....this is my sister and we have no parents, I was keeping her as her parent; if I was to inform my husband about her status I thought he might discriminate her, he wouldn't have accepted to keep her in his house; am the only one who could care for her."* (Mrs Mbalume, Chitsanzo's caregiver, 28)

On the other hand, Gonjetso, Dalo and Tanyada reported keeping the information about their status a secret since disclosing their status would mean their parents' status would also be disclosed, thus subjecting their family to social isolation and embarrassment. This clearly signifies that living with HIV involves keeping many secrets

which deprives young women of potential social networks or relationships and proper support which they might desperately need to live positively. This risk was probably greater where Mrs Mwatipa, Dalo's mother and Mr and Mrs Mipando, Tanyada's parents informed their children to withhold the status information from relations, close friends and neighbours thereby excluding them from providing a supportive and normalizing experience for the family.

> *".....we said let's not tell them (the children) about the status ……..will they not tell others? If others know, how will they treat us as a family? Later we disclosed the status to them because the older daughter (Tanyada) kept on demanding reasons for taking her daily drugs; but we told them not to tell our relations, family friends to avoid social isolation." (*Mrs Mipando, Tanyada's caregiver, 40)

While Gonjetso felt the involvement of a supportive adult in school preferably her head teacher or closest friend was ideal, Alindine and Mrs Ndazi, Fatsani's mother reported keeping the status a secret from teachers and peers for fear of stigma, losing social support networks, relationships hence social identity. Apart from publicising her status, Alindine perceived that her teachers would treat her more protectively. This signifies that for young women, the need to rely on adults because of the illness is often in sharp contrast to the developmental need of establishing independence from adults and identifying with one's peer group.

> *"I could have informed my teachers in case of illness, but may be they could have been controlling me like a school child, not as a young woman. Will they keep my status a secret? I don't trust them so I kept quiet."* (Alindine, 19)

Few service providers also seemed to reinforce secrecy around HIV positive status to maintain self-image. For instance, Mrs Yinde and Mrs Monali (Alindine's caregiver but also a community nurse by profession) shared the same views about maintaining HIV status a secret as they both perceived that lack of secrecy could expose the young women to stigma and discrimination and threaten their self-image. However, the burden of secrecy seemed to promote feelings of isolation for the young women as they made every effort not to be discovered that they are HIV positive or are taking ARVs.

> *"I told her (Alindine) not to reveal her status to friends not even to teachers, otherwise they will publicise her status. Though not easy, whenever coming for drug refill, I feel sorry seeing her hiding her ARVs sachets inside her blouse to ensure that her friends do not see the drugs….."* (Mrs Yinde, Alindine's service provide, 45)

6.5.2 Resisting stigma through academic and vocational achievements

Section 6.2 reveals that social relationships and the enabling environment seem to have the ability to enhance young women's lives and self-image in various ways. These include being the source of emotional attachment, intellectual motivation, personal security and social companionship. They allow young women to attain levels of agency that would otherwise be unachievable and make them feel more positive about their future, hence achieving their goals in life. However, lack of the same demoralised young women and/or undermined their capabilities to succeed in life, hence diminishing their self-image. Therefore, academic and vocational achievements enhanced young women's sense of worth and thus buffered their threatened emotional well-being and also helped them to cope with the negative repercussions of having a stigmatised illness or being a devalued social entity. For instance, Nane, Penina, Ulemu, Gonjetso, Alindine and Tanyada who enjoyed substantial advantages that included strong family support and other supportive relationships yielded social capital that they needed to achieve their self-determined goals. These goals were significant to define their identity, guide behaviour, buffer against life stress/challenges hence build their self-confidence.

In the cases of Nane, Penina, Gonjetso, Alindine and Tanyada, their intimate relationships with their caregivers/parents and the support provided were powerful influences on their self-determination. This made them accept their status quo and made them more determined to achieve their academic goals. The young women gave the impression that they never minded any devaluation in the eyes of the others as long as they achieved their academic goals. Nane's, Gonjetso's and Tanyada's overarching goal of becoming caretakers of their younger siblings in a meaningful way and desiring to reward the support rendered to them by the father, grandfather and parents respectively enabled them to become more goal-oriented and focused on their studies.

"Mum believed I could care for my siblings. I accepted the challenges of living in the village and going to a community day secondary school; mum was a motivator and believed school would take me up high; now is grandpa who values education. He usually says, 'my daughter advanced with her education and was independent - in you I see the spirit of your mother, who made a difference in life; work hard to be independent.' I know I will make it, I want to become a doctor to support grandpa and my siblings. Am his only grandchild who has gone to secondary school and am always on top ten….."
(Gonjetso, 16)

Reflecting on her anticipated responsibilities, Gonjetso reported aspiring to become a medical doctor. Her ability to settle on vocational identity seemed to unleash her full potential of academic excellence (see Panel 1). Gonjetso's career aspirations were integral to the identity formation process and seemed to be associated with positive outcomes and behaviours.

Similarly, Alindine reported that the psychosocial and financial support rendered by both Mrs Monali (her caregiver) and Mrs Yinde (her service provider) reduced the likelihood of her succumbing to paralysing feelings of self-doubt and incompetence; instead she developed confidence in her abilities to succeed in life. Ideals of diligence were inherent in Alindine's statements and actions, which fostered and sustained her self-determination to advance with her studies despite the one year break due to severe illness. She perceived that life had a purpose and a meaning and did not allow her HIV positive status to dissuade her from her goals. Mrs Yinde attributed Alindine's positive coping to Mrs Monali's consistent support. They both emphasised the need for Alindine to set and achieve academic goals in order to be independent in the future. Alindine accepted her status and made use of all opportunities and supports to achieve her academic and vocational goals. She acknowledged the change in her identity from a 'young woman with internal injuries' to a primary school teacher and that boosted her self-image.

"……I accepted my status and live like any other normal young woman, it is not easy withdrawing from school, being at home sick for over nine months, being stigmatised, 'a young woman with AIDS or internal injuries'; but I felt it

was necessary to accept, so I could achieve my dreams …….. I live positively and determined to achieve my goals in life. Aunt and my service provider always kind of talked about how education is important - people tend to respect you, and thus what encouraged me to advance with your education." (Alindine, 19)

Unlike Gonjetso and Alindine, Tawina reported that after her father's imprisonment, she was determined to achieve her academic goals, despite limited support systems in the village since her uncle could not afford her academic costs. Tawina's overwhelming emphasis on her former self (e.g. having better clothes, better uniform and a pair of shoes, attending a private secondary school) made her drop out of school as her desires to return to her former self was unrealistic, as she had experienced dependence on her uncle who had limited resources.

"I had only school fees for community day school; but I did not have a pair of shoes and a better white blouse for school uniform; so I gave up school in form 3 of secondary school level. With dad I used to have good clothes, attend private secondary school; I wish I could have a good pair of shoes to go back to school, if funds are available I want to go to a private school, my dad used to pay but now uncle cannot afford." (Tawina, 18)

While Tawina felt her future was lost due to limited resources, Mr Pamba, her service provider, contrarily perceived that she dropped out of school in the village because of social isolation by her peers as a result of her visible skin condition.

"I feel most of her friends in school were avoiding her because of her skin condition, thus why she dropped out of school. This is the reason why she doesn't like mixing with her friends. In her village, people still look down upon those with positive HIV status particularly with her skin condition that worsens her situation." (Mr Pamba, Tawina's service provider, 25)

Apart from dealing with the effects of the chronic illness, the young women struggled to cope with negative consequences of having a stigmatised illness. In this section therefore it is clear that young women and their caregivers employed several strategies in dealing with stigma and discrimination.

6.6 Burden of caring for the caregivers

Caregivers who had adequate resources to meet young women's needs reported emotional satisfaction related to being able to assist the young women attain independence and meaningful life and their caregiving became a rewarding experience. For instance, Mrs Monali, Alindine's caregiver, expressed excitement when Alindine completed her teaching course and became a primary school teacher. However, a number of caregivers acknowledged that they were unable to provide for the young women's basic survival needs, which contributed to young women's negative self-image and/or lack of attaching a purpose to their lives. Mrs Botolo, Mr Zaneni, Ms Linyang'wa, Mrs Metani, Mrs Ndazi, Mrs Mbalume, Mr Menda, Mrs Mwatipa and Mr and Mrs Mipando revealed how hard it was for them to fulfil the needs of the young women, when they were struggling in their own lives or they were themselves still very young. As such, the majority of young women engaged in sexual activities for financial and material gains. The vulnerabilities/risks associated with sexual relationships as an economic strategy for young women as they struggled to earn a living are highlighted in Section 7.3.1. However, some of the reasons cited by caregivers for not providing for the young women's survival needs included lack of employment, loss of productivity due to illness, increased caring burden, lack of social and financial support for themselves or rule-breaking by the young women. Mrs Botolo, Mrs Metani, Mrs Ndazi and Mrs Mbalume attributed their inability to provide the needs for Ziliwe, Mwatitha, Fatsani and Chitsanzo respectively to lack of consideration on the part of their husbands as the main source of income in their families.

> *"My husband could not spare a penny on her (Chitsanzo); it has been difficult for me to ask money from him to meet her basic needs; with no other support I have been using whatever little I get from the sales of second hand clothes to buy her clothes or give her money to buy what she wanted. I don't have enough resources; you know girls have several needs, men provided instead and she became pregnant."* (Mrs Mbalume, Chitsanzo's caregiver, 28)

Mr Malido, Chitsanzo's service provider, concurred with Mrs Mbalume that being a young woman herself and mainly dependent on her husband for survival seemed to undermine her ability to provide for Chitsanzo's basic needs. Instead Chitsanzo looked for alternative sources of financial support in order to live like any other young women.

> *"She (Chitsanzo) has been raised up by her sister - less than 30 years, with her own financial challenges as she also depends on her husband for support. I feel meeting her needs as she was growing was a big challenge, so it could be that she found other means of support." (Mr Malido, Chitsanzo's service provider, 37)*

Similarly, Mr and Mrs Mipando, Tanyada's parents, acknowledged that as a family they were struggling to earn a living because of her father's inability to run the business that was the main source of their income. Mr Mipando asserted that as a sole provider, he used to supplement his monthly pay from the civil service with income earned through a small scale business, but his ability was disrupted by the illness leading to loss of productivity. This signified that Mr Mipando was challenged since the demand for care of his family (four HIV infected family members) increased as his ability to provide it diminished. Mrs Mipando, Tanyada's mother expressed concern over lack of other family members to replace the income, so that coupled with nutritional and medical expenses for more family members with HIV was a burden to his family's limited resources. However, the stigma attached to HIV prevented the family from seeking support from other relations and significant others.

> *"……my husband works as a policeman, so the little salary he receives does not meet all our needs; life has been very hard for us, our business of selling Irish potatoes and freezes is down because we have blown up the capital on medical and nutritional expenses for the four of us. My husband's sister is very talkative we wouldn't ask money from her, we don't even want her to know our status."* (Mrs Mipando Tanyada's caregiver, 48)

Mrs Ndazi also reported encountering the stress of mothering five children without stable support. As a sole bread winner for the family, Mrs Ndazi indicated that she did not suffice all Fatsani's needs, especially the clothing and nutritional supplements. She attributed her failure to meet increased medical and nutritional expenses to the loss of

her main source of financial support (the husband) and her lack of productivity as she had to care for Fatsani in hospital. As such, Mrs Ndazi believed that Fatsani looked for alternative means of financial support as she could not suffice her needs. Mr Menda, Tawina's caregiver shared the same views that their family was hard hit with poverty and meeting Tawina's basic survival needs was a major challenge. As such, Tawina engaged in sexual relationships for financial support, to which her caregiver seemed to turn a blind eye as he was unable to provide for her basic needs. On the other hand, Fatsani's and Tawina's behavioural and school problems could be attributed to being raised in the polygamous family structure and community, respectively.

> *"Our family is poor; we fail to send her back to school since she dropped out due to lack fees and clothes. In rural area, we rely on farming to get basic needs, so as she is growing with HIV, she cannot manage to cultivate crops in order to earn her living. Am afraid she needs support; as a girl she may engage in male relationships for support in order to look like her friends."* (Mr Menda, Tawina's caregiver, 39)

Additionally, Ulemu, and her sister, Linyang'wa and Mwatitha and her service provider, Mrs Tayenda, disclosed the struggle female caregivers encountered in controlling their spouses' sexual behaviours towards the young women. They indicated that when they themselves were young (Ulemu's aunt was 30 years) and fully dependent on their spouses for survival, it was difficult for them to take action against the husbands if they sexually abused the young women because that meant loss of their source of support as the family.

> *"I wished I was dead; aunt's husband used to sexually harass me. Whenever aunt was not home, he touched my breasts and bum, held me tightly and started caressing me; I cried and he stopped. He could invite me to his bedroom or bathroom but I refused; whenever I informed aunt, she kept on saying, 'what do you think I can do about it, just avoid him'; is it because he provides for the family? I told him I would take a legal action, so he stopped but it still tortures my mind especially that he stopped providing for my basic needs including my school fees."* (Mwatitha, 18)

Furthermore, Mrs Botolo, Ziliwe's aunt and Mr Zaneni, Nane's father acknowledged that their failure to provide for the young women's basic survival needs made it difficult for them to control the young women's sexual behaviours, which they employed as an economic survival strategy.

> *"…..her sexual behaviour annoyed my husband; she was sent to live with my brothers; but they couldn't control her behaviours; she could leave and come home late around 1:00am. When questioned about her whereabouts, she would shout at them saying, 'don't bother about my whereabouts as if you provide for my needs'. We couldn't control her sexual behaviour, she was dating a lot of men ……..It's very difficult when you lack resources, may be she couldn't have been pregnant, if all her needs were provided for……"*
> (Mrs Botolo, Ziliwe's caregiver, 30)

It is clear in this section that some young women asserted their autonomy as evidenced by some kinds of rebellious activities which could be attributable to general adolescent development as well as HIV related issues. However, a number of caregivers acknowledged that their lack of support structures exposed young women to sexual exploitation as they sought alternative means of survival.

6.7 Conclusion

This chapter has highlighted that life for these young women is full of challenges. However, social relationships and social support networks (including strong family structures) acted as a very important buffer – even when things went wrong or when they suffered a setback - as many did. Having these kinds of relationships seemed to be critical in enabling the young women to retain hope and to imagine a future for themselves. From this chapter, it seems significant to give the young women a chance to have loving, supportive relationships (including peer relationships) but to try and ensure that they do not lead to negative consequences such as unwanted pregnancies.

Caregivers' resources were often over-burdened and several lacked the capabilities required to provide young women with an adequately supportive environment. Consequently, some young women engaged in sexual relationships as a strategy for financial and material gains as they struggled to earn a living and autonomy and/or to boost their self-image, hence their stories are more prominent in the next chapter. The next chapter illustrates how young women promoted their 'self-worth' in different contexts using various strategies, downplaying the anticipated dangers on their health and well-being.

CHAPTER SEVEN

BECOMING A WOMAN: NAVIGATING A COMPLEX MORAL AND SOCIAL TERRAIN

"My father doesn't earn enough to meet the needs of our family; so he (Mr Mwendo) has been supporting me since I was 10 years - including my family……I felt like paying back in kind (exchanging his kindness with sex) particularly when he demanded it; I could go to his shop or at times to his house but the issue was how could I tell him about my status? If he knew my status, I felt like losing my SACCO (Savings and Credit Cooperative – a money lending agency in Malawi); how about transmitting the virus to him? I conceived, how about my baby?" (Tamando, 17)

7.1 Introduction

This final findings chapter illustrates the social, structural and clinical complexities associated with growing up HIV among young women. Young women faced many HIV related risks embedded in the social relations and structural realities in their societies as reflected in Figure 7. Culturally in Malawi, women are taught to abstain from sex until they are married and to be subservient to male partners thereafter in sexual and reproductive health matters; as such, the power imbalances inherent in such stereotypical gender constructions are thus internalised as they grow up to womanhood. The chapter illuminates the diverse sexual experiences challenged by the normative expectations as the young women sought love, acceptance and economic gains for social status and identity. This chapter focuses on what young women thought they could gain; and what they felt they could stand to lose by having sex or behaving in any way that could be perceived to be in jeopardy by older women, caregivers or service providers. The conception about 'what is risk', 'what is acceptable' and 'what is important' from the young women's perspectives was different from that of older women or caregivers or service providers. As a result, they were navigating a complex moral and social terrain within a particular set of normative expectations and service delivery options. Figure 7 illustrates the structural realities that shaped the young women's lives within the family, societies and the health systems and are the focus of this chapter. The chapter highlights the balancing act between the priorities of gaining

the perceived advantages while downplaying the anticipated dangers and explore the consequences for young women's sexual health.

Therefore, the chapter is composed of three sections. The first section focuses on young women's desire to be like their peers sexually reflecting normal developmental processes. The second section highlights how young women utilised sexual relationships to gain resources required to boost their self-image, apart from fulfilling their own sexual desires. The section further illustrates how difficult it was for young women to disclose their status if the sexual relationship was an economic strategy for modernity or idealised lifestyle and means of survival. The third section examines the ways in which health system/services did or did not address young women's sexual needs. The section explores how young women viewed the SRH services, including their experiences, approaches, barriers and their preferences for the services as they are growing up to womanhood. All young women presented in Table 2 underwent various sexual experiences and challenges (including SRH services) as they are growing up to womanhood (see Table 9). Two of these young women were sexually abused within their foster families (Ulemu and Mwatitha). Ten engaged in sexual relationships to seek love, acceptance, sexual fulfilment, and/or for financial gains. Out of the ten, Nane, and Fatsani had relationships terminated for disclosing their status; Ziliwe, Zawo, Chitsanzo, Tawina, Tamando and Dalo experienced early sexual debut and child bearing; Penina and Alindine terminated their relationships for fear of being discovered as HIV positive and felt they could not succumb to their partners' sexual desires. Though Gonjetso and Tanyada did not demonstrate signs of being sexually active, they expressed the need for SRH education on individual basis as they were approaching womanhood. Therefore all these cases were represented with pseudonyms as presented in Table 6 in Chapter Four. Their quotes and those of significant others are used to exemplify the moral and social terrain highlighted in this chapter.

Table 9 Cases to illustrate moral and social terrain

Name	Caregiver	Age at sexual risk	Family situation	Means of survival	Sexual experiences & challenges
Ziliwe	Aunt (her mother's sister)	14	Lived with three uncles/mother's brothers - not married; consuming a lot of alcohol; then with partner	Doing piece work (washing clothes in homes); engaged in sexual activities for financial gains	Struggled on condom use with her partners exposing her to early child bearing & potential for re-infections hence ill-health; felt she lacked individual SRH education and access to injectable contraceptives.
Nane	Father	18	Living with her father, but not working & living with uncle during school blocks	Dependent on her uncle; engaged in sexual activity to supplement finances offered by her uncle	Her father felt he lost control of her sexual behaviour; had her sexual relationship terminated upon disclosure of her HIV status; felt she lacked individual SRH education
Penina	Aunt (her mother's sister)	17	Living with father and step-mother; kept status a secret to a partner	Fully dependent on her father for financial & emotional support	Terminated her relationship for fear of being discovered HIV positive; felt lacked SRH education at the centre
Ulemu	Aunt (her mother's sister)	14	Living with her aunt; sexually abused by aunt's husband;	Independent – relies on own business – sell fried pan cakes at school & second hand clothes	Felt she lacked individual SRH education at the centre as all her friends were boys though not sexual partners; sexually harassed by aunt's husband
Mwatitha	Aunt (her mother's sister)	16	Living with her aunt; sexually abused by aunt's husband; kept her status a secret to her partner	Fully dependent on her aunt's husband, who rejected her for whistle blowing his sexual advances	Loss of support from aunt's husband for disclosing his sexual abuse; in jeopardy of establishing unhealthy sexual relationships for emotional support
Gonjetso	Aunt/ school headmaster	16	Living with school head master – who did not advocate for condom use;	Dependent on grandfather & aunt; her head teacher & service provider meet her academic needs;	Felt she lacked individual SRH education at the centre though not sexually active

Name	Caregiver	Age being at risk	Family situation	Means of survival	Sexual experiences & challenges
Fatsani	Mother	13	Living with mother; father left for another wife; kept her status a secret to sexual partners	Dependent on her mother; engaged in sexual activities for material & financial gains	Had four partners serially in four years; had her first relationship terminated upon disclosure of her HIV status; lacked individual SRH education and access to injectable contraceptives
Alindine	Aunt - her mother's sister	13	Living with aunt; kept her status a secret to her partner	Fully dependent on her aunt for material and financial support	Terminated relationship for fear of being discovered HIV positive; felt she lacked individual SRH education at the centre
Chitsanzo	Sister	14	Lived with sister but was finding it difficult to provide for her basic needs; now living with husband but unaware of her status	Dependent on sister's husband; engaged in sexual activities with older & married men for support; now fully dependent on her husband who adopted her pregnancy	Impregnated twice – first pregnancy aborted; engaged in unsafe sexual practices leading to early child bearing for failing to negotiate for condom use; felt she lacked individual SRH education & access to injectable contraceptives.
Tawina	Uncle	14	Living with her uncle but was finding it difficult to provide for her basic needs; kept her status a secret to her partners	Dependent on uncle; engaged in sexual activities for financial and material gains	Had five sexual partners in five years serially; yielded to partner's choices to keep relationships & engaged in unsafe sex three days after menstruation; felt she lacked access to injectable contraceptives.
Zaiwo	Mother	14	Living with her mother; kept her status a secret to her partner	Fully dependent on her mother; engaged in sexual relationships for companionship & emotional support	Impregnated twice with less than one year spaced pregnancies; felt she lacked individual SRH education & access to injectable contraceptives.
Tamando	Her husband	10	Lived with her parents but were finding it difficult to provide for her basic needs; now living with husband who is aware of status	Selling groundnuts at market – engaged in a stable relationship to supplement her income & support her family; fully dependent on husband for financial support	Early marriage & child bearing at the age of 15 years; felt she lacked individual SRH education & access to injectable contraceptives.

Name	Caregiver	Age being at risk	Family situation	Means of survival	Sexual experiences & challenges
Dalo	Mother	11	Lived with her parents but were finding it difficult to provide for her basic needs; living with fourth partner, who is not aware of her HIV status	Selling groundnuts - engaged in sexual activities with older & married men to supplement her income & for support of her family; now fully dependent on her fourth partner	Early child bearing (at the age of 15 years); HIV transmission to her two children - first child is HIV positive; lost first husband & second child to HIV related illness; second husband terminated relationship after discovering her HIV status
Tanyada	Both her father & mother	10	Living with her parents; kept status a secret to relatives, peers & neighbours	Fully dependent on her father for material and financial support	Felt she lacked individual SRH education though not sexually active.

7.2 Having a sexual relationship is normal

The sexual experiences of the perinatally HIV infected young women were not different from those of their HIV negative counterparts. They reported engaging in sex as early as 12 years and in multiple sexual partnerships for pleasure, love and support (see Table 2). The majority do not consistently adopt protective measures in sexual encounters and some have initiated child bearing. The details of their sexual terrain remained clear that they sought love, acceptance and desired to be like any other young woman.

> *"I feel it's normal having a boyfriend like any other young woman; having a boyfriend is part of life as am growing up; I just feel that there is need to have someone who can love and accept me as I am (with my positive HIV status). Someone I can share my feelings and issues with; I needed support, I started doing it (sex) at the age of 12, by age 15 I was impregnated and he married me."* (Tamando, 17)

"…..as am growing it's normal to have a partner, I have sexual desires like any other young woman, I want to feel loved, and this is my fourth partner. The first three partners terminated relationships: after discovering my HIV positive, being shouted by my mum, and the third one was annoyed with my collection of condoms from the centre; I was frustrated losing my partners but now I have a fourth partner, am so glad being in love." (Fatsani, 17*)*

7.2.1 Fulfilling sexual desires versus societal and familial norms/expectations

As young women enter into new social relationships, they are challenged with reconciling the cultural and family norms of behaviour (see Section 2.3.1) with the emerging demands of adolescence and the social groups. While abstinence could be an idealized behaviour, the influences and preferences of social groups or sexual partners become more important as they seek acceptance of their newly developed sense of belonging. Therefore, conforming to sexual abstinence does not resonate with the reality of the economic strategy and the shared social identity which serve as the basis for the receipt of effective support from peers or sexual partners. The young women had to deal with the consequences of losing parental support and often disregarded the risk of sexual behaviours because their economic and psychological well-being was more important as illuminated in Panel 3. As such, they pretended to be 'doing the right thing' like being abstinent from sexual relationships so as not to be seen as sexually active by family members and the service providers, conforming to social expectations; however, they covertly engaged in such relationships. Almost all service providers (Mr Hanuya, Ms Kando, Mrs Rwinu, Mr Mbalame, Mr Tayenda, Ms Mbenu, Mr Zidelu, Ms Benga, Mr Malido, Mr Pamba, Mr Khambi and Mrs Nganya) reported that young women's discussions with them could not portray the true reflection about their sexual behaviour. Both service providers and caregivers were astonished with increased incidences of pregnancies among young women contrary to their expectations that HIV positive young women should abstain from sexual activities. For instance, Mwatitha, Tamando and Dalo indicated that they initiated sex as early as 12 years for sexual pleasure, companionship and financial gains Zaiwo, Fatsani and Tawina initiated sexual activity at the age of 14 years; Ziliwe and Chitsanzo engaged in sexual relationships at the age of 15 years; and Nane at 16 years old.

"……you may not understand why I engaged in a sexual relationship at the age of 12. Though they (adults including my aunt) may not approve it but as I was growing, I had sexual desires, coupled with feeling lonely because I was isolated in my uncle's house, I needed someone to love me; my boyfriend was my companion. But I ensured that my uncle was not aware of our relationship, otherwise he could have whipped me as he did not expect me to have a boyfriend despite my feelings." (Mwatitha, 18)

"I was shocked to discover that she (Mwatitha) has a boyfriend, I expected that she would abstain especially considering her positive status. Surprisingly, when I visited the centre……I heard one of the girls almost of her age on a mobile phone, I believed she was talking to her boyfriend, 'please take care do not move out with other girls, I love you.' I was paralysed, these girls are engaging in sexual relationships; we expect impossibilities, they are engaging in sex as they are growing……" (Mrs Metani, Mwatitha's caregiver, 40)

However, the young women who engaged in sexual activities (Ziliwe, Nane, Mwatitha, Fatsani, Tawina Chitsanzo, Zaiwo, Tamando and Dalo) reported finding it difficult to collect condoms at the centres for fear of being discovered sexually active and due to feelings of embarrassment. Simultaneously, the service providers asserted that since the young women reported that they were not sexually active and were not collecting condoms, and that they found it difficult to discuss relevant sexual issues with them. In addition, they did not want to be perceived as coercing young women to initiate sexual activities especially when they considered their ages and the small stature of some of them, only to be shocked later seeing some of them pregnant, contrary to their expectation that the young women were abstaining from sex.

"While we were thinking that she (Zaiwo) was still young, we were shocked to see her pregnant or could it be because she wasn't saying the truth about her sexual behaviour? We couldn't discuss with her relevant sexual issues, not even offering her condoms? But it was a wakeup call. We have realised that these young women pretend, they are not abstaining as we expect them to do; age and stature is not a determinant for sexual education. We should

keep on asking them if they are sexually active and offer SRH information and services to all." (Ms Benga, Zaiwo's service provider, 33)

"I was in a sexual relationship at the age of 14, I had sexual desires and he is the same young man responsible for my child; but I never collected condoms I was shy. How about my age? Looking at my height, I couldn't collect the condoms and I pretended not to be sexual active." (Zaiwo, 19)

Mrs Mbalume (Chitsanzo's caregiver) reported that Chitsanzo's general outlook of quietness and innocence was incongruent with her multiple sexual partnerships. She described Chitsanzo as *'ndi njinga'* ('a bicycle') characterising her as a young woman dating a lot of men, including older and married men, despite spending most of her time in the home. This gave Mrs Mbalume the impression that possibly Chitsanzo's sexual behaviour was attributed to their limited discussions on sexual issues or financial insecurity rather than just fulfilling her sexual needs, as evidenced by her two pregnancies.

"My concern with her (Chitsanzo) has been that, you would think she is a quiet, guiltless young woman but in secret 'ndi njinga' (a bicycle); I couldn't tell that she engaged in sexual relationships as she was always seen around the house. Her poor choices; imagine including married men with children; I think it was for support than meeting her sexual desires, but we could not discuss. She had three known relationships, they could be more…….may be she was looking for support; this child was a second pregnancy, she aborted the first pregnancy." (Mrs Mbalume, Chitsanzo's caregiver, 28)

Both Tamando and Dalo also indicated that, as they were growing, they supplemented the money gained through the sales of cooked fresh groundnuts with money earned through sexual relationships without their parents' knowledge. Both reported pretending as if they were not sexually active, for they feared that their service providers and parents would not approve of their sexual behaviours for they felt they were still young. Tamando reported that initially her parents were not aware that she was dating Mr Mwendo, despite the financial support they were receiving from him. Later, Mr Mwendo intensified his support to the family and disclosed that he decided to assist Tamando so that she could concentrate on her studies rather than selling

groundnuts at the market. While the young women pretended not to be having sex, the parents and service providers reticently colluded in this, as they could not discuss with the young women about the sexual behaviours despite knowing that it might be taking place. Both the service providers and the parents turned a blind eye to consequences of such relationships, which exposed Tamando to her early marriage and child bearing at the age of 15 years.

> *"…..as I was growing the intimacy with him (Mr Mwendo) was just too strong; I could not resist it than fall in love with him. At age 12, I was already having sex with him. Initially, my parents were not aware of his sexual advances and my source of income, they just thought it was from the sales until when he personally told them of his support to me and he increased his support to them; my parents were not suspicious of anything."* (Tamando, 17)

However, there was a strong belief among service providers (Mr Hanuya, Ms Kando, Mrs Rwinu, Mr Mbalame, Mrs Tayenda, Ms Mbenu, Mr Pamba, Ms Benga, Mrs Khambi and Mrs Nganya) that as they were growing, young women were engaging in sexual activities but were not open to the service providers about these. The service providers believed that such behaviour deprived the young women of the relevant SRH information or/and services exposing them to risks like teenage pregnancies and secondary transmission as the service providers made efforts not to be seen as coercing the young women to access the condoms or contraceptives.

> *"…she (Ziliwe) was such a role model in our teen club, ever happy and no one could tell that she had issues. I believe we missed her, only if thorough risk assessment was done possibly she couldn't have been pregnant; but her usual response was deceiving, majority of female adolescents pretend not to be sexually active. With such behaviour, you fail to discuss condom/contraceptive use; you don't want them to think that you are suggesting that they try it."* (Mr Hanuya, Ziliwe's service provider, 33)

> *"….with the girls, it is difficult to find the truth about their sexual behaviours; am not sure whether it is a true reflection or are just not being honest on their sexual behaviours or they think they will be judged. Most of them including her (Penina) always say, 'I do not indulge in sexual activities', so you are kind of being blocked to hold a detailed sexual discussion with them because you don't want to seem like sending them out to initiate sex."* (Mrs Rwinu, Penina's service provider, 33)

This section clearly shows that young women living with HIV tended to behave like HIV negative young women. This likely exposed them to various jeopardies as they strived to look as normal as their female counterparts, protect themselves from social isolation and losing their sources of support which could have negative impact on their self-image.

7.2.2 Being susceptible to peers pressure on sexual activities

Young people are universally acknowledged to be particularly susceptible to peer influence. This study found that low socio-economic status, low self-image, minimal parental care and supervision facilitated young women's conformity to peer pressure to engage in early sexual debut and multiple sexual partnerships. Peer pressure was commonly implicated in many accounts of young women's risk-taking, because most risky behaviours in which young women engaged took place in the company of peers. Most young women looked to a peer group for their models of how to dress, social activities, entertainment preferences and behavioural expectations. The increased importance of peers led the majority of young women to want to alter their behaviour in order to fit in a social group, because they cared more about what their peers thought of them and were likely to conform to behaviours of the group to avoid being rejected, hence downplaying the associated dangers upon their health. For instance, Mrs Zangawe reported that Zaiwo, with minimal parental supervision, initiated sexual activities under the influence of her peers without regard for the associated risks like teenage pregnancy and HIV transmission. She also perceived that Zaiwo admired her friends who were in sexual relationships to boost her self-worth which led to her early child bearing.

> *"All her friends have babies; so it's not surprising that she has a baby. I believe she was doing what her friends were doing just to look like them, thus how she initiated sex that early; and it was difficult for me to follow her up as I have been out to my business while she was going to school with her friends and we were meeting in the evening."* (Mrs Zangawe, Zaiwo's caregiver, 48)

Fatsani also admired her friends including her young sister, who acquired basic and luxurious items through sexual relationships that made them look attractive. They engaged in sexual activities for financial and material gains thus promoting their self-image despite the associated risks like teenage pregnancy.

> *".....like other girls I need better pants, body lotion; so my boyfriend buys my needs; my younger sister has also a boyfriend who buys her needs; we do not reveal each other's secrets to our mum; but she is pregnant now (at 15 years) and mum is not aware about it; she has not yet informed her, may be she is afraid."* (Fatsani, 17)

Caregivers (Mrs Botolo, Mr Zaneni, Mr Menda, Mrs Mbalume and Mrs Mwatipa) acknowledged the strong influence of peers on young women's sexual behaviours and feelings of self-worth as exposing them to early sexual debut and child bearing.

> *".....her (Ziliwe) challenge is the type of friends she has, all of them have unacceptable behaviours (prostitutes) so maybe she wanted to look like them that by age 15 she was already sleeping out with men; it's possible that she wanted to look like her friends who put on nice clothes earned through engaging in sexual relationships.....her reward is the baby."* (Mrs Botolo, Ziliwe's caregiver, 30)

Nevertheless, Mrs Nganya (Dalo's service provider) felt that Dalo succumbed to both peer and familial pressure to fit in the society and to meet the needs of the family respectively.

> *"She (Dalo) is influenced by her friends who are engaging in sexual relationships; at times I suspect the mother sends her to look for money, so that they can have something to eat in the home; her parents are generally poor."* (Mrs Nganya, Dalo's service provider, 62)

Similarly, Tamando's caregiver and service provider, (Mr Mwendo and Mrs Khambi respectively) believed that Dalo, being the older sister, likely influenced Tamando, her younger sister to initiate sexual activities without regard for the associated dangers. They perceived that Tamando looked up to Dalo, who got married twice and engaged in multiple sexual partnerships for financial gains and luxurious items, hence promoting her self-image. Mrs Khambi believed that this exposed Tamando to early marriage, early child bearing and higher risk of becoming potential source of secondary transmission to her partner and the baby.

> *"She (Tamando) has an older sister who has a four year old child, she has been having multiple partners as means of survival; she was married more than twice. The younger sister was influenced by her (Dalo) to engage in sexual relationships; but she is in a stable marriage and she looks happy than her sister."* (Mrs Khambi, Dalo's service provider, 53)

It is clear in this section that peer pressure influenced young women to engage in early sexual activities in order to fit in their social groups.

7.3 Status disclosure to sexual partners

Status disclosure to sexual partners was more complicated, especially if the main driving forces for establishing the relationship were emotional support and financial gains. The detailed presentation of findings on status disclosure to sexual partners in relation to young women's struggles to earn a living is exemplified in Section 7.3.1. However, there was a strong belief among young women that disclosing their positive status would lead to loss of their sources of support. For example, Zaiwo kept her status a secret from her sexual partner for over two years for fear of having her relationship terminated, which she feared would mean the loss of her companion, her sense of belonging and source of self-worth as a young woman. In addition, she indicated that she was not sure about how to communicate with her partner about HIV.

> *"My sexual partner did not know that I was HIV positive, I did not know how to inform him. But some of these boys are just too clever, if I had disclosed my status to him, could he not terminate the relationship? Am used being with him; I was afraid…."* (Zaiwo, 19)

Zaiwo followed her mother's lead in concealment of her positive status to her sexual partner for over two years. However, Mrs Zangawe perceived that if Zaiwo was to reduce the risk of transmitting the virus and re-infections, she had to disclose her status to her sexual partner. Giving Zaiwo a deadline of disclosing her status to the sexual partner could signify Mrs Zangawe's high regard for Zaiwo's life and the value she upheld on the significance of disclosing the status to the sexual partner in order to adopt protective measures, with which Zaiwo reluctantly complied.

> *"I have been asking her (Zaiwo) if she informed her sexual partner about her status; but her response was 'can I inform him that I take ARVs?' I told her, if she wanted to be in a sexual relationship, should disclose her status by month end or should go for blood testing together with her partner to protect each other. Am worried, is she not increasing her viral load, should I lose her again? She is the only one I have."* (Mrs Zangawe, Zaiwo's caregiver, 48)

The risks associated with secrecy toward sexual partners were also evident in Nane's, and Fatsani's expressions of their sexual relationships. They reported experiencing termination of their relationships upon disclosure of their positive status to their sexual partners, as the partners attributed their positive status to promiscuous behaviours. The young women expressed concerns that termination of their sexual relationships affected their sexual identity. It created uncertainty about their social status and prospective marital status as young women. However, terminating the relationships before having their blood tested could signify that the male partners placed the responsibility of HIV positive status on their female partners, or illustrate the consequences of sexual power imbalances inherent in sexual relationships.

> *"……when I disclosed the status to my boyfriend, he called me 'a prostitute' and terminated the relationship before he even thought of having his blood tested. May be because I did not inform him about my status the time he proposed me as we have been having sex 1-2 times per week for two months; but we were using condoms throughout. This to me means that I will not have a boyfriend; every young man I inform about my status will be*

terminating the relationship thinking that I have been promiscuous." (Nane, 19)

".....I thought my first partner was very caring but when I disclosed my status to him, he shouted at me, called me all sorts of names and that was the end of our relationship; is it worth disclosing my status? It's a challenge……I thought he will have his blood tested as well. I have never disclosed to the other three partners; unless we visit the clinic together." (Fatsani, 17)

The service providers, Mr Hanuya, Ms Kando, and Mr Zidelu acknowledged the risks associated with status disclosure for young women like termination of their relationship and loss of their sources of support. They believed that this made it difficult for the young women to comply with the guidance given.

"……we emphasise on disclosure of status to sexual partners, but the young women are in dilemma; majority engage in these relationships for support, so if they disclose their status thus risking loss of their support. Many of them have had their status publicised and sexual relationships terminated after disclosing the status to partners, so they fear repercussions. This has been very difficult to handle, but we still emphasise the need to disclose the status for partners to make informed decisions." (Mr Hanuya, Ziliwe's service provider, 32)

"…majority of these girls even if they are advised to disclose their status to sexual partners, they keep their status a secret to them, like Fatsani had her relationship terminated upon disclosure of her status so she doesn't like to lose the subsequent partners." (Mr Zidelu, Fatsani's service provider, 26)

While Fatsani was more concerned with the previous experience with her first sexual partner and stood her grounds that she would still keep her status a secret to her consecutive partners for the fear of having the relationships terminated, Mrs Ndazi, her mother, was more concerned with legal implications if the partners discovered themselves that Fatsani was HIV positive.

> *"I know she may not disclose her status to her sexual partners but I have always told her its dangers, we may be sued if she does not disclose her status and infect her partners. Personally, I feel she better get someone who is already infected so that they disclose their status to each other without any challenge."* (Mrs Ndazi, Fatsani, caregiver, 41)

Mrs Metani, Mrs Mbalume and Mrs Zangawe shared their views with Mrs Ndazi of advising their children to disclose their status to sexual partners in order to protect the young women and their families from having a bad reputation, social isolation and legal implications in anticipation of the partners discovering that the young women were HIV positive. Surprisingly, there was silence on male's responsibility in status disclosure. The caregivers who emphasised on status disclosure being women themselves, which implies how they valued women's responsibility in communicating HIV positive status to male partners, which signifies gender power imbalances in responsibility over sexual issues.

> *"……'am anxious if she has an HIV negative boyfriend, will he not publicise her status or implicate us legally? I feel getting someone who is HIV negative without disclosing the status is a crime or will he not terminate the relationship upon discovering that she is HIV positive? Will that not tarnish our image as a family…but I have no answers to her questions, 'does it mean that being HIV positive, I should not be in love? Should my status be publicised for me to be loved? Is that not stigmatizing? Did I choose to be HIV positive?'" (Mrs Metani* Mwatitha's caregiver, 40)

However, the young women had their own valid reasons for not complying with their caregivers' reasoning of disclosing their status to sexual partners (see Panel 4).

Panel 4: Chitsanzo 19 years

Chitsanzo is the last born child in the family of five children. She lost both parents at the age of nine years. After death of her mother, Chitsanzo was living with her oldest sister. She described her life with her older sister as terrible possibly because she was marginalised and treated differently from the other children. "…life with my older sister was a nightmare; I was not regarded as a human being but rather a burden." Her sister found it difficult to conceal Chitsanzo's status because of her visible HIV marks. She felt not loved and accepted in her sister's family: "my older sister never loved me, until when I moved to live with my younger sister (Mrs Mbalume) to repeat the class." Chitsanzo felt Mrs Mbalume loved her, but she could not afford to provide for her basic survival needs. Instead, Chitsanzo, non-teen club participant engaged in sexual relationships with multiple partners; however she struggled with status disclosure.

Chitsanzo's initial sexual relationship was with a married man (bicycle taxi driver) who was providing for her needs. "I was in a relationship with a married man; he was a bicycle driver, but how about my status? How could I disclose my status when I desperately needed support?" Chitsanzo could not negotiate for condom use because she did not disclose her status; instead she succumbed to her partner's decisions and choices which led to teenage pregnancy. But the pregnancy was aborted (at three months) at a private clinic because her partner was afraid of his wife and wanted to preserve his marriage (clearly the news of Chitsanzo's pregnancy could have jeopardised his marital relationship with his official wife). However, within six months, Chitsanzo became pregnant again with another married man (a tailor), but the man denied the caring responsibility. "How could I live as a young woman without support? I found a tailor; but how could I tell him about my status? Will he not terminate the relationship? I needed support so I pretended I was a 'normal young woman' (HIV negative) but without condoms I became pregnant again; he refused to marry me." At six months gestation, her second pregnancy was adopted by a young man (waiter), which is unusual in Malawi. Chitsanzo reported experiencing unprotected sex with her husband as she could not negotiate for condom use since she was unable to disclose her status. "He married me despite my pregnancy; but should I disclose my status? Who will support me?" Mrs Mbalume wished Chitsanzo had disclosed her status to her husband for fear of legal implications: "will her husband not sue us if he discovers that she is HIV positive? I wished he was aware of her status." Chitsanzo was more concerned with meeting her basic needs, financial security and securing a safe place and these were the driving forces to her status non-disclosure to her husband. She had lived with her husband for over six months without disclosing her status and their baby was three months old: "over six months now; he is still not aware of my status; if am divorced who will care for me and the baby? He loves us; always I wait until he goes to work to take my ARVs and give the baby her Bactrim."

7.3.1 Status disclosure vis-à-vis struggles to earn a living

Safer sexual practices were advocated for among the infected young women by the service providers, not only to prevent secondary transmission of HIV but also to avoid exposure to and possible infection with other sexually transmitted infections. The disclosure of one's HIV status and the use of condoms became the primary consideration in sexual relationships. However, these are difficult actions to execute and may be fraught with anxiety, fear and even danger as the young women engaged in sexual activities for survival needs or financial gains. As shown in the previous chapter, the majority of young women often had to survive independently due to lack of adult support networks. In the face of the acknowledged, very real, dangers some young women were forced through circumstances like economic pressures and some social values not to disclose their HIV positive status. How the young women actively chose to engage in behaviours described as risky by adults or caregivers/service providers for financial gains and to promote self-worth was evident in young women's struggles to earn a living, resistance to authority and their increasing control and autonomy (see Panel 4). While the young women downplayed the dangers associated with such behaviours, adults or caregivers/service providers perceived that the behaviours were risky as could negatively affect the young women's health or well-being.

> *"……she engages in sex like any other young woman to earn money; as a parent you are so concerned about her positive status; has she disclosed it? Should she get sick again? How do I convince her about all these…?"* (Mrs Ndazi, Fatsani's caregiver 41)

On the other hand, a number of caregivers (Mrs Botolo, Mr Zaneni, Mrs Mwatipa, and Mr Menda) turned a blind eye to young women's sexual activities for financial gains as they were unable to meet young women's basic survival needs because of their own gaps in finances, support structures or relatively young age.

> *"Her (Tamando's) parents are poor, and they are never suspicious of their daughters' actions; while I was supporting her (Tamando) to get back to school, I was very disappointed to see her parents happy seeing her older sister (Dalo) bringing cash home without cautioning her on dangers of such behaviour; could it be because they had no other means of survival? I didn't*

want her (Tamando) to do that, I loved her so much, thus why when my plan of sending her back to school failed, I opted to take her for a wife." (Mr Mwendo, Tamando's caregiver, 28)

Reflecting on Mr Mwendo's account, it is more complex, though it seems he had taken advantage of Tamando's low socio-economic status to control their sexual relationship. There was strong belief that the inabilities of the caregivers to provide for young women's basic survival needs induced the latter to develop intimate and supportive relationships with male partners for financial gains, hence promoting their self-image as young women. A number of young women, Ziliwe, Nane, Fatsani, Chitsanzo, Tawina, and Dalo, including Tamando, indicated that they engaged in male relationships for support, apart from fulfilling their sexual desires, and had to keep their status a secret to their sexual partners to maintain their relationships and source of support. For instance, Tamando reported developing a supportive relationship with Mr Mwendo (her caregiver), who had been providing for her family throughout her adolescence period. Tamando described Mr Mwendo as very understanding, affectionate and supportive as he provided for her basic survival needs including those of her parents (rentals and utility bills). However, Tamando's and her family's dependence on Mr Mwendo seemed to provide him with position of control and limited Tamando's decision making power on sexual issues. Interestingly, despite the increased support, Tamando still had to keep her status a secret to Mr Mwendo for fear of losing her source of support until he discovered on his own.

"He (Mr Mwendo) has been very kind to me; initially he was not aware of my positive HIV status until one day when I was coming from the centre that he took my health passport book to check why I visited the hospital; when he saw CD4 count, he was shocked and decided to ask his doctor friend, who confirmed that I was HIV positive. His immediate reaction was a week of silence but later he bounced back on me, and I was very excited having him back." (Tamando, 17)

By making up for the lost adult support through paid sex, some young women had their sexual debut at an early age with older men. For example, Tamando's full dependence on Mr Mwendo for support resulted in initiating sex at the age of 12 years with Mr Mwendo, who was 23 years by then. However, Tamando, Ziliwe, Tawina, Chitsanzo and Dalo perceived that their sexual autonomy was limited by their young age and the support they gained from their sexual partners. This made it difficult for them to deny their partners' sexual demands and choices or disclose their HIV positive status, hence negotiating for safer sex could have endangered their source of income and relationship with their partners. Thus, it provided their sexual partners with positions of control and they had to succumb to partners' desires in order to maintain the relationships, which exposed them to potential of transmitting the HIV, early marriages and unwanted pregnancies.

> *"My father doesn't earn enough to suffice our basic needs as a family. He (Mr Mwendo) has been supporting me since age 10, he had a shop and a house and having nothing to show my gratitude for his kindness, I felt like paying in kind (exchanging his kindness with sex) particularly when he demanded it; I could go to his shop or at times to his house but the issue was how could I tell him about my status? If he knew my status, I felt like losing my SACCO (Savings and Credit Cooperative – a money lending agency in Malawi); how about transmitting the virus to him? I conceived, how about my baby?"* (Tamando, 17)

Drawing from Tamando's account, it seemed she intentionally made herself available to Mr Mwendo in order to maintain her source of income and support. From this perspective, fear of termination of her relationship with Mr Mwendo was associated by her with loss of her financial support hence status quo was a major reported barrier to her HIV status disclosure. However, Mrs Khambi (Tamando's service provider) perceived that the age gap between Tamando and Mr Mwendo limited Tamando's capacity to negotiate for condom use, in addition to the material basis of the relationship, putting her at several risks including early child bearing which could likely lead to poor sexual and reproductive health outcomes.

> *"……..I suspect that lack of basic needs thus what made her get into early marriage. She was being advised to negotiate for condom use to avoid pregnancy complications with her age. But being young with an older partner, coming from a poor family, I feel it was difficult for her, she might have been looking for support."* (Mrs Khambi, Tamando's service provider, 53)

Mr Mwendo reported acknowledging that he was at risk of HIV infection and social isolation, which included risking his relationship with his mother and significant others for Tamando's sake. However, he believed that he had a God-given obligation over Tamando's life, despite his HIV negative status, hence he accepted to share the stigma or be discredited by her HIV positive status.

> *"I know 'moyo wanga uli pa chiswe' ('my life is at risk'), I married her because I feel pity for her poor background and I just feel God entrusted me with her caring responsibility. I love her though I realised that she is HIV positive; I don't want her to engage into prostitution in search of support. I test my blood every six months and am still HIV negative; if my mother and brothers know about her status, they would be mad at me."* (Mr Mwendo, Tamando's caregiver, 28)

While Tamando engaged in a stable relationship with Mr Mwendo, Ziliwe, Tawina Chitsanzo and Dalo engaged in multiple sexual partnerships with older and married partners for financial gains, risking re-infections, hence ill-health secondary to increased viral load. However, Dalo reported encountering several misfortunes, including divorce by her second husband after being discovered to be HIV positive, as she struggled to secure her financial support (see Panel 5).

Panel 5: Dalo, 19 years old

Dalo is the oldest child in a family she described as 'poor'. In a situation where her father works as a guard and the sole bread winner, Dalo felt the need to assist her family financially. "I had to look for means of survival as an older child." Dalo engaged in multiple sexual partnerships with older and married partners to secure funds but she kept her status a secret to maintain her source of support, "I had two sexual partners - one was married, both were not aware of my status. I had both protected and unprotected sex with them, they were supporting me." However, Dalo was impregnated and was taken for a second wife at the age of 15. She believed that her burdens would be taken care of, because her husband was also supporting her parents but two years later the husband died of HIV related illness. Dalo has a four year old daughter, who tested HIV positive at six months old: "I conceived; and I was taken for a second wife but I lost him to this disease; my child is a victim of my efforts of looking for support; she is on ARVs."

After death of her husband, Dalo lived with her parents but was finding it difficult to secure her basic survival needs and that of her child. "When I lost my husband, I still needed support." Hence, she started selling groundnuts at the market again. Since the cash earned from the sales was insufficient to meet the needs of her family, Dalo engaged in multiple sexual partnerships to supplement her income. Dalo indicated that she did not disclose her status to her partners (customers) for it was not her intention to have sexual intimacies with them, but because she was often asked to keep the change from a business transaction or some could offer her money and food to eat, it was difficult for her to refuse their sexual advances. The special offers limited Dalo's sex autonomy and made it difficult for her to negotiate for safer sex when her customers demanded sex in exchange. Dalo became pregnant again by a man who divorced her after discovering that she was HIV positive. Dalo felt that her pregnancy was an added burden to her parents' hard earned resources. Interestingly, Mrs Mwatipa (Dalo's mother and caregiver) described Dalo's pregnancies as an outcome of sexual abuse by married men, who took advantage of Dalo's age, inferior position (a minor) and her low socio-economic status to advance their sexual ambitions. "Since she is young, when going to school married men were raping her in exchange for money." Dalo's second child died of HIV related illness at the age of ten months. Dalo is living with a fourth sexual partner, who is not aware of her positive status. However, there was a sharp discrepancy between Dalo's and Mrs Mwatipa's account concerning status disclosure to Dalo's fourth husband which could signify a collective collusion to maintain face or the family's reputation. While Dalo had kept her status a secret as she was more concerned with securing financial support including that of her family, "I have not disclosed my status to him; will he not divorce me? Who will provide for our needs including my parents?" Mrs Mwatipa indicated that Dalo's husband was aware of her status. "Her husband knows about her status……."

Similarly, lack of finances was cited as a driving force for Tawina and Zaiwo to engage in unprotected sex, risking HIV transmission and/or teenage pregnancies at an expense of their optimal health outcomes. They acknowledged the risks and expressed strong desire to protect their partners from the infection but they lacked finances to purchase condoms from the shops, despite not disclosing their HIV positive status. They both expressed feeling embarrassed to collect condoms from the centre for fear of being judged sexually active or being laughed at by peers if seen carrying condoms as they could not afford handbags to hide condoms like their peers.

> *"Use of condoms depended on availability of money to buy them from shops, if no money, we do it plain (unsafe sex). I have had five sexual partners consecutively from 2008 to 2012; they are not aware of my status. Some were older than me, two were married; I took the risk because sometimes they give me money to buy clothes. I don't want to pass on the virus, money is a challenge; usually I have unprotected sex three days after menstruation because am sure that I cannot become pregnant and my partners are happy to have sex without a condom. I wished we had money always, my friends could hide condoms in their hand bags but I don't have, so if girls see me with condoms could laugh at me; but also I don't want to be seen as sexually active by my service provider."* (Tawina, 18)

The majority of both caregivers and young women have shown that they were struggling to earn a living. For the young women, it is evident that some engage in risky activities with both older and married men for personal and financial security. This exposed them to potential of transmitting the virus to their sexual partners and prospective babies while they increased their viral load risking ill-health.

7.4 Female gender and decision making challenges

Apart from fulfilling sexual desires and promoting self-worth, the male relationships and economic dependence on men increased the likelihood that young women submitted to unsafe practices like unprotected sex as a surety against abandonment. Young women's inferior social and economic status made them succumb to male partners' decisions and choices despite what service providers or caregivers perceived as the greater risks. For instance, while Mr Mwendo, Tamando's husband reported consistent use of condoms

since he discovered that Tamando was HIV positive, Tamando reported the many times she had considered resisting her husband's wishes for unprotected sexual encounters despite him assenting to consistently use the condoms. She reported making repeated efforts to negotiate condom use, but what became apparent in her expression was a common trajectory of events in which talking about condom use resulted in arguments. Instead she succumbed to her husband's demands and several episodes of unprotected sexual encounter occurred. Tamando indicated that yielding to her husband's demands and choices resulted in another pregnancy six months after delivery of her first child which she felt exposed her to ill-health following reduced body immunity. Nevertheless, as a couple, they agreed to terminate the pregnancy at the private clinic because they felt their first child was still young and to avoid societal scolding.

> *"Since I discovered that she is HIV positive we always use condoms up to date to prevent HIV transmission."* (Mr Mwendo, Tamando's caregiver, 28)

> *"My husband despite knowing that am HIV positive, he usually insists on having sex without a condom. To show him that I mind about HIV transmission to him; should I still put his life on danger? I get out of our bedroom to another room but he finds me there; we argue and I just give up and yield to his demands. After delivery of our child, it took us a month to resume sexual act, within six months I conceived; we couldn't keep the pregnancy because our child was young (9 months old); people could have been laughing at me; we opted for an abortion at a private clinic and I had severe abdominal pains a week following the procedure. Am not using any method, he argues that injectable contraceptives cause tumours."* (Tamando, 17)

Tamando expressed concern about her husband's unwillingness to identify with her concern about the need for safer sex and the rationales she drew from her husband's actions included denial of the risk possibly because he was still HIV negative and desired full sexual pleasure and control.

> *"….he refuses condom use, he says, he loves me and he 'cannot eat a sweet in its packet' it loses its sweetness. He denies use of other methods of contraceptives and yet he says he does not want another child; I have been thinking, is it because he wants me to feel that he is a man or because his blood test for HIV remains negative so he thinks he is safe? But am afraid, he can be positive if we are not mindful. Could it be because I have never been sick? If I was hospitalised or I was taking ARVs than Bactrim he could have not resisted use of condoms."* (Tamando, 17)

Contrary to his behaviour, Mr Mwendo seemed to acknowledge the significance of condom use for both. He indicated that as long as they were consistently using condoms they were safe from pregnancy and other infections transmitted sexually as compared to the other methods of contraceptives.

> *"We often use condoms as a method of choice; I feel we are safe from pregnancy and any other diseases transmitted sexually. The condom protects both of us than other methods. She (Tamando) expresses desire to have tubal ligations, for she feels her life may be in danger, but I always say she is still young, may be she may need to have another child."* (Mr Mwendo, Tamando's caregiver, 28)

Drawing from Mr Mwendo's account, it seemed Tamando acknowledged the dangers of increased child bearing on her positive status as she opted for permanent contraceptive (tubal ligation). However, Mr Mwendo seemed to downplay the greater risks as perceived by Tamando to advance his demands and choices.

There was strong view that young women struggled with their partners on condom use, especially with older and married men. They were faced by unequal power relations and sexual coercion which became an array of negative effects on their sexual, physical and mental well-being. Ziliwe, Tawina, Chitsanzo, Tamando and Dalo indicated that their partners' reluctance to use condoms was often through their emphasis on sexual pleasure without condom use – under a common analogy, 'could not eat a sweet in its packet'. Hence, the young women succumbed despite the associated risks to maintain their status quo and source of income thus promoting self-image.

> *"Though I felt excited with sexual activities, all my partners never liked condoms; they felt sex with condom was not exciting – they ask why taking a sweet in its packet? It doesn't taste sweet, what mattered was the support I needed, and I was impregnated. My first partner suggested an abortion at a clinic for fear of his wife; after 4-6 months of first abortion, I became pregnant again by a second married man, who also refused to marry me, instead he suggested I drink baking soda (sodium bicarbonate) dissolved in water to abort but nothing happened; how about my health?"* (Chitsanzo, 19)

There was also strong belief among caregivers (Mrs Botolo, Ms Ndengu, Mrs Monali, Mrs Zangawe, Mrs Mbalume, Mr Menda and Mrs Mwatipa) and service providers (Ms Benga, Mr Mbalame, Mr Zidelu, Mrs Khambi, Mrs Nganya and Mrs Yinde) that the majority of young women struggle about condom use with sexual partners. They acknowledged that young women instead yielded to sexual partners' demands and choices in exchange finances or support, resulting in teenage pregnancies, hence exposing themselves to ill-health and reduced body immunity. Since, the prime concern for a number of caregivers was prevention of teenage pregnancies rather than HIV transmission, they suggested that young women should be given injectable contraceptives.

> *"…I wish she (Ziliwe) is given injectable contraceptives because these young women engage in sex in exchange of money in order to look like their friends. When men pay for sex, they wouldn't like condom use; they would appreciate a real feel of what they have paid for, so strengthening condom use in girls is a challenge."* (Mrs Botolo, Ziliwe's caregiver, 30)

Nevertheless, Ziliwe, Chitsanzo, Tawina and Tamando perceived that if they were given an opportunity and had support to do business, they could be self-reliant like Ulemu. For example, Tamando complained that only if her husband had allowed her to engage in business, her parents could have been taken out of their impoverished status. Since her husband was reluctant, she yielded to his opinions as an expression of gratitude for his acceptance of her positive status.

"I wished I could to do business but my husband always denies; he says, he provides everything for me; so why struggle with business? I appreciate his love for accepting me as I am; but I wanted to do business to assist my parents (Mrs Mwatipa family); most of the times, they have nothing to eat; all I can give them is US$1 for charcoal and food items; unless I ask from my husband." (Tamando, 17)

One afternoon, when the researcher visited Mrs Mwatipa's home for her interview (Dalo's caregiver), she found one of the siblings (a seven year old boy) crying uncontrollably. Mrs Mwatipa (Tamando's mother) indicated that the boy was crying of hunger, since morning they had not eaten anything despite taking their ARVs at 6:00am. (Interviewer's observation notes)

A number of caregivers, particularly the females, also felt marginalised and had diminished decision making power as female parents. Mrs Ndazi and Mrs Zangawe felt being blamed as sources of the infection to their young women, which also paralysed their role in controlling the young women's sexual behaviours as parents. For instance, Mrs Ndazi indicated that she hesitated to disclose the status to Fatsani, her daughter, because her power to disclose was paralysed by her husband's response to Fatsani's illness. As such, her secrecy was rooted in her feelings of shame and parental guilt for passing on the virus to Fatsani. Mrs Ndazi reported feeling like being blamed for breaching morality as evidenced by her husband's desertion while she was attending to hospitalized Fatsani. These feelings of guilt and shame led to Mrs Ndazi's marginalisation, uncertainty and adversity limiting access to social and financial support she desperately needed and indirectly affecting Fatsani's sense of self-worth.

"…….her father's reaction drained my strength in disclosing the status to her; I was not sure how; I think I felt deserted by him as if I was the one to blame and just being tensed up, feeling responsible for her illness as a mother without her father's support which I can't ask from others; I just feel like being victimised, my daughter is affected unintentionally; this disease is surely a disgrace." (Mrs Ndazi, Fatsani's caregiver, 41)

Similarly, Mrs Zangawe despite regarding Zaiwo as her consolation, reported feeling demeaned by Zaiwo's remarks as she expressed her bitterness over her positive status. Mrs Zangawe as a mother perceived being blamed for breaching morality evidenced by Zaiwo's continuous reminders on being inconsiderate and accountable to her positive status and her anticipated untimely death. Mrs Zangawe indicated that Zaiwo's persistent blame evoked her feelings of shame and parental guilt for passing on the virus to her daughter and triggered the grief of losing her husband and eight children.

> *"She (Zaiwo) was bitter about being HIV positive; initially she could not eat, I have been in pain, hearing her saying……..Is it not you who passed on HIV to me with your husband?' 'Take it off, you want me to die?' I accept the blame. Before she conceived, whenever I cautioned her to refrain from sexual activities; she used to say, you want me to die without feeling what it means to be loved? I feel this disease is a disgrace; I cry for losing my husband and eight children." (Mrs Zangawe, Zaiwo's caregiver, 48)*

Zaiwo blamed Mrs Zangawe for violating her rights to sexual fulfilment while her mother, Mrs Zangawe exercised her rights without restrictions with her sexual partner (her father) with whom Zaiwo felt were responsible for her HIV positive status. Zaiwo seemed to use the blame game in order to paralyse her mother's powers to control her risky sexual activities.

Conversely, Mrs Botolo and Mrs Mbalume expressed the challenges they encountered with their husbands particularly in regard to dominance in decision making regarding issues affecting the young women (Ziliwe and Chitsanzo). Despite the young women breaking household rules, the female caregivers felt that they could have been involved in the negotiations made. Instead, there were no negotiations with them rather their husbands just imposed their decisions regarding the discharge of young women from their homes which they felt was attributed to their inferior social and economic status making them succumb to all decisions made by their husbands.

> "…..*it was my husband who sent her away because of her sexual behaviours and I could not reason with him. Now with a baby, is that not an added burden? 'I wished I had lived with her, but my husband is not willing; he says who will support her baby? I wished I had capacity to support her."* (Mrs Botolo, Ziliwe's caregiver, 30)

The majority of young women and their female caregivers were vulnerable to male hegemony as a result of their dependence on men for financial and material support, giving their male partners' positions of power and control, including decision making on significant issues regarding their own health.

7.5 Young women's experiences and perceptions of SRH services

As shown in Sections 6.3.2 and 7.2, as young women grew to womanhood, they engaged in sexual activities for pleasure and also because male relationships boosted their self-image. This placed an increased burden on their caregivers' and service providers' caring responsibilities. While access to SRH information and services could alleviate some of the burdens or concerns of caring by reducing perceived fears and misunderstandings, young women in this study expressed different views regarding SRH education and services in different contexts. This section therefore describes young women's perceptions, barriers to and preferences on SRH education and services.

7.5.1 Meeting young women's SRH needs

HIV Positive status makes a young woman's sexual lives more complicated, demanding risk-reduction strategies. The young women cited the use of condoms and several activities conducted during teen club meetings as key strategies offered in the centres to cater for their sexual well-being. The information on sexual and reproductive issues often helped young women understand what was happening to them sexually, physically and position themselves appropriately in a medical and social world. However, a number of young women (Ziliwe, Nane, Penina, Gonjetso and Zaiwo) felt silently being left alone as they lacked individual counselling on sexual and reproductive issues.

> *"It is only during teen club that we have group discussions and trainings on pregnancy prevention, sexual and gender issues but there are no discussions with us as individuals, apart from offering condoms if you are sexually active; so you have no-one to ask, how can I open up in a group on my sexual issues?"* (Penina, 19)

> *"Though I benefit from participating in teen club, I wished sexual issues were discussed in consultation rooms with us as individuals, not just offering condoms; discussing sexual issues in a group no-one could freely talk personal sexual challenges, it's embarrassing……"* (Gonjetso, 16)

Similarly, during researcher's familiarisation phase, it was noted that in the consultation rooms, service providers never spent time on sexual well-being of the young women, and the young women were not given an opportunity to make decisions and choices. Mostly it was top-down interaction and task-oriented approach.

> *In the consultation room, young women were merely asked how they were feeling and whether they had any problems, and their medication was checked (e.g how many tablets were remaining). They were instructed to collect condoms if they required them; not all young women were asked if they were in a sexual relationship, and the few who were asked were never asked if they have had any problems with their sexual partners, or if they have ever used condoms/contraceptives or any problems with methods in use. (Interviewer's observation notes)*

7.5.1.1 Benefitting from teen club meetings

At both Chiyembekezo and Maziko Centres, teen club meetings are conducted on monthly basis to equip young people (ages 11 to 21 years) with HIV related information in a participatory way hence reinforcing behavioural change. Using facilitated discussions, dramas, debates, in-door and out-door games, the service providers (Mr Hanuya, Mr Mbalame, Mrs Rwinu, Ms Kando, Mrs Khambi, and Mrs Nganya) believed that the club meetings assisted young people to associate with others, share experiences for peer support and gain knowledge on stigma and discrimination,

adolescent-caregiver communication, drug adherence, family planning, status disclosure and career path.

> *"Teen club meetings are conducted once every month for all young people aged 11 to 21 years with major emphasis on behavioural change. Adolescents discuss in groups various issues that affect their lives like psychosocial affairs, gender, drug adherence, family planning, adolescent-parent/guardian relationships for those with or without parents; and we conduct in-door, and out-door activities. This promotes their emotional well-being…."* (Mr Hanuya, Ziliwe's service provider, 32)

As reflected in Section 6.3.1 the majority of young women concurred with service providers that teen club meetings assisted them to share experiences with peers and gain significant information necessary to reduce risks. However, they felt the club meetings deprived them of an opportunity to discuss their individual and practical sexual challenges and needs. They reported finding it difficult discussing personal and sensitive sexual issues in a mixed gender group and/or of both younger (11-14) and older (15-21) adolescents rather than if they were being given an opportunity in the consultation rooms to discuss their sexual challenges.

> *""……we are not given time in the consultation room to ask questions on issues affecting us as young women, I wished I could have detailed sexual information in the consultation room; it is during teen club meetings that we discuss sexual issues, how to prevent unwanted pregnancies. Group discussions do not address some of my personal questions or challenges. We are offered chances to ask questions on issues affecting our lives; but how could I ask personal, sensitive issues regarding sex or condom use with my boyfriend in the presence of all my friends including younger adolescents and boys? It is difficult to discuss some of these issues in a group……"* (Nane, 19)

While young women felt the group discussions were not adequately confronting their practical sexual issues, service providers (Mr Hanuya, Mrs Rwinu, Ms Kando, and Ms Benga) cited advantages for utilizing group discussions as to reinforce behavioural change.

> *"We opt for group discussions during teen clubs because among the adolescents, there are several others, who understand better their positive HIV status, explain issues in relation to lived experiences. This creates an understanding of their concerns from within themselves to make informed decisions."* (Mr Hanuya, Ziliwe's service provider, 32)

Service providers at Maziko Centre have separate teen club days for younger and older adolescents whereas Chiyembekezo Centre combines the two groups; both offered different reasons for their strategies.

> *"…with increased number of teens, there was increased workload for service providers combining the young and older teens so we divided them in two groups for separate days…….. But also we do not want the older teens to negatively influence the younger teens through peer pressure for they have different needs as they grow up.* (Ms Benga, Zaiwo's service provider, 33)

> *"Apart from lack of funds to have all adolescents involved in teen club, we pair the younger and older teens so that they learn from each other and that works well."* (Mr Hanuya, Ziliwe's service provider, 32)

However, there was strong view that there were contradictions between what was being learnt at teen club and the actual practice in service provision. Ziliwe Nane, Mwatitha, Fatsani, Chitsanzo, Tawina, Zaiwo, Tamando and Dalo felt that some of the service providers were reluctant to offer contraceptives (i.e. injectable depo-provera) as a pregnancy preventive strategy, instead were offering condoms, and they also lacked friendly attitudes towards them. They attributed their lack of openness on sexual issues to non-conducive environments with unfriendly or judgemental attitudes on the part of service providers, including lack of privacy (particularly in rural setting). Cultural and religious norms also seemed to influence provision of sexual and reproductive health services. As highlighted in Section 7.5.2, a number of service providers (Mr Hanuya, Ms Kando, Ms Mbenu, Mr Mbalame, Mrs Tayenda, Mr Pamba, Mr Malido and Mr Zidelu) concurred with the young women that the major challenge with SRH services was that majority of the service providers were restricted by normative expectations and a lack of youth friendly skills. Hence, they were not in a position to provide appropriate,

effective and non-judgemental information on sexual issues to assist young women to balance rights and responsibilities.

> *"……we should accept the reality that some of these adolescents are sexually active and we need youth friendly trainings to help them to open up on sexual issues, to know their rights and control themselves. Often we are judgemental to them, or is it our culture? If we remain unfriendly they will never be collecting the condoms from us."* (Ms Tayenda, Mwatitha's service provider, 39)

> *"One day after we had a lesson on contraceptive use to prevent pregnancies, three of us went to meet a nurse to access injectable contraceptives as our partners were refusing condoms; I was the first one to get into the room, surprisingly she shouted at me that I was young why asking for contraceptives; I felt we cannot access contraceptives."* (Fatsani, 17)

Tawina and Chitsanzo, non-teen club participants, also felt that some of the service providers portrayed negative attitudes towards their sexual well-being. They reported finding it difficult requesting for injectable contraceptives at the centres as compared to collecting condoms, which their sexual partners disliked to use (see Panel 6).

Panel 6: Tawina, 18 years

Tawina is the youngest in a family of four children. Her mother died when Tawina was young, and since then she had been staying with her father and step-mother. She reported facing hard times when her father was imprisoned and she experienced parental rejection from her step-mother. This coupled with social exclusion by peers as a result of her visible skin condition, led Tawina, a non-teen club participant, to reported having her first sexual relationship at the age of 14 for companionship apart from sexual pleasure. Tawina's poor relationship with her step-mother strongly influenced her to seek love and acceptance from individuals whom she considered to be safe and trustworthy. "I lost my father to imprisonment; poor me! I was a burden to my step-mother; she never liked me, so I wanted someone who would be by my side to keep me going." Tawina initiated sexual contact in 2008 and by 2012 she had her fifth consecutive sexual partner. She reported experiencing both protected and unprotected sex usually with older and married partners.

Tawina, though exposed to many HIV prevention messages promoting abstinence and condom use, felt embarrassed to collect condoms from adult service providers because in her community adults do not approve condom use in young people generally. This was also reflected in her partners' demands for unprotected sex. Additionally, she feared being judged as being sexually active (i.e. promiscuous) by the service providers if she asked for injectable contraceptives. Tawina wished she was offered injectable contraceptives to prevent pregnancy but was not given an opportunity to make choices and decisions on her sexual rights: "if only I was offered injectable contraceptives than condoms but we do not choose, I do not want to be pregnant…" Instead, Tawina had unprotected sex within the three days after menstruation (to prevent pregnancy) as she strived to gratify the demands of her sexual partners to reinforce her effective source of income: "I heard from people that if you have unprotected sex three days soon after your monthly period you cannot become pregnant; usually this is the time I have it (unprotected sex) and my partners are happy…… they demand sex without a condom".

Furthermore, Ziliwe, Zaiwo, Tamando and Dalo reported ceasing to attend teen clubs or visiting the centre for doctor's appointments after getting pregnant until they delivered their babies. They expressed lack of relevant services for pregnant young women in the centres, particularly antenatal services which led them and several others to access such services in adolescent unfriendly environments. They reported having to access services with adult clients, exposing them to judgemental attitudes and remarks from older women.

> *"When I got pregnant I disappeared at teen club and appeared after delivery; I started attending antenatal clinic at Tachira Central Hospital, which is attended by both adults and young women and I felt out of place to access services with adults who looked at you, talk about you, as if you had committed a crime. I could have loved if we have antenatal services in the centres than being mixed with the adults."* (Zaiwo, 19)

Mrs Khambi perceived that young women's behaviour of discontinuing participating in teen club could signify lack of appropriate services for pregnant young women. Instead they had to be accessed from other facilities or attitudinal implications on the part of service providers towards young women who fail to comply with medical expectations for optimal health outcomes.

> *"Usually when these young women get pregnant automatically they disappear from the centre, is it because of our attitudes towards them? Like her (Tamando) when she conceived she disappeared and came back after she had delivered; I have never seen her with her baby, yet she still attends teen club meetings. May be because we do not offer such services here but it's high time that we offer the services for continuity of care."* (Mrs Khambi, Tamando's service provider, 53)

7.5.1.2 Fear of pregnancy is a big deal, but not HIV

While condoms are offered to young women in the centres as a preventive strategy for secondary transmission and unwanted pregnancies, many of the young women's accounts of sexual relationships indicate partners' pressures and demands pulling them in different directions and make safer sexual practices relatively unpredictable. Many young women lacked confidence, particularly in relation to sex, and when the risk of pregnancy was a possibility, they preferred contraceptives which were not dependent upon their sexual partners, thus ignoring the risk of HIV transmission. However, the struggles with condom use exposed young women to risk of early child bearing which majority of them associated with ill-health. Nane, Alindine, Mwatitha, Fatsani and Tawina indicated that in their relationships with men, they were more scared of pregnancy than HIV transmission. They specifically attributed fear of pregnancy to poor

health outcomes. The perception that pregnancy can weaken body immunity and expedite progression to AIDS was common among the young women.

> *"Majority of us (HIV infected young women) fear pregnancy than HIV; we are already infected so offering contraceptives thus giving us freedom to have unprotected sex, because we know that we will not be impregnated. We fear pregnancy because it can reduce body protection, thus getting sick often; so use of injectable contraceptives should not be reinforced because thus a warrant for HIV transmission."* (Alindine, 19)

Mr Mwendo, though responsible for Tamando's early childbearing, acknowledged that the majority of HIV infected young women who engage in sexual activities fear pregnancy rather than HIV transmission. Similarly, Mrs Monali (Alindine's caregiver) shared the fear of pregnancy with the young women as she expressed uncertainty on the outcome of the pregnancy, hence increased the caring burden.

> *"…will she cope up with child bearing? Will she not reduce her body immunity? What if she gives birth to an HIV infected child? Will that not be another burden; I feel pregnancy should not be advocated in these girls. But as a mother, I always feel inhumane to tell her not to have children, it is her right; I wish she does not bear children."* (Mrs Monali, Alindine's caregiver, 55)

Tamando, Dalo's mother Mrs Mwatipa and her service provider, Mrs Nganya, also acknowledged the dangers subsequent pregnancies posed upon the compromised body immunity.

> *"When I heard that my daughter (Dalo) was pregnant, I said, oh! My God, my daughter knows that if she gets pregnant, her immunity would get lower; will she not get sick; likewise myself I have delivered a sixth baby, maybe am not being exemplary to my daughters; increased child bearing may further reduce my body protection but it was situational. I missed my appointment date for injectable contraceptives; I went for a funeral ceremony where I stayed longer. Upon return, I visited the hospital for my contraceptives but I was sent*

back because I was late I had to walk - no money to go by bus so I gave up, I conceived." (Mrs Mwatipa, Dalo's caregiver, 38)

Although Mrs Mwatipa was quick to report that she was not being exemplary to her daughters, as she had just delivered her sixth child despite being HIV positive herself, her case signifies ambivalences in priorities and values. This can be reflected in the differences between caregivers' and service provider's priorities and values regarding care rendered to young women. However, the association of pregnancy with ill-health made majority of young women including their caregivers to prefer injectable contraceptives to prevent pregnancy downplaying the risks of HIV transmission.

7.5.1.3 'If only we had access to other methods of contraceptives'

Young women reported encountering several challenges that influenced their sexual and reproductive health choices contrary to caregivers' and service providers' expectations. Young women's sexual health became more complicated as they sought love, acceptance and/or financial support. This provided their sexual partners with the position of power and control in sexual encounters and paralysed young women's efforts to negotiate for safer sex, which also became more difficult when there were wide age gaps with their sexual partners.

"It's normal to have sex but their situation becomes difficult with the positive status; promoting abstinence or condom use to prevent transmitting the virus becomes a challenge because most adolescents are young and finding it difficult to negotiate for safer sex with older partners whom they look to for support or can't disclose their status." (Mrs Khambi, Tamando's caregiver, 53)

Ziliwe, Chitsanzo, Tamando and Dalo believed that if the other sexual and reproductive health services apart from condoms were readily available to them and the environment was conducive for them to access SRH services without fear and embarrassment then their teenage pregnancies could have been prevented. They reported being in a dilemma because their partners, upon whom they were materially dependent insisted on sex without condoms as a demonstration of love and for sexual pleasure, leading to early child bearing. For instance, Tamando indicated that Mr

Mwendo, her husband, refused condom use and did not allow her to use injectable contraceptives due to the belief that they cause uterine tumours (fibroids).

> *"…..my husband refuses condoms; he could not allow me use other methods, he says he heard that injectable contraceptive cause tumours in the womb, so I conceived barely six months after I delivered my first child."* (Tamando, 17)

Some service providers (Mr Hanuya, Mr Mbalame, Mr Nandi, Mrs Khambi, Mr Zidelu, Ms Benga, Mrs Nganya) shared Mr Mwendo's views regarding adverse side effects and risks associated with injectable contraceptives on young women like bleeding, delayed fertility return and secondary transmission. As such, they emphasised abstinence and condom use as the best options. Furthermore, Ms Kando, Ms Mbenu, Mrs Tayenda and Mr Malido perceived that injectable contraceptives should never be reinforced, as they exposed young women to potential for other STIs or secondary transmissions. They perceived that other STIs which could expose them to ill-health to be the greater risk for the young women as they engaged in sexual relationships for financial gains.

> *"Condoms are safe in preventing HIV transmission; but most men including girls dislike condoms for they feel 'skin to skin' during sexual act is pleasurable. Other STIs are a risk in addition to many effects of injectable contraceptives like delayed fertility return or bleeding, which coupled with HIV positive status likely exposes them to anaemia."* (Mrs Tayenda, Mwatitha's service provider, 39)

The other striking issue was where caregivers desired that young women should be given injectable contraceptives to avoid teenage pregnancy or childbearing when they get married. Yet all young women expressed desire to get married and have children.

> *"I intend to have two children; my plan is to come here with my husband, to be counselled so we do not pass on HIV to our children." (Penina, 19)*

> *"When she gets married, I wish she does not bear children so that her immunity is not lowered; why not give them injectable contraceptives?"* (Ms Ndengu, Penina's caregiver, 45)

There were ambivalences regarding contraceptive use among caregivers and service providers. It is clear that service providers and caregivers were influencing decisions concerning contraceptive use more than the young women themselves. However, service providers were more concerned with the prevention of other STIs and HIV transmission and advocated condom use, whereas the prime concern of the young women and their caregivers was prevention of teenage pregnancies. Young women and caregivers attributed their preference for injectable contraceptives to young women's struggles concerning condom use with sexual partners, exposing them to early child bearing.

> *"I wish service providers could give her (Fatsani) injectable contraceptives; I don't want any more HIV infected children. I don't think they can use condoms all the time; will she not become pregnant? Condoms are not reliable; let her have injectable contraceptives;"* (Mrs Ndazi, Fatsani's caregiver, 41)

> *".....as the centre we advocate for sexual abstinence but adolescents, who cannot abstain, are encouraged to use condoms not injectable contraceptives, otherwise have to seek consent from their caregivers; but none has ever come with a caregiver. Prevention of STIs or HIV transmission is very important and needs to be reinforced or they should abstain; other methods be used with condoms though it's a challenge."* (Mr Zidelu, Fatsani's service provider, 26)

While service providers considered condom distribution as a preventive strategy for secondary transmission, Ulemu, Gonjetso, Alindine and Tanyada perceived that condom distribution to young women was triggering early sexual debut hence making them become potential sources of secondary transmission to their partners or babies. They indicated that the danger is particularly in situations where condoms are not 100% effective, where they are not used consistently and where male resistance to condom use is encountered. Likewise, offering injectable contraceptives, they felt that young women were liberated to indulge in unprotected sex hence were at increased risk of other STIs or HIV transmission to prospective partners and babies.

"……I tell them I don't have a boyfriend and they ask me to collect condoms for what? Is it what they expect from me? Thus stimulating immature mind to think of sex, they should offer condoms only to those who cannot abstain. I wish service providers do not offer injectable contraceptives to young women because thus fuelling sexual activities; they feel free to have unprotected sex, which is preferred by many male partners. (Alindine, 19)

Service providers (Mr Hanuya, Mrs Rwinu, Mr Mbalame, Ms Benga and Mr Nandi) seemed to share the young women's views that condom distribution and too much information on sexual issues, especially for those who out rightly indicated that they were not sexually active, could be misinterpreted as an expectation or approval of the sexual behaviours in young women. However, there was strong belief among the service providers that most young women were not open about their sexual behaviours. Mrs Rwinu perceived that it was a general trend among the females in Malawi not to be open about sexual issues and they could not collect condoms even if there was a perceived need. She felt it was attributed to age difference, cultural influences, fear of being judged to be promiscuous and general feelings of embarrassment.

"Most girls in Malawi tend to be sort of shy; you ask them about their sexual behaviour, do you need condoms? They remain quiet, so you just end the discussion; may be it could be due to age difference or else cultural influence." (Mrs Rwinu, Penina's service provider, 33)

"……..most girls don't tell us the truth about their sexual behaviours; we are not sure how much information to give them; don't we stimulating them to initiate sex with our condom distribution? As a provider am always careful not to be misinterpreted; giving her (Tanyada) condoms after making it clear that she is not sexually active, what is my expectation? It's like you want her to practice; it's a dilemma." (Mr Nandi, Tanyada's service provider, 37)

In the consultation room, the few young women who were asked by service providers whether they were in a sexual relationship never disclosed such relationships, but were open with the researcher and revealed their sexual experiences including number of partners, sexual encounters, and their challenges with condom/contraceptives use. (Interviewer's observation notes)

Reflecting on the service providers' accounts, it is clear that there are dilemmas in service provision, especially on whether to take young women's expressions on sexual behaviours at face value, or still to offer condoms in anticipation of the risk, which is somehow misinterpreted as an expectation or approval of sexual behaviour among the young women.

7.5.2 Cultural and religious beliefs influencing SRH experiences and services

The majority of young women cited several barriers to SRH services that were culturally and religiously related. The degree to which cultural and religious beliefs and attitudes influenced the young women's decisions about access to sexual and reproductive health (SRH) services, practising safer sex or engaging in sexual behaviours depended on the social support, economic pressures, self-image, and caregivers/service providers' beliefs. These included men disliking condoms, the importance placed on male relationships and child bearing; denial of HIV positive status; fear that suggesting condom use would elicit suspicion from one's partner and result in social rejection; and caregivers and service providers upholding strong cultural and religious beliefs or assuming parent-child relationships with the young women. Similarly, while young women were expected to conform to cultural and religious norms and expectations surrounding sexual relationships like abstinence until marriage to safe-guard their own or their families' reputations, some cultural and religious beliefs led them to engage in unsafe sexual activities. All these influenced young women's sexual decision making power, leading to negative outcomes.

"…..In our culture, parents are discouraged to talk about sex with their children; my mother or service providers did not talk with me about contraceptive use or sexual issues apart from being encouraged to collect condoms; though I looked young I engaged in sex." (Zaiwo, 19)

The impact of cultural and religious beliefs was reflected in the quality of SRH discussions conducted and services offered to young women. A culture of silence blinded the service providers, including the caregivers, to perceptions of sexual risks making young women vulnerable. For instance, Ziliwe, Nane, Penina, Ulemu, Mwatitha, Gonjetso, Fatsani, Alindine, and Tawina reported a lack of discussion on sexual issues with their parents/caregivers, including service providers. As such, they attributed their early sexual activities and child bearing to lack of relevant information from their caregivers and service providers which they felt could also be attributed to cultural influence. Ms Kando added that some young women complained of having challenges with storage of condoms at home and anticipating trouble if they were ever seen by their caregivers. Thus, unless caregivers understand the adolescence phase as a period of sexual experimentation, adolescents are unlikely to collect or consistently use condoms.

> *"Several adolescents have complained about lack of sexual discussions with parents or service providers and proper place of storing condoms in homes and feel that if seen keeping condoms, they can be sent away. I think caregivers need special sessions on adolescent sexual health to support adolescents' sexual well-being."* (Ms Kando, Nane's service provider, 39)

A few caregivers, (Mrs Botolo, Ms Ndengu, Mrs Zangawe and Mr Tambula) asserted that they had briefly discussed sexual issues with the young women. However, the majority (Mr Zaneni, Mrs Ndazi, Mrs Mbalume, Mrs Monali, Mr and Mrs Mipando) disclosed that culturally discussion on sexual issues with one's own child was disapproved. Instead, they delegated the responsibility to others like religious counsellors and grandmothers to discuss sexual issues with the young women. Furthermore, they emphasised the need for service providers to offer the young women detailed sexual discussions, including the risks.

> *"Could the service providers discuss with our girls the sexual issues including contraceptive use? We are limited with our culture, you just feel like, you are out of bounce; I feel now stopping her from indulging in sex is difficult and if she continues without any protection her life is in danger; I wish she knows the dangers of early sex."* (Mrs Ndazi, Fatsani's caregiver, 41)

However, Zaiwo, Fatsani, Tawina, Chitsanzo, Tamando and Dalo, felt that collecting condoms from the centre, keeping and bringing the condoms for the sexual act was the responsibility of their male counterparts.

> *"I thought the partners would bring the condoms for the act; is it not them that have to bring it? But they did not; and many preferred unprotected sex; though I wished I had protected sex, but I could not tell them. I collected condoms once and I gave them all to him (sexual partner). I feel as a boy is the right person to keep them."* (Tawina, 18)

The service providers (Ms Kando, Mr Mbalame, Mrs Tayenda, Ms Mbenu, Mr Zidelu and Mr Pamba) cited the widely held belief among young women, who proclaim that it is the males' responsibility to collect or bring condoms for the sexual act. As such, mostly condoms in the centres are collected by the male than female young people. Interestingly, the young women felt the female condoms were too big for them to use.

> *"They engage in unprotected sex, while we have both male and female condoms in stock; the females feel their male counterparts should collect condoms; the female condoms they think are too big for them, such that when you show them they laugh their lungs out."* (Mr Mbalame, Ulemu's service provider, 38)

Conversely, there was a belief that condoms are for those who are HIV positive and unfaithful to each other as sexual partners. This was a challenge for a number of young women (Tamando, Tawina, Chitsanzo, Dalo), as they could not negotiate for condom use with their sexual partners for fear of being deemed unfaithful or disclosing their positive HIV status. This further subjected them to risks of early child bearing and potential to transmitting the virus. Tamando also believed that since she was in early adolescence and had just initiated sexual contact, she could not be impregnated despite the risk of transmitting the virus. The association of condom use with unfaithfulness was also shown in Fatsani's experience with her third sexual partner. Her partner terminated the relationship when she collected condoms from the centre, possibly signifying the gravity of the issue.

> *"…I thought of collecting condoms from the centre, I left them at his (boyfriend) house, but when he found them he shouted at me asking where and why did I collect the condoms? He told me that he has been faithful to me, called me a prostitute and terminated the relationship? Is it that collecting condoms means you are unfaithful? Is it such a big blunder for a girl collecting condoms? I will never collect them again."* (Fatsani, 17)

Mr Menda (Tawina's caregiver) as a man aware of sexual behaviours in his (rural) area, emphasised the use of injectable contraceptives to prevent pregnancies among young women rather than condoms. This signified strong cultural value attached to unprotected sex for men in rural area.

> *"Use of injectable contraceptives among young women is a welcome idea if you are to prevent unwanted pregnancies in this area, where men hate condoms; let her have injectable contraceptives than condoms because chances are high to engage in plain sex."* (Mr Menda, Tawina's caregiver, 39)

The influence of culture was also reflected in the service providers' approach in offering SRH services, displaying judgemental attitudes on sexual issues and reluctance to offer contraceptives to young women, which is incongruent with the National Sexual and Reproductive Health policy.

> *"I think culture greatly influences our perception towards adolescents' access to SRH services. Sexual issues are very sensitive, adults including service providers do not freely discuss with them. Always I say to myself should I really give her (Alindine) condoms or not; I reluctantly offer condoms after asking lots of questions, this makes many not to collect condoms - our attitude..... even home I don't discuss sexual issues with my children, I just tell them avoid men they will infect or impregnate you, but not the 'how' aspect."* (Mrs Yinde, Alindine's service provider, 45)

There was strong view among the service providers (Mr Hanuya, Ms Kando, Mr Mbalame, Mrs Tayenda, Ms Benga, Mrs Khambi, Mr Pamba, Mr Zidelu and Mr Nandi) that sexual discussions between parents and their children are culturally disapproved of, and are regarded as obscene or taboo, despite being incorporated in the school

curriculum. Similarly, assuming parental roles towards young women, service providers felt culturally restrained to provide contraceptives to young women and often emphasised abstinence, turning a blind eye to young women's sexual well-being. They perceived that offering condoms was approving of sexual activities among the young women, which exposed most young women to unwanted pregnancies, re-infections and HIV transmission.

> *"As a mother, assuming a parental role, I feel very uncomfortable offering contraceptives to these girls; it is like encouraging them to do it (sex). Could they have benefited from school curriculum may be? Culturally one feels restrained to offer them contraceptives; you would wish they could abstain but many are becoming pregnant."* (Mr Khambi, Tamando's service provider, 53)

The male service providers (Mr Hanuya, Mr Mbalame, Mr Zidelu, Mr Pamba and Mr Nandi) indicated that culturally they were also challenged about discussing sexual issues in details with the young women for fear of being misinterpreted as advancing their sexual agendas. There was strong belief, particularly among the male service providers, who were single (Mr Zidelu and Mr Pamba), who felt it could risk their professional integrity.

> *"Though 'am a service provider, culturally being a man, it's challenging to discuss sexual issues, menstrual period with the girls; it requires the females to explain. These issues are sensitive, have cultural and social implications; fear of being suspected otherwise." (*Mr Zidelu, Fatsani's service provider, 26)

Nevertheless, some service providers (Mr Hanuya, Ms Kando, Ms Mbenu, Mr Mbalame and Mr Nandi) reported being controlled by their strong religious beliefs that those who are not married should abstain from sexual activities. They believed this could be one of the reasons for the providers' judgemental attitudes in the provision of SRH services to young people leading to young women's concealment of their sexual behaviours.

> *"Our religious belief, 'no sex till marriage' so you just feel like not doing the right thing offering contraceptives to adolescents. Our religious and cultural beliefs, it's like you are promoting prostitution. Even myself at the age of 39, though am an adult, but because am not married, people can easily associate presence of condoms in my house with prostitution. With this mentality, most providers are reluctant to offer condoms to adolescents….."* (Ms Kando, Nane's service provider, 39)

Ms Kando's account remarkably signifies how service providers reflect on their own cultural beliefs as they provide SRH services to young women.

While some young women feared pregnancy as they associated it with ill health, there was strong view that a number of young women (Ziliwe, Zaiwo, Chitsanzo, Tamando and Dalo) valued child bearing to maintain their sexual relationships and meet society's expectations, hence promoting their self-worth as young women and as a mark of their femininity. This was evidenced by their subsequent pregnancies and lack of compliance with service providers' and their caregivers' instructions on contraceptive use. For instance, after her first abortion, Chitsanzo was very grateful to God that He had made her life purposeful and her womanhood complete by giving her a second child thus promoting her self-worth as a young woman. In contrary, Mrs Mbalume felt that getting married and child bearing were very risky for Chitsanzo despite the need to be like any other young woman and to meet societal expectations.

> *"I told her that she made a mistake to have a baby because that may reduce her body immunity; but I know she desires to be like anyone else and do what is expected of her as a young woman in the society."* (Mrs Mbalume, Chitsanzo's caregiver, 28)

> *"I lost my first pregnancy but now am very excited that I have a baby, am married, am a mother despite my HIV status; others are unable to bear a child though happily married."* (Chitsanzo, 19)

Drawing from Chitsanzo's account, it seemed that she strongly valued child bearing as a married young woman. Culturally, there was strong connection between childbearing and a positive marital relationship. However, Mrs Mbalume indicated that culturally,

Chitsanzo's husband, apart from raising the child from the adopted pregnancy, would be longing to have his own biological child as a mark of his masculinity, which could expose Chitsanzo to ill-health with increased childbearing. Mrs Mbalume further indicated that there was a high risk for Chitsanzo to transmit the virus to her potential babies, as she never disclosed her status to negotiate condom use, hence her children would be an added burden upon her family.

> *"She appears excited being married; but her husband will not be interested just to have an adopted child, he will also ensure he has his own to show that he is man enough. There is little I can do about that but if she continues bearing children will that not have negative effect upon her health? How about the possibility of giving birth to an HIV child? Will that not be an extra burden?"* (Mrs Mbalume, Chitsanzo's caregiver, 28)

Similarly, the male sexual partners culturally valued child bearing as a mark of their masculinity. For instance, Mr Mwendo's (Tamando's husband) decision to have at least one child was to abide with cultural norms and to avoid any form of societal reproach of his family. This likely exposed Tamando to risks of poor reproductive health outcomes considering her age at child bearing (15 years) and the potential for transmitting the virus to her husband and the baby.

> *"……..my plans had been to have an HIV negative child and maintain my negative status. Thinking of the possibility that I can be HIV positive, I adopted another safe measure which may not be 100% safe, I went for circumcision in 2010 in order to have unprotected sex, so as to ensure that she gets pregnant then we continue using condoms. She conceived at the age of 15, the baby has been on artificial milk, am glad that his first HIV test came out negative."* (Mr Mwendo, Tamando's caregiver, 28)

However, there were conflicting views between the caregivers and service providers regarding child bearing in young women. The service providers Mr Malido, Mr Mbalame and Mrs Yinde shared their views with some of the young women on the need for them to align themselves with society expectations (having a child) if they were to be considered a woman or an adult or to avoid societal reproach. This was contrary to caregivers' views (Ms Ndengu's, Mrs Ndazi, Mrs Monali's, and Mrs Mbalume's) as the

latter were more concerned about young women's risk of passing on the virus to their potential babies. While the service providers were concerned with meeting societal expectations, the caregivers were concerned with the consequences of HIV positive status on child bearing and the anticipated increase in caring burden.

> *"Child bearing is in line with the expectations of this rural area, if she (Chitsanzo) is to be considered a grown-up has to have a child; otherwise she is still regarded as a girl."* (Mr Malido, Chitsanzo's service provider, 37)

> *".....when she (Alindine) gets married she should have at least one child……. Our culture without a child, you are scolded by people especially the husband's relations, you are not respected as the wife, and marriages get disrupted; my sister because she does not have a child for several years, her marriage is chaotic."* (Mrs Yinde, Alindine's service provider, 45)

Reflecting on Mr Malido's and Mrs Yinde's accounts it is interesting to note that service providers also associate womanhood with child bearing, and are more concerned about societal expectations. The ambivalences in cultural and religious beliefs among young women, caregivers and service providers are significantly linked to differences in their SRH priorities influencing young women's SRH outcomes.

7.5.3 "We need to be heard"

While sexual activity is a basic source of gratification, well-being and intimacy, and is important for overall health, it appears to be associated with emotional/interpersonal conflicts and situations that jeopardize young women's optimal health outcomes. Therefore, a number of young women (Ziliwe, Nane, Penina, Fatsani, Tawina, Chitsanzo, Zaiwo, and Dalo) expressed the need for individualised SRH discussions with service providers. They felt individualised SRH education would provide them with opportunities to express their concerns and ask questions on personal sexual issues for informed decision making, rather than the group discussions that are prevalent during teen club meetings. They perceived that being deprived of appropriate sexual education was exposing them to various dangers ranging from unsafe sexual practices to early child bearing.

> *"Before I became pregnant, the service providers or my sisters didn't discuss with me about sexual related issues. They need to hear my concerns; I needed information as an individual especially on other methods of contraceptives apart from condoms; if that had happened possibly my pregnancies could have been prevented."* (Chitsanzo, 19)

Ziliwe, Fatsani, Zaiwo, and Chitsanzo reported lacking an opportunity about decision making and choices regarding contraceptive use and they felt that jeopardised their SRH outcomes. They strongly perceived that only if they were heard and provided with other options of contraceptives without restrictions, their pregnancies could have been prevented. Ziliwe and Zaiwo perceived that lacking proper guidance on sexual issues exposed them to teenage pregnancies.

> *"….we are not given an opportunity to choose the method we want. In consultation rooms, we are just told to collect condoms in case we may need them without hearing what I wanted; they never checked whether I had problems with condom use or not? We were informed to ask our caregivers to come, if we were to access injectable contraceptives; how could I ask my aunt to approve my sexual behaviour? I could not; now I have a baby because I was not heard……"* (Ziliwe, 18)

Reflecting on Ziliwe's account, it is clear that she felt that her sexual being was not considered by her service providers. This was also reflected in Ms Benga's sentiments; they thought Zaiwo was too young for sexual discussion and only to be shocked with her pregnancy.

> *"…we thought she was still young….we were surprised to see her pregnant as early as age 14."* (Ms Benga, Zaiwo's service provider, 33)

A number of young women preferred younger professionals, who they perceived to be more friendly and understanding of their sexual issues than nurses who had been in contact with them since their childhood. This could be due to perceptions and companion-like rapport with people closer to their own age rather than the approaches by the service providers.

"Whenever I visited the centre, I was not open with them, the same nurses who have been here since I started getting treatment at age 10; looking at you as her own child; how could I tell her the truth about my sexual behaviour? We need the youth to talk the same language." (Tamando, 17)

Service providers believed that appropriate, effective and non-judgemental information could assist young women to balance sexual rights and responsibilities. However, Mr Hanuya, Ms Kando, Ms Mbenu, Mr Mbalame, Mrs Tayenda, Mr Pamba, Mr Malido and Mr Zidelu perceived that lack of child counselling and youth friendly skills led to service providers' judgemental attitudes towards the young women, thus inhibiting their sexual well-being by presenting a barrier to young women's access to SRH services and openness on sexual issues.

"……many of us lack child counselling and adolescent friendly skills, yet our adolescents are sexually active and need us to provide appropriate information on sexual issues rather than being judgemental. Lack of these skills makes many of us unfriendly to them; thus why they remain closed up." (Ms Tayenda, Mwatitha's service provider, 39)

On the other hand, a number of young women believed that being reviewed by specific service providers would assist in following up their personal and sexual issues. They perceived that being seen by several service providers at the centre became a challenge because there was always disruption to personal care, especially education and counselling whenever they had to meet different service providers. Ziliwe, Zaiwo, Chitsanzo, Tamando and Dalo perceived that this was even worse when they had to attend antenatal clinic in a different health facility where they felt like being lost to follow-up by their service providers who knew them better.

"Being seen by different service providers is challenging, every time you start with a new aspect, being asked the obvious things, which you were supposed to continue from where you stopped during last visit; and this becomes a bigger challenge when you are lost to antenatal clinic where you are a stranger in a strange environment; starting all over again, not even sure what to disclose and to reserve." (Dalo, 19)

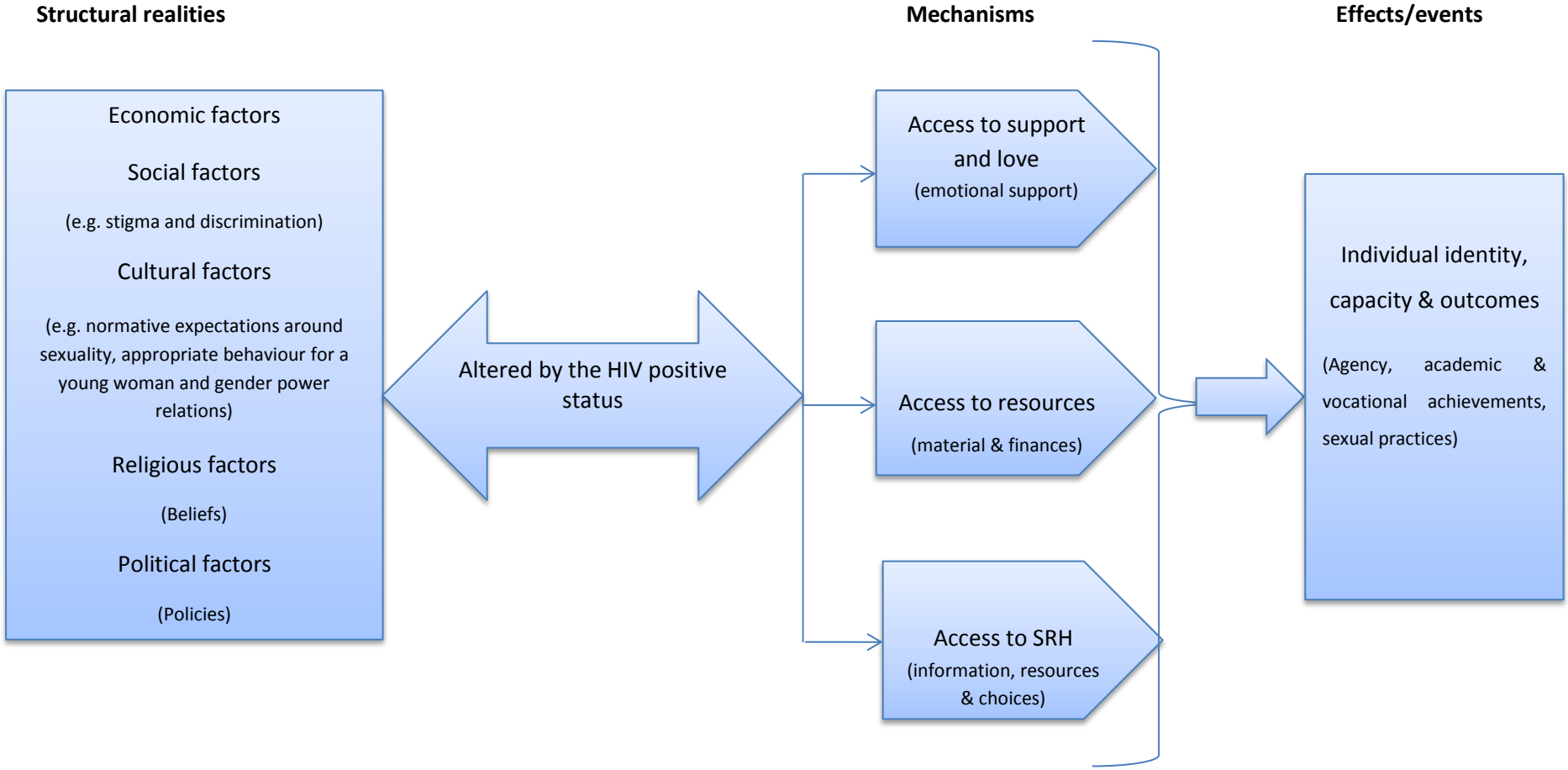
Service providers like Mr Hanuya, Mrs Rwinu, and Mrs Nganya highlighted that despite the increased workload, lack of continuity of care in the centres also contributed to young women's loss to follow-up.

> *"There is no continuity of care due the setup of our clinic. I have a number of adolescents that I see and it becomes easier in terms of quality of care I provide because I know them better. It is more challenging if we keep on transferring patients amongst providers because it's like you are starting all over again; I think with Penina there was no continuity of care and she got lost in the process till she came with suicidal ideas." (Mrs Rwinu, Penina's service provider, 33)*

In this section, it is clear that young women encounter socio-economic, moral and sexual challenges and would like to be heard and exercise their agency in making decisions and choices regarding SRH services.

Figure 7 illustrates the structural realities within the family, society and the health systems that influenced the young women's trajectory to womanhood, which was complicated by the HIV positive status. When the young women were able to access emotional support, love, resources (material and financial) and SRH information, and make significant SRH choices, they were able to build a positive identity, exercise their agency, achieve academic and vocational goals and adopt safer sexual practices. This in turn enabled the young women delay childbearing as demonstrated in Figure 7.

Figure 7 Structural realities in young women's trajectory to womanhood



7.6 Conclusion

This chapter has explored young women's representation of their sexual well-being and how their sexual needs are met. It is evident that perinatally HIV infected young women engage in sexual activities as they approach womanhood and they consider it as normal. However, their sexual being was more complicated with their HIV positive status leading to a complex social and moral terrain. It is clear that financial pressures, cultural and religious beliefs/expectations and service providers' attitudes towards their sexual well-being seemed to put young women in a dilemma as they approached womanhood. Yet, this is the time they need to make independent, critical and reliable decisions towards optimal SRH outcomes.

The young women's sexual behaviour was perceived by caregivers and service providers as posing danger to their health or well-being, especially when it was used as an economic strategy in order to conform with peers and to secure material advantages. Young women's strategies to seek love, acceptance or material advancement often led them into complex situations where they were taking sexual risks or had little control over their reproductive health. Accessing SRH care was hindered by normative cultural practices that made it hard for providers, caregivers or young women to talk about relationships, sexual behaviour or contraception. This exposed a number of young women to early child bearing and poor SRH outcomes. Young women desire integrated models of care, offering a 'one-stop shop' including continuity of care, practical/material support, expanded contraceptive services and support for those who become pregnant or have children.

CHAPTER EIGHT

DISCUSSION OF THE FINDINGS

8.1 Introduction

The findings of the current study suggest that the complexity of the social, cultural, economic and moral contexts diminishes young women's agency, decision making power and choices in sexual issues hence increasing their vulnerability to poor life prospects as reflected in Figure 7. Positive HIV status negatively impacted upon young women's sense of belonging and self-worth, with many of them enduring a sense of sadness that was rarely openly addressed. Their lives were full of tensions and complications, particularly around socio-economic realities and status, self-image, intimacy, identity choices, peer pressure, loss of physical attractiveness, gender power imbalances and social and cultural normative expectations. Young women's strategies to seek love, acceptance or material advancement often led them to take sexual risks and left them with little control over their reproductive health. Both the caregivers and service providers often 'turned a blind eye' to young women's sexual activities, leading to poor SRH outcomes. However, Figure 7 demonstrates how access to emotional support, affection, resources and SRH information and choices significantly enabled some of the young women to cope with their complex situations within the family and at community level and influenced their individual identity, capacity and SRH outcomes. This chapter therefore demonstrates that several factors shaped the young women's psychosocial and sexual experiences.

The chapter will discuss these key findings in conjunction with the relevant literature and will relate the main themes to the two overarching study objectives which are:

- To explore the psychosocial experiences and challenges of growing up with perinatally-acquired HIV for the young women
- To explore the sexual and reproductive experiences and SRH challenges for young women growing up with perinatally-acquired HIV and the impact of the current HIV related and SRH services

The chapter is therefore divided into two main sections. The first section discusses young women's psychosocial experiences of living with HIV. The key issues that influenced young women's psychosocial experiences included stigma and identity issues, cultural silence, coping capabilities and caregiving challenges. Adult support networks, early status disclosure, spiritual and religious practices emerged from the data as effective coping strategies among young women. The impact of the complex dynamic relationships between the young women and their caregivers on young women's psychosocial experiences is also illustrated. The feelings of being neglected or rejected by their caregivers for years and living with cultural silence made young women endure their long suffering on their own. However, lack of support networks and decisions about telling young women about their HIV status were fundamental struggles for caregivers that had considerable impacts upon young women's psychosocial experiences. These struggles affected the ways caregivers dealt with the practical psychosocial and economic issues affecting young women and are presented in light of the previous literature.

The second section focuses on the sexual and reproductive experiences and challenges for the young women as the main issues that emerged in the data. The researcher argues that the challenges regarding sex and relationships were influenced by three main issues: (i) socio-economic factors, (ii) gender and power relation factors, and service provision and service provider factors. This section particularly illustrates how cultural/religious issues create tensions and ambivalences in the health systems affecting young women's SRH decisions and ability to access care. In light of the findings of this study and in the context of the literature and current SRH policy, emphasis is placed on the roles of young women themselves, caregivers and health care systems in promoting agency[24] and empowerment[25] among the young women. This will counteract the negative impacts of stigma, social, cultural, and moral norms and gender power relations upon the young women, hence facilitating their healthy womanhood with optimal SRH outcomes.

[24]In this study, agency refers to young women's ability to reflect and act on issues affecting their lives including SRH related, make effective choices and transform the choices into desired outcomes (Alkire 2009).

[25] Empowerment defined as 'a social process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their lives' Gibson, 1991:355.

8.2 Psychosocial experiences and challenges in growing up with HIV

The discussion in this section illuminates the first study objective and focuses on the psychosocial experiences of the young women. Participants' accounts identified several key issues that influenced their psychosocial experiences, namely: building a positive identity, cultural silence, coping capabilities and caregiving challenges.

8.2.1 Building a positive identity

The findings of the current study show that young women strived to build a positive social identity for themselves upon finding out about their HIV positive status. The majority of the young women experienced low socio-economic status, physical limitations and loss of physical attractiveness, which they perceived resulted in them being viewed negatively by others in society, including their peers, particularly the males. Erikson (1977 :106) indicates that *"the process of identity formation depends on the interplay of what young persons at the end of childhood have come to mean to themselves and what they now appear to mean to those who become significant to them in the society."* For the young women in the current study, coming to terms with their HIV positive identity, in addition to feelings of looking different from their female counterparts and experiencing social rejection within society (including peers) was challenging to their social identity. As asserted by Coleman and Hendry (2002), identity formation among young people is often based on social comparisons. Hence, *"young people need to identify with others is an important factor in developing their growing sense of identity"* (Bohlin, 2005:16). Similar to previous work (Busza et al., 2013 , Obare and Van der Kwaak, 2010 , Birungi et al., 2009), young women in the current study desired to lead a normal life like their HIV negative counterparts in order to fit in their social groups. This typically had positive implications upon their self-worth and social identity. Close (2010) affirms that adolescence is the stage during which young people want to fit in, feel normal and exert their independence. Therefore, in deciding who to associate with for social support and identity, the young women were active agents, engaging in strategies which were both financially and socially empowering.

Identity formation is a fundamental aspect of psychosocial development during adolescence, and chronic illness like perinatal HIV exposes young people to the *"risk of developing a spoiled identity"* (Petersen et al., 2010:975). In the current study, young women's perceptions of looking different from their peers and being rejected by the society (including peers) emerged as key psychosocial challenges and often led to feelings of embarrassment. They described HIV infection as a 'shameful' disease since it is associated with immoral sexual behaviours which they believed was not a true reflection of their own behaviours. This triggered internalised stigma that negatively affected their feelings about self and association with peers, hence affecting their psychosocial well-being. Individuals living with HIV have long been associated with sexual promiscuity and immorality (Campbell et al., 2010 , Mbuno et al., 2009 , Bogart et al., 2008 , Parker and Aggleton, 2003). Kang et.al. (2008) found that young people find it difficult to cope with their HIV identity as they struggle to disassociate themselves from adults who acquire HIV through socially unacceptable behaviours such as risky sexual activities.

Ferreira et. al. argued that the challenges of accepting the HIV identity comprise a phase in the developing adolescent identity, in which the young woman does not recognise the HIV identity as part of the self (Ferreira et al., 2014). When a young woman does not adjust to illness identity, she may manifest emotion-centred coping strategies which may result in display of problem-centred coping associated with negative consequences on her physical and mental well-being (LeBlanc et al., 2003). In contrast, when the young woman accepts her HIV identity, that allows her to set goals for her future (Hosek et al., 2002).

Like the young people in Greifinger et al.'s (2008) study, young women in the current study perceived that they were treated differently to their HIV negative peers, rejected and marginalised - leading to reduced sense of belonging to families, peers and society and loss of their personal and social identity. Several young women recounted instances of stigma such as name calling and experiencing discriminatory behaviours from caregivers, community members and service providers. According to Campbell et al. (Campbell et al., 2010), name calling among HIV infected young people disrupts their self-image. These findings though supported by several previous studies conducted in Malawi (Muheriwa et al., 2013 , Njunga, 2008 , Muula and Mfutso-Bengo, 2005), HIV-

related stigma still remains highly pervasive despite the government efforts to mitigate this.

The psychosocial impact of stigma on young women was a significant finding in the current study affecting their personal and social identity. The social and physical changes the young women encountered constituted the complex milestones for them to pass through. Several studies reported that young women who are not satisfied or feel embarrassed with their physical appearance are less likely to assert themselves sexually, including negotiating for safer sex with a sexual partner or exerting their ability to make healthy sexual relationships (Rohleder, 2010 , Gillen et al., 2006). Physical appearance is the main factor influencing the experiences of young women's sexuality and sexual identity (Schooler et al., 2008). Females typically become more concerned with their appearance than their male counterparts, as they strive to develop an identity. While a recent study (Bale and Archer, 2013) has revealed that facial attractiveness is associated with more positive friendship, professional and familial relationships in women, previous studies found that any visible disease in young women is more likely to elicit depression and stigmatization from peers (Impett et al., 2006, Tolman et al., 2006). The current study has extended these findings and added a new insight that the stigma related to the change in physical appearance (body image changes) amongst young women more commonly stems from the perceptions of their female counterparts. They seemed to uphold masculine dominance in evaluating or targeting feminine physical outlook for sexual advances, which signified how the young women based their self-worth and physical attractiveness from others (particularly men) on their appearance. This placed the marginalised young women at risk of forming unhealthy male relationships in which they were sexually abused as they strived to form their social identity. Similarly, a study in Kenya found that a significantly higher proportion of HIV infected female adolescents than their male counterparts experience physical and sexual abuse as they associate with males for social status (Obare and Van der Kwaak, 2010).

Young women's capability to build an identity which was lost to HIV infection was dependent on several factors, including adult support networks and the perception of self in the current study. The findings have revealed that adult support networks and positive self-image were associated with a sense of belonging to the family, peers and

society (regaining their identity). Similarly, a loss of adult support networks and negative self-image was associated with limited capabilities to exercise their agency or lost opportunities for young women to advance academically and in a career. This made many young women more vulnerable to sexual activities in exchange of financial and material gains in order to promote their social identity. These strategies increased young women's already marginalised and subordinate status in the society (UNAIDS, 2008).

It is important to note that not all young women in the current study experienced HIV infection as a threat to their social identity. Several young women engaged in various compensatory behaviours such as small-scale businesses and/or engaging in sexual activities for financial and material gains to boost their social status hence social identity. Nevertheless, some of these strategies posed risks to their well-being, as reflected in Section 7.3.1. By adopting compensatory strategies and limiting their interactions to those with whom they felt loved and accepted, they attempted to preserve their normalcy. This signifies that young women do have the agency and capability to autonomously deal with their social challenges, limits and demands in their everyday lives.

8.2.2 Living with cultural silence

The current study has shown that within most families and health services, young women's thoughts and feelings about their positive HIV status, living with a stigmatised disease, disruptions in family structures and sexual relationships are not addressed, with the result that they endure their suffering alone. This was epitomised by young women's expression of suicidal ideas or attempts, and unspoken grief when they were given an opportunity to share their lived experiences with the researcher. A number of young women were heartbroken as they explained about their traumatic experiences of feeling neglected or rejected for years after being diagnosed HIV, or loss of their parents, antagonistic relationships with their caregivers (especially step-mothers), and lack of a safe place following physical and sexual abuse. The young women felt they endured this long suffering on their own. They silently felt the absence of adult support in their lives, particularly the caregivers/service providers, as they endured the hidden

pain and tragedy of the disease, whilst looking for subsistence to meet their basic needs.

It has been argued that culture in Africa is often used as an excuse for silence surrounding discussions of sensitive topics like sex, illness and death with young people (Daniel et al., 2007 , Daniel, 2005). Culturally people believe that death is too traumatic and often difficult for young people to cope with. In the current study, it could be that cultural silence made young women endure the suffering on their own, as death and sexual issues are not commonly discussed with children in many Malawian cultures (Watkins and Swidler, 2009). Cultural silence in the current study refers to cultural taboos against discussing with young people about sex or death (Daniel et al., 2007). Such beliefs and fears limited young women's opportunities for talking about bereavement and sexual issues, and hindered them from dealing with their intense feelings and challenges. Some young women in the current study also described ruminating ('thinking too much') about their multiple losses as having negative impact upon their academic endeavours and association with peers, especially those who they perceived to be attractive, with parents that were providing for all their basic needs. They felt they were easily identified as looking different from others. The current study shows that young women's inability to communicate intense feelings, hidden pains and experiences is evident in that their voices remained unheard or misinterpreted.

The current study has shown that silence prevailed in the lives of the young women. However, it was not only the young women who practiced silence when coping with their challenging situations. The culture of silence was also reflected in decision to disclose the HIV status and their sexual relationships (as discussed in Section 8.3.1.1). The study also demonstrated how caregivers and service providers turned a blind eye to young women's sexual activities in exchange for financial gains and in some cases there was a collective collusion to maintain face or a family's reputation, as discussed in Section 8.3. It is apparent that lack of knowledge about young people's sufferings left many caregivers, even service providers, struggling to deal with the practical psychosocial, economic and sexual issues affecting the young women, leading to poor mental health and SRH outcomes.

8.2.3 Coping capabilities

Young women's daily lived realities were complicated by the intersections of mental health problems, oppression (e.g. low socio-economic status, gender power relations), identity choices and normative expectations. However, early status disclosure, strong support networks, on-going counselling, spiritual experiences and religious practices emerged as key factors that assisted young women in coping with their difficult situations. Some young women found narrating their hidden agony to the researcher itself to be therapeutic. However, young people vary greatly in the way they cope with their difficult situations. In the current study, while some young women coped positively with their positive status, others coped negatively, affecting their psychosocial well-being.

Young women who had early status disclosure together with their families/caregivers demonstrated that early disclosure of HIV holds the promise of the young women gaining sense of normalcy about HIV early, taking control of their situations and its on-going exigencies as they develop into womanhood. This finding substantiates prior qualitative work (Hazra et al., 2010), which found that early status disclosure is particularly important for young people as it facilitates positive coping, allowing them to participate in their care. The study further showed that early status disclosure reduces the likelihood of unprotected sex. In the current study, early status disclosure was significantly linked to young women's psychological well-being. However, the findings contradict the results of a prior study (Hazra et al., 2010) in that early status disclosure was not found to reduce the likelihood of unsafe sex in the current study, as there were no apparent differences in sexual behaviours between those who had early and late disclosure. Nevertheless, when the young women became aware of their positive status they followed their caregivers' lead in concealment for fear of social rejection and to maintain their social supportive networks in which they felt loved, accepted and assisted to cope with their difficult situations.

In the current study, having strong family relationships, adolescent–caregiver/service provider supportive and trustworthy relationships and peer support groups (teen clubs), enabled some young women to remain positive about their status. Strong family support networks, strong relationships with peers and significant others were

instrumental in the broader aspects of young women's lives. This includes reducing young women's vulnerability to sexual activities in exchange for financial and material support, hence providing them with opportunities to focus on academic and vocational achievements. The social capital (strong support of caregivers, service providers, peers or teachers) and the enabling environment (opportunity to make decisions) facilitated young women's coping capabilities in various ways. For example, social capital and the opportunity to make choices enabled some young women to achieve their self-determined goals or adopt alternative strategies to maintain their self-worth. Success in academic progression and vocational achievements were identified as realistic sources of feelings of self-worth and promoted a strong sense of personal self-efficacy. This increased young women's capability to exercise agency and hence positively coping with their positive HIV status, as discussed in Sections 6.2.1 and 8.2.3. Strong family social support or more extensive supportive networks were particularly associated with better coping with HIV (see Panel 1). Battle and Wiener (2002) suggested that parental presence, social support and early status disclosure can help buffer some of the painful experiences endured by perinatally HIV infected young people.

It evident that there is a close relationship between social support and health outcomes in general (Kempf et al., 2010 , Brion and Menke, 2008). The happiness, value and security found in peer groups has been documented among adults with HIV and young people living with other chronic conditions (Johnston et al., 2012 , Gately et al., 2007 , Koch et al., 2004). Coping with HIV among young people is poorly documented (Miller, 2008). In the current study, peer support groups were found to boost young women's psychosocial well-being and self-worth as they shared their status and experiences. They believed that peer groups instilled social inclusion, value for life and sense of belonging to peers where young women were otherwise socially marginalised and isolated. Young women were also able to access social support and shed a potential social cost specifically discrimination, because of the shared status with their peer group. Previous qualitative studies have also exemplified that individuals who are motivated, have greater morale, or who are less depressed cope better with their chronic illness and may be better at self-management (Spitze and Ward, 2000 , Clark et al., 1997).

Many informants in this study noted that provision of psychosocial support (including on-going counselling) was key to assisting young women to cope positively with their HIV positive status. However, the process of counselling young people is very challenging and different from that of adults (Ministry of Health, 2007). It was not surprising therefore that all participants in the current study were unable to precisely describe the type of counselling that was provided to the young women, although they frequently used the term. However, it was clear that the counselling available was reactive to situations like disclosure of status, drug non-adherence and/or any deviant behaviour (as reported by the caregivers), rather than planned and proactive individual counselling about sexual and relationship issues. Although the young women felt that counselling helped them to cope with their positive status, they felt they could have benefited from proactive on-going individual counselling sessions to help them cope with other issues that were affecting their lives. Chirawu et al. (2010) suggested that counselling for young people should be focused on reducing risky behaviours. Young people should be informed of the risks in order to alter or stop their risky behaviours thus preventing negative coping with their positive status. However, the current study suggest that proactive counselling would need to deal with multiple forms of loss including many other significant issues affecting young women's lives, such as adolescent-caregiver relationships, setting overarching goals of becoming self-reliant, mediating gender power relations to reduce vulnerability through the promotion of young women's agency and decision making power, and choices in sexual issues.

The role of property rights in poverty reduction and economic development, through their impact on distribution of wealth and patterns of production, has been emphasized in the economic literature (Besley and Ghatak, 2009 , Field, 2007 , Banerjee et al., 2002). Roy (2011) suggests that economic opportunities and expanding women's rights can foster women's ability to exercise agency and become resilient. Some of the cases in the current study support these assertions. The cases demonstrated the positive impact of strong support networks and the use of opportunities and resources made available to young women in achieving resilience. In the current study, resilience refers to young women's ability to bounce back from tough times, or capacity to overcome their challenges or adversity (Ungar, 2004). Resilience involved young women's personal responsibility, self-discipline, positive relationships, self-confidence and self-image. For

instance, some young women tried not to allow their low socio-economic status to hamper their potential to achieve their goals in life. Setting themselves overarching goals of becoming self-reliant or caregivers of their younger siblings in a meaningful way enabled several young women to become goal-oriented and to focus on their studies. One young woman who attributed her delayed academic progression to a lack of school fees engaged in a small-scale business to raise funds for her basic survival needs, including the school fees. Being resilient and financially self-reliant gave her the capacity to advance with her education without interruptions and gave her a position of power to desist being vulnerable to her uncle's sexual harassments, as she was partially supporting the family with her finances. She indicated that she was even able to buy for herself well-fitting outfits that completely changed her outlook as a young woman. Thus, it changed her perception of her negative body image (big breasts and abdomen following intake of ARVs) with the result that she attached more value to her life. The life experiences of the young women who coped positively reveal the extent to which young women exercised agency in their lives to overcome the identity problems resulting from their positive HIV status.

On the other hand, Alkire (2009) argues that women's agency is shaped by social norms and beliefs regarding gender roles and institutional structures. Social and cultural norms determine women's opportunities in society and whether they can exercise the choices to use them. Although the young women in the current study were challenged with the social and cultural norms associated with positive HIV status, some were able to reflect and act upon the issues that affected their lives including sexual relationships, and make informed and effective decisions resulting in desired outcomes like academic and vocational achievements. For example, some young women built and used strategic relationships to achieve their academic and vocational goals. Adult support networks and positive self-image promoted their capabilities to adopt safe sexual behaviours, set and achieve their academic and vocational goals and resist peer pressure. Despite their delayed academic progression, they accepted their status quo, chose not to involve themselves in sexual activities and instead they engaged in, and became involved with, meaningful learning activities until they achieved their academic and vocational goals. The support of others directly influenced sexual behaviour choices by meeting the young women's survival needs, providing an enabling environment which provided

them with opportunities to make significant decisions and to cope positively with their status. The strong support networks and provision of required resources improved their emotional well-being and quality of life (see Panels 1 and 2).

Although spiritual and religious practices are significant to most young people in Malawi and other parts of Africa (Watt, 2009 , Cotton et al., 2005 , Smith, 2005), in the international literature both have received less attention as potential resilience factors for coping with HIV infection compared to social support (Roberts, 2003). As the diagnosis of positive HIV status has a profound impact on all facets of the young person's life including spiritual life, some young women in the current study used spiritual experiences and religious practices as a source of support. Prayers and meditation assisted some young women and their caregivers to cope with stresses associated with the positive HIV status. Previous studies also found similar results (Li et al., 2010 , Bernstein et al., 2009). Adolescents in Bernstein's study wanted their healthcare providers to openly raise religious and spiritual matters with them during at least some visits. From this perspective, it could be appropriate for the service providers to consider asking young women's spiritual/religious beliefs and reflect on how this could be incorporated or assist in meeting the young women's spiritual needs.

It is clear in the current study that several young women who felt unattractive due to lipodystrophy, skin conditions (e.g. verruca vulgaris) or abdomen and breasts getting bigger were additionally hurt by social isolation. As such, they avoided social interactions with female peers as they were the targets of teasing behaviours causing emotional distress. Feeling rejected, being of low socio-economic status, bearing visible marks of HIV infection and/or experiencing less success in academic functioning made the young women feel insecure in themselves. Hence, they reduced their reliance on female support networks, as they felt different from other females. It could therefore be argued that the young women perceived that they no longer fit in with their social groups, particularly with female peers, which threatened their identity as young women. Almost all the affected young women with changed physical appearance felt more marginalised by fellow females and perceived themselves as being more accepted and loved by their male counterparts, leading to more interactions with the males than females. This presented risks for the young women's sexual health as they sought acceptance, support and personal security in relationships with males. On the other

hand, this could reflect on the societal values which emphasise that the ideal qualities of a young woman are physical attractiveness and personal accomplishment, yet they collide with the reality of HIV infection.

The current study has provided insight that young women's desire to form an attachment and establish relationships with male partners outweighed the need to protect themselves or others, as discussed in Section 8.3.1.1. Though not as a single factor, the findings clearly show that male relationships boost young women's self-image, mitigating their negative feelings due to changes in their physical appearance that undermine their perceptions of femininity. Several studies have found that anatomical changes caused by HIV infection exacerbates feelings of depression and negative self-image (Aka Dago-Akribi and Cacou Adjoua, 2004). This is particularly intense among women who make every effort to monitor their bodies to look attractive to their male counterparts, hence promoting their self-worth and social identity (Impett et al., 2006 , Tolman et al., 2006 , Aka Dago-Akribi and Cacou Adjoua, 2004). This could also signify the close link that exists between young women's self-image[26], and sexual agency. Sexual agency in the current study refers to young women's ability to reflect and act on sexual issues affecting their lives, including SRH related issues such as making active, informed, effective, responsible sexual decisions and transforming choices into optimal SRH outcomes (Impett et al., 2006). Self-image is defined as how a young woman perceives herself, her characteristics and abilities and generally how she evaluates herself (Health Canada, 1994). The body image can change as a result of HIV infection or intake of ARVs, leading to diminished self-image and sexual agency. Therefore, it is essential to consider self-image as the constituent of the comprehensive sex education to promote young women's agency in sexual issues.

8.2.4 How caregiving influenced young women's psychosocial experiences

This section discusses two key issues that affected the kind of care that young women received from their caregivers and thus had a major impact on their psychosocial experiences: (i) lack of support networks, and (ii) decision about telling young women about their HIV status. The majority of caregivers reported chronic financial and food insecurity, which is closely linked to poverty and deteriorating socio-economic status.

[26] Both body image and self-esteem contribute to a broader self-image.

Prior studies (Daniel and Thamuku, 2007 , Hosegood et al., 2007 , Stover et al., 2007 , Howard et al., 2006 , Miller et al., 2006), affirm that the majority of carers of people living with HIV are challenged by food insecurity and financial difficulties. The current study builds on the findings of previous studies (Punpanich et al., 2012 , Evans and Becker, 2009 , Chimwaza and Watkins, 2004 , Steinberg et al., 2002). However, the majority of these prior studies concentrated on household poverty as accounted by caregivers of people living with HIV. The current study focused on exploring caregivers' views in order to understand young women's experiences rather than many studies which have sought to understand the problems encountered by caregivers themselves.

8.2.4.1 Lack of social support networks

The findings suggest that the majority of caregivers have difficulties themselves which in turn influenced the care and support they were able to provide to the young women. Most caregivers were women and were dependent on their male partners or others for support, as found elsewhere in Africa (Chimwaza and Watkins, 2004 , Young and Ansell, 2003 , Steinberg et al., 2002). In contrast to the aforementioned studies which found that the majority of the caregivers were elderly women or grandmothers, in the current study the majority of the caregivers were young themselves, with all parents involved being HIV infected (see Table 3). Thus the young caregivers were overstretched with caring responsibilities, lived in poverty and all experienced emotional distress in their caregiving. This limited their power in making decisions affecting the young women as they themselves needed support. A recent study has shown that the cost, time and emotional burden of HIV infection seems to take a toll on caregivers, leaving them with little or no means of protecting themselves (Punpanich et al., 2012). The physical and emotional burdens of caring for HIV infected young people can exacerbate caregivers' socio-economic and psychological conditions, hence affecting their caring capacity and perceptions of the young people's behaviours (Punpanich et al., 2012). While caregivers in the current study were concerned about increased caring responsibilities, HIV-related stigma significantly shaped the way in which their care was enacted. This compelled the majority of them to prioritise the maintenance of secrecy surrounding the HIV infection over meeting young person's caring needs. In turn, it deprived the young women of the support they desperately needed. A life of secrecy and silence around the HIV status was reported to be very distressing, promoting social exclusion and feelings of

bitterness among the young women in the current study. Similar findings were reported in a study conducted in Ethiopia (Biadgilign et al., 2011).

The societal expectation that women are the prime or only caregivers for their infected family members (Evans and Becker, 2009) created a disproportionate social and economic burden on females in the current study. The majority of caregivers acknowledged that their inability to provide for the young women's needs increased the women's vulnerability to risky sexual activities. In other studies conducted in Africa, lack of social support has been associated with poor quality of life, higher perception of stigma and poor mental health among young people (Evans and Becker, 2009, Hosegood et al., 2007). However, it is evident that there is a greater socio-economic impact of HIV infection upon women (Shacham, 2008 , UNAIDS and WHO, 2002). The wider literature acknowledges that women suffer from a disproportionate lack of support due to HIV/AIDS (de Souza, 2010 , Shacham, 2008 , de Bruyn, 2000). The findings of the current study particularly support these assertions as many female caregivers lacked support and depended on their male partners or others specifically relations for financial support. Therefore, this research presents a new insight into psychosocial experiences of the young women and their caregivers. Some young women felt the need to identify alternative means of survival, often resulting in seeking financial security through sex in order to alleviate the financial and material burden on their mothers/caregivers. In this context, the caregivers lost control of the young women's sexual behaviour.

The majority of the young women engaged in sexual activities for financial gains and to secure financial support for their families. However, the majority of the young women could not disclose their sources of additional income to their parents/caregivers, and their caregivers did not ask them. In cases where some sexual partners provided financial and material support to the families, the parents/caregivers also turned a blind eye to consequences of such male relationships for the young women. Hence, in some cases, there was a collective collusion and silence to maintain face or the family's reputation.

Gender was further found to be a key element in determining how parents share caring responsibilities for an HIV infected child. For instance, in the current study, Fatsani's father separated with Mrs Ndazi (his third wife), to marry a fourth wife at the time Mrs Ndazi was looking after Fatsani, who was then critically ill in the hospital. This deprived the young woman of the paternal love and support she desperately needed contributing to severe depression. Mrs Ndazi as a sole caregiver also felt vulnerable to marginalisation, with limited access to the social and financial support she desperately needed as a female parent. The current study demonstrates that caregiving coupled with low socio-economic status and lack of support can overpower the caregivers' stamina, productivity and economic security, and can lead to conflict and psychological distress among young women. Whilst the findings of the current study were in line with previous studies (Kuo and Operario, 2009 , Van Blerk and Ansell, 2007), which found that men rarely share domestic responsibilities and care of the family with their partners, there was new insight into experiences of the caregivers, by showing how their own experiences strongly shape the care that they can subsequently provide to the young women who they look after.

Interestingly, culturally in Malawi, sharing and talking about problems is a typical social norm, getting involved and being concerned with other people's issues is how people connect and support each other. In the current study, almost all caregivers demonstrated fears of facing negative reactions from society as they made every effort to conceal the young women's positive status. While some caregivers expressed feelings of shame when living with young women whose physical appearance had changed due HIV infection, a number of caregivers whose HIV positive status was publicly known reported being socially marginalised. All these situations hindered caregivers' access to social support, which they desperately needed. Although the caregivers' stressful life events and their related coping strategies were not the specific focus of the current study, participating in this study offered them an opportunity to express their views and experiences of caregiving, hence having their voices or concerns heard. As shown by previous studies (Chimwaza and Watkins, 2004 , Young and Ansell, 2003 , Steinberg et al., 2002), caregivers encounter a crowd of psychosocial and economic burdens on daily basis. Hence, provision of problem-centred coping strategies, stress management techniques, ideal social support networks, and access to

basic resources can be beneficial to many caregivers. This in turn would positively impact on the quality of care they could provide to young women hence promoting optimal psychosocial well-being and SRH outcomes.

8.2.4.2 Decision to disclose the positive HIV status to young women

Several social barriers to HIV disclosure to young women were reported by caregivers in the current study. The caregivers, particularly biological parents, were challenged and reluctant to tell the young women about their diagnosis. They were afraid of disclosing their own status, were unsure how to communicate such information or felt unskilled in dealing with disclosure. Some caregivers thought the young women would not keep the status a secret. A study on HIV diagnosis disclosure in South Africa found similar challenges (Mahloko and Madiba, 2012). As highlighted in prior studies (Biadgilign et al., 2011 , Rujumba et al., 2010 , Vaz et al., 2010 , Rwemisisi et al., 2008), caregivers in the current study felt they had to first deal with their personal fears in anticipation of young women's questions about how they got infected. Giving detailed explanations of their sexual behaviour in an attempt to explain the nature of the disease to their own children was also perceived as problematic, especially for biological caregivers. In this context, they had to deal with feelings of guilt for not protecting their children from the HIV infection or they were restricted by cultural barriers of not discussing sexual issues with their own children (Watkins and Swidler, 2009). Domek (2010) argued that the anticipated negative consequences related to status disclosure are very real for most caregivers and they may delay or prevent them informing their children. The current study supports this argument and exposes caregivers' personal insecurity, concerns about stigma, social rejection and attempts to protect themselves clouded the disclosure process to a greater extent. However, uniquely, this study is able to show how this delayed disclosure was associated with poor coping among the young women. For instance, some of the young women who had delayed status disclosure expressed suicidal ideas or attempts following accidental disclosure.

In the African context, HIV disclosure is regarded as a highly gendered phenomenon, shaped by socially constructed roles and expectations for women and men (Lynch et al., 2010 , Ragnarsson et al., 2010 , Visser et al., 2008). Several studies (Deribe et al., 2009 , Medley et al., 2004 , Black and Miles, 2002) show that men and women vary in reasons,

contexts and targets of HIV disclosure. While women more often fear loss of financial support and marital status, and gende based violence, men more often are concerned about being deemed unfaithful, hence undermining their social-worth (Deribe et al., 2009 , Medley et al., 2004 , Black and Miles, 2002). Similarly, in the current study, some female caregivers' concealment of young women's status was extended to their spouses. The majority of female caregivers felt side-lined in decision making regarding issues affecting the young women, and as such they felt that disclosing young women's status would jeopardise their care, causing psychological distress for the young women. This clearly reflects the masculine dominance in decision making in issues regarding care provision in foster families.

Almost all female biological caregivers in the current study felt blamed and responsible for passing on the virus to their daughters. This diminished their capability to inform their daughters about their HIV status. They described HIV infection as a 'disgraceful disease' and their secrecy of the young women's positive status was rooted in their feelings of shame and parental guilt of passing the virus on to them. Duffy (2005) attributes the secrecy surrounding HIV to feelings of shame rooted in the culture of blame, specifically for breaching morality – which is often ascribed to women (LeClerc-Madlala, 2001). This adds to women's already marginalised and subordinate social status. Although the caregivers wanted to play the main role in status disclosure to their adolescents, all biological caregivers reported feeling incapable of doing so. It has been reported elsewhere that gender disparities trigger women's greater vulnerability to effects of stigma and unwillingness to disclose illness (Medley et al., 2004).

The current study provides the new insight that female biological caregivers delayed status disclosure or were unable to disclose the HIV status to young women because they felt paralysed by their male partners' reactions of neglect or blaming them as sources of the infection. Interestingly, this was the general feeling even among non-biological female caregivers, who had adopted the parental role for the young women. These findings further provide an insight that HIV responsibility is placed on women, possibly as a strategy employed by the males to defend their dominant masculinity hence safeguarding their social-worth and status. From this perspective, it can be argued that the underlying causes of caregivers' feelings of shame are attributed to morality and cultural norms that enforce gender power relations, as the source of

blame-related stigma in situations where HIV infection is linked to immoral and preventable behaviours (Sandelowski and Barroso, 2003). It is clear that HIV-related stigma and their accompanying feelings of loss of control affect both the young women and their caregivers, particularly female biological caregivers.

Participants in the current study acknowledged that a life of secrecy deprived young women of potential social networks, optimal relationships and mental health support for positive living. Similar findings were found in prior studies (Vaz et al., 2010 , Smith et al., 2008 , Moodley et al., 2006). However, the current study uncovers that the attitudes, values and actions of other community members compelled the caregivers to keep young women's status a secret. This necessitates the need for service providers to support caregivers with disclosure, so that their adolescents are informed of their status shortly after diagnosis to promote their psychosocial well-being. Support from health care providers does not imply making the caregivers less responsible for disclosure; almost all caregivers in the current study stated that they would like to participate in decision making about when the young woman should be informed of the diagnosis. They felt that service providers had the relevant training and skills to assist with the process of disclosure and could offer appropriate interventions to support the young person. These findings are in contrast to results of previous studies conducted in Congo, India and Thailand in which only half of the caregivers reported that they would like to be responsible for HIV disclosure to their children (Biadgilign et al., 2011 , Vaz et al., 2010 , Oberdorfer et al., 2006). However, based on the findings from the previous studies and from the current study, it is significant to consider personal, familial, social and medical contexts (i.e. characteristics of the caregivers and young women such as age, coping abilities, style of communication within the family and access to relevant supportive services) when deciding the most appropriate person and time to disclose status to young women.

The current study has added new insights into psychosocial experiences among young women, which are not only influenced by personal but also familial, contextual and cultural issues. Cultural normative expectations and gender roles seemed to influence young women's psychological experiences in different contexts. However, the discussion on psychological experiences also shows how caregivers' lack of social support influenced young women's sexual behaviours – this will now be considered in

the section below that focuses on health, sex and relationships challenges with perinatally-acquired HIV.

8.3 Sexual and reproductive health experiences and challenges

The section discusses the findings that respond to the second objective of exploring the health, sex and relationship challenges of growing up with perinatally-acquired HIV for the young women. Interestingly, even though the study intended to explore young women's health issues from a broad and holistic perspectives, the key health issues that emerged in participants' accounts, concerned SRH (rather than other health issues). The findings show that socio-economic factors, service provision and service providers are key in shaping young women's sexual experiences and these factors will be the main focus of this section. Gender and power relation issues continue to be reflected in this section as the overarching theme across the participants' accounts.

8.3.1 Sex, relationship and health challenges for young women

Several studies have shown that perinatally HIV infected young people engage in sexual activities for pleasure and financial gains (Busza et al., 2013 , Hodgson et al., 2012 , Li et al., 2010). The current study provides a new insight that young women engage in sexual activities to seek love and acceptance, for procreation to meet societal expectations, or as a mark of their femininity, hence promoting their self-worth. As highlighted in Section 8.2.3, it is clear that the majority of young women (after the loss of adult support networks), constructed a new self-concept by discovering new actions and relationships including sexual partnerships in which they felt loved, accepted and supported, hence boosting their self-image. Male relationships were reported to boost their self-worth as young women following multiple losses and social exclusion. In line with this finding, this study has found several factors as key to influencing young women's sexual agency and decisions. The key factors that emerged from participants' accounts included: socio-economic status, access to SRH services and cultural and societal expectations that influenced service providers' attitudes towards young women's sexuality.

8.3.1.1 Socio-economic factors versus gender and power issues

Young women's low socio-economic status was associated with early sexual debut and multiple partnerships leading to unwanted pregnancies for which most sexual partners refused the caring responsibilities. This added a new blow to young women's self-worth and increased their vulnerability. Some of the cases provided clear examples highlighting how low socio-economic status aggravated young women's struggles to earn a living and to exercise autonomy exposing them to risks of early marriages and unwanted pregnancies (see Panels 3, 4 and 5). In this context, sexual activities were employed as an economic strategy for modernity or idealised lifestyle, or as means of survival hence increasing their vulnerability. This section builds on prior studies that show how women's subordinate social position may leave them with little power or agency to prioritize their health over meeting their survival needs (Kuo and Operario, 2009, Van Blerk and Ansell, 2007).

The majority of young women in the current study, who had limited adult support networks, struggled to earn a living, and they resorted to using sexual partnerships for financial gain and survival. In this context, instead of being self-reliant or resilient they had limited capability to exercise agency. Thus, they tended to succumb to their male partners' sexual decisions; most of the partners were older and married men. This increased the likelihood for the young women to submit to unsafe practices such as unprotected sex as a surety against abandonment and to maintain their sources of financial support. The male relationships and economic dependence on men diminished young women's autonomy on sexual issues as it gave their older partners positions of power and control in sexual encounters. These findings illustrate that young women's inferior socio-economic status, lack of bargaining power in sexual relationships coupled with gender power inequality (in terms of experience, authority, and control over sexual activity) affected their ability to take informed decisions particularly on safer sex and contraception (Masanjala, 2007 , United Nations Development Fund for Women, 2001). A growing body of qualitative studies has shown similar findings that due to poverty, many women including girls engage in sexual relationships as means of survival (Evans and Becker, 2009 , Hosegood et al., 2007 , Tawfik and Cottas Watkins, 2007). However, this becomes complicated in the context of HIV positive status, in which tension exists between the young women's sexual needs and the economic and social

realities/expectations and HIV prevention issues. Hence, protecting themselves and others became less likely and this increased their vulnerability even when they had access to appropriate information.

Furthermore, many young women in the current study struggled with condom use with their sexual partners, which led to unplanned pregnancies. The common reasons cited by young women about partners' refusal of condom use included desire to have children as a mark of masculinity, beliefs that condoms reduce sexual excitement ('sweetness') and a perception that condoms are for those who are HIV positive and unfaithful to each other. Previous studies in Malawi (Muheriwa et al., 2013 , Woodsong and Alleman, 2008 , Chimbiri, 2007) found similar findings. In these situations, many young women were unable to disclose their positive HIV status or negotiate condom use with their older partners. This was because the older partners dominated them in terms of both age and gender, thus they had less decision making power. Instead, they engaged in unprotected sex as they could not negotiate for condom use for fear of being deemed unfaithful and of their HIV status becoming known. The findings regarding young women's struggles with condom use contradict those of Chimbiri (2007) in Malawi which proposed that there is considerable talk about condom use, especially among men, in the context of preventing infection in extramarital partnerships rather than within marriage. The current study provides an insight into complexity of developing programmes that offer realistic risk reduction strategies for the prevention of unwanted pregnancies in the context of low socio-economic status including secondary prevention. In addition, more qualitative research on men's experiences in sexual relationships with young women who are HIV infected would enable a greater understanding of interpersonal dynamics of sexual risk reduction.

In the current study, since young women's interest in male relationships was for companionship, economic benefits and social status, refusing sex or proposing condom use or disclose their HIV status would have jeopardised their goals for the relationship. Consequently, almost all sexually active young women chose to keep their status a secret to sexual partners, to maintain their source of financial support and hence social status. While status disclosure to a sexual partner can encourage adoption of protective measures (Kadowa and Nuwaha, 2009), two young women in the current study encountered termination of their sexual relationships upon disclosure of their positive

status to their sexual partners. This greatly affected their sexual identity because their physical attractiveness and self worth as young women (which was lost to HIV) was attributed to having a sexual partner. Similarly, a prior study in Malawi revealed that women are more likely to get divorced after disclosing their HIV positive status, though the male partners' status remains unknown (Reniers, 2008). In contrast, findings of a study in Kenya (Obare and Van der Kwaak, 2010), revealed that a significantly higher proportion of female young people had talked to their sexual partners about their own HIV status and knew the partner's status. This could signify cultural and gender power differences that exist in different countries regarding gender sexual norms/roles. Nevertheless, these findings provide the insight that, in sexual relationships, the male partners place the responsibility of the positive HIV status upon their female partners, as evidenced by termination of the relationships by the former.

This study has also provided another new insight regarding differences in perceptions between the young women and their caregivers regarding status disclosure to sexual partners. Kalichman (2000) asserts that older adolescents internalise the HIV-related stigma and perceive a risk (real or foreseen) associated with status disclosure to peers including sexual partners, which adversely affects their sexual practices. In the current study, almost all caregivers, whose young women were sexually active, raised concerns about the lack of status disclosure to young women's sexual partners. While young women's prime concern was loss of their relationships and source of support following status disclosure, caregivers were more concerned with protecting their own families from a bad reputation, social isolation and legal repercussions if male partners discovered the young women's HIV status on their own. Caregivers' concern and pressuring young women to disclose their status to male partners than vice versa, uncovers lack of attribution of responsibility to men but rather placing the HIV responsibility upon women.

The termination of sexual relationships by male partners upon status disclosure reveals the influence of gender sexual roles/norms and the sexual power imbalances that exist in sexual relationships. This signified that the male partners placed the responsibility of HIV positive status on their female partners as they had the capacity to terminate the relationships before having their blood tested. These gender power imbalances gave the male partners power to make decisions regarding their sexual affairs without

necessarily negotiating with their female partners or reflecting on their own HIV status. The findings of other empirical studies concur with these findings that the effects of life-long illnesses, especially HIV infection and visible diseases, on sexual identity are greater for females than for males (Pinquart, 2012). This is because the females often base their self-worth on physical appearance and approval of others, including males (Harter, 1999). In other words, this significantly denotes that young women with positive self-image can become less threatened by the decisions of others such as sexual partners and still feel better about themselves or maintain a positive self-perceptions (Ferreira et al., 2014), adopting constructive coping strategies.

The current study has also discovered that cultural and societal expectations restricted young women's abilities to adopt protective behaviours. The behaviours included seeking sexual information, accessing and utilizing SRH services, talking about sex and negotiating for condom use with their partners, and rejecting coerced sex. As indicated by Jewkes (2010), young women's vulnerability was partly attributed to cultural and social norms, which shape family and societal views of femininity and masculinity. This ultimately gave their male sexual partners position of power in sexual encounters. They succumbed to familial, peer and social pressures to conform to risky sexual behaviours in order to avoid social rejection. The majority of young women who engaged in sex for financial gains prioritised the social costs of adopting preventive behaviours over the repercussions of not negotiating for condom use on their health. For instance, the young women were more conscious about societal and male approval than consequences of male relationships upon their health like unwanted pregnancies. Some valued child bearing as a mark of womanhood/femininity or to maintain sexual relationships, or meet societal expectations, hence promoting their self-worth. These findings therefore suggest that interventions to promote adoption of protective behaviours must take into consideration the socio-economic context of the young women's lives, meanings attached to sex in their society, and gender power relations in intimate relationships, familial and social milieus. The involvement of young men, adult women and men in the interventions is also crucial in order to counteract gender specific needs of both females and males as well as to promote gender equality and equity. As alluded to by Hulton et al. (2000), programmes that protect young women's

SRH, improve their social standing and help them gain resources that are not reliant on their sexuality can promote their ability to exercise agency and autonomy.

The majority of young women were challenged with low socio-economic status, cultural and social norms and lack of protective methods that they can control, which significantly limits their power to exercise agency. Previous studies have recognised the importance of economic deprivation as fuelling initiation of sex and formation of sexual relationships. The current study provides an insight into the specific mechanisms and dimensions of these sexual relationships in the context of HIV. As suggested by Bakeera-Kitaka et al. (2008), to reconcile survival, status disclosure and sexual agency demands a need to address the undesirable consequences of sexual activities. These findings confirm the need for policies and programmes that recognise the achievements of young women and challenge gender norms to provide equal opportunities for both young women and men to have their voices counted in society and designing of programmes. Healthcare services need to equally acknowledge young women's capabilities to exercise agency, facilitate their ability to make strategic life choices and greater access to SRH information and care (including partner disclosure) to promote optimal SRH outcomes, as reflected in the next section.

8.3.1.2 Service provision and service providers

This section discusses the challenges identified at health system level as shaping young women's health seeking behaviours (particularly related to SRH services) and the ways in which their health decisions were made. Key findings that emerged about service provision included: (i) model of service provision, (ii) nature of relationships with service providers, (iii) content/focus of the services, (iv) young women's need to be heard by the service providers, and (v) the need for integrated services for young women to effectively utilize the SRH services. The section further contextualizes the sexual experiences and links the young women's health-related practices to the broader cultural and social contexts.

8.3.1.2.1 Model of service provision

From the findings of the current study, it could be argued that although the young women are aware of the risk reduction strategies, their priorities are not in line with the service providers' adult-led priorities. This study has discovered that in the HIV centres, the HIV management services are predominantly organised around paediatric and adult care rather than adolescent care. This posed a barrier to young women accessing the services they need. Furthermore, a number of young women in the current study perceived that most decisions about their sexual health were being made by service providers and/or caregivers. The top-down strategies implemented in the centres are contrary to the recent literature that emphasises the positive role of empowering young people (Ansell, 2014 , Spencer, 2013). The recent literature advocates participatory approaches or bottom-up strategies, informed by young people's own concerns, values and priorities, thus increasing feelings of value and sense of control in young women. Laverack (2005) asserts that young people become more active in their healthcare and comply with guidelines through their own sense of worth rather than from a simple transfer of information. This is critical in the promotion of greater access to SRH services among young women.

The current study provides new insight about the ambivalences that exist in service provision. These significantly compromised young women's healthcare seeking behaviours, particularly regarding the use of contraceptives, as evidenced by subsequent pregnancies and non-compliance to service providers' instructions. For example, the young women desired injectable contraceptives to prevent pregnancies in anticipation of struggles with condom use with their partners. However, service providers were reluctant to condone injectable contraceptives they were concerned with adverse physical and social side effects, particularly delayed fertility, bleeding and reinforcement of cultural, social and religious beliefs/morals. Interestingly, the service providers reported being mindful that once the young women got married they would be expected to have children to avoid societal reproach. In contrast, young women acted in accordance with their own needs and priorities as evidenced by incidences of pregnancies in the centres to which the service providers turned a blind eye.

The findings show that young women's challenges to comply with guidelines were embedded in interrelated structural constraints such as socio-economic, gender and power inequalities, as discussed in Chapter Seven. To a greater extent their dependence on their male partners for survival, and dominant construction of masculinity and femininity limited their power to demand for their SRH rights like consistent use of condoms, as they prioritised gratifying the demands of their sexual partners. The most practical healthy decisions were overshadowed by these socio-economic, cultural and structural constraints. Thus, young women's decisions against bringing their partners to the health facility for status disclosure and using condoms were influenced by the broader social contexts (including gender power inequalities and nature of relationship with the service providers).

8.3.1.2.2 Nature of relationships with service providers

A common concern amongst the young women in this study was the 'parent-child' relationship that they had with service providers. Assuming parental roles towards young women, service providers correspondingly felt culturally restrained from providing contraceptives to young women and often emphasised abstinence. This prevented the majority of young women from being open about sexual issues with the service providers for fear of being discovered to be sexually active and due to feelings of embarrassment. This is contrary to the National SRH and Rights Policy, which emphasises young people's access to SRH services that provide respect and informed consent (Ministry of Health, 2009). This implies that the HIV management services are not effectively prepared to deal with the young women's complex SRH issues (WHO and UNICEF, 2008).

The current study draws attention to the fact that the young women's lives were full of tensions and complications particularly around socio-economic realities and status, self-image, identity choices, sexual relationships and gender power imbalances which require adolescent services. From this perspective, the service providers are in a distinctive position to acknowledge and embrace the complexity of young women's lives and its consequences on their sexual health. The young women stated that individualised attention could assist service providers to understand their concerns and challenges to effectively empower them with appropriate information and skills. Service

providers need to facilitate the delivery of risk reduction programmes targeted at empowering young women to acquire appropriate SRH information, decision making and negotiation power and skills on sexual issues, including access to SRH services.

Interestingly, while young women were concerned about parent-child relationships with the service providers, simultaneously they desired supportive and trustworthy relationships with the service providers in which they would easily access SRH information and services. In the current study, the challenge has been that a close relationship also hindered close communication about sexual issues. While the literature is silent on the specific components that make up these important patient-provider relationships, the current study suggests that a safe and supportive environment, youthful professionals, child counselling and adolescent friendly skills are essential in understanding and embracing sexual issues dominating young women's lives. This further provided an insight that strong, trustworthy, supportive adolescent–service provider relationships developed when service providers were able to spend ample time to effectively deal with the young women's issues without judgemental attitudes. This is consistent with WHO's (WHO, 2012 :37) standards for adolescent-friendly services which stipulates that, "adolescents may find it difficult to communicate, be shy or frightened, and may need extra time and encouragement to talk about their real concerns and service providers need adequate time to deal with their adolescents in an effective manner." The current study suggests the need for service providers to understand the significance of their relationships with the young women and to constantly reflect on their attitudes towards the young women's sexuality to promote optimal SRH outcomes. However, further research is required to explore how these supportive adolescent-provider relationships can be maintained over time as the young women adapt successfully to living with HIV, self-manage their challenges of living with positive HIV status and get discharged to adult care or develop into womanhood.

While there is strong link between adolescent-friendly health services and substantial increase in use of the services by adolescents (Ferguson, 2010), young women in the current study perceived that SRH services were not appealing.

8.3.1.2.3 Content/focus of service provision

All young women who participated in this study from the urban setting attended support groups (teen clubs). These groups aimed to provide HIV education from a health protection perspective. These included promoting risk reduction strategies like abstinence, being faithful and condom use (ABC), information on contraceptive use, assisting with HIV status disclosure and negotiation skills. However, the majority of young women who were sexually active did not adopt the protective measures such as consistent condom use and disclosure of HIV status to their sexual partners. This suggests that these strategies are not always realistic or practical or are beyond the control of the young women. Thus, the young women would be empowered to employ the strategies only if the young women themselves saw the strategies as being a feasible way of promoting their optimal SRH outcomes. For instance, the current study provides insight that abstinence and condom use in relationships, whereby young women were financially dependent on sexual partners or where prevailing gender power relations rendered autonomy difficult for them. Several studies found similar challenges in Africa among both the HIV positive and negative young women (Bakeera-Kitaka et al., 2008 , Poulin, 2007). This is critical because it is apparent that despite being advised to abstain from sexual activity or use condoms, young women still engage in unprotected sex as evidenced by their unwanted pregnancies. There is a gap between having knowledge about the risk reduction strategies and their practical application (including contraceptive advice and condom use), which needs to be further researched and addressed within the health systems.

In the current study, almost all service providers indicated that they also place emphasis on the significance of HIV status disclosure, particularly to sexual partners, but receive resistance from the young women about this. This could signify young women's increasing autonomy (Spencer, 2013), as they actively engaged in practices recognized as risky by the service providers despite being aware of the health risks presented to them. Despite giving young women several options to bring their partners to the centre for counselling and HIV testing, none took up this opportunity. Whilst evidence supports that risk-taking is a characteristic of normal adolescent development (Coleman, 2010), the common reasons given by the young women for not complying with the guidance included the desire not to be seen as sexually active by the service providers, who have

been providing care to some of them since they were young, and service providers' judgemental attitudes. As reported elsewhere (WHO, 2012), this study confirms that judgemental, inconsiderate or unfriendly behaviours of service providers ultimately hinder mutual communication and access to SRH services for the young people. In the current study, service providers' attitudes suppressed young women's ability to make decisions on their SRH needs and may have made them resist the imposed interventions. This is contrary to the National SRH and Rights Policy, which advocates age-appropriate services that address gender equality, empowerment, rights and responsibilities, negotiations and decision making skills in sexual and reproductive issues (Ministry of Health, 2009).

The current study shows that the young women's greatest need was for the service providers to take time to hear and address their complex practical issues, and provide them with an opportunity to access the services of their preference. They felt that planned and proactive on-going individual counselling sessions on many other issues affecting their lives could be beneficial. In addition, this study has shown that preconception counselling and parenting information were not offered in the centres, despite a number of young women becoming pregnant. This deficit in health provision could be culturally influenced or because the focus of the programs/clubs was to discourage teenage pregnancies. As pointed out by Brion et al. (2012), answering all patients' concerns helps to facilitate empowerment, trust and overall acceptance of diagnosis and remedies. From this perspective, it could be argued that, overwhelmed with gender power imbalances, familial and socio-economic pressures, the young women wanted concrete and appropriate answers to their basic questions about survival strategies and safe sexual practices in individual context. The current study has provided a new insight that young women strongly felt that their personal and sensitive questions or needs could not be answered or addressed through group discussions during teen club meetings. Some of the universal SRH strategies employed in the centres like offering condoms to every adolescent, and holding group discussions are not appropriate for meeting individual needs of young women.

From these findings, it is clear that to some extent, failure on the service providers' part to create an atmosphere in which the young women could be heard as individuals, express their individual concerns, observations, expectations, limitations, participate in

decision making and have their opinions respected, fuelled poor SRH outcomes. It can further be argued that appropriate SRH decisions and strategies depend on input from both the service providers and young women themselves. This enhances young women's perceptions of being valued, respected thus promoting their self-worth and compliance. Therefore to understand and address the young women's complex sexual, social and moral terrain, there is need for mutual participation that evenly divides power between the service providers and the young women so that both are satisfied with the decisions made for optimal SRH outcomes. The young women presented a strong desire to have their concerns and views about their SRH needs heard which can ultimately assist in designing appropriate and realistic programs.

8.3.1.2.4 The need to be heard

In the current study, the quality of adolescent–service provider/caregiver relationships like in other studies (Brion et al., 2012 , Ncama et al., 2008) was identified as a significant factor impacting on young women's coping ability, self-confidence and self-management. The findings have further shown that healthy, supportive relationships promote optimism and an orientation towards the future; including identifying oneself as a partner in making healthcare decisions within a supportive, adolescent-focused relationship. Some cases, such as Ulemu, Gonjetso, Alindine and Tanyada show that the collaborative, positive, adolescent-centred, adolescent-provider relationships enabled young women to voice their concerns and confidently played an active role in making significant decisions affecting their lives. However, the majority of the service providers and parents/caregivers seemed unprepared, unmotivated and uninterested to find out about young women's sexual desires, choices and challenges. This section builds on WHO's recommendations for adolescent-friendly services and the National SRH and Rights Policy (WHO, 2012 , Ministry of Health, 2009).

In their description of the quality of SRH services they accessed, the young women in the current study pointed out that in some centres access was restricted and they were put through difficult processes. For example, they had to obtain consent from caregivers if they wanted to access injectable contraceptives. Condoms were offered to every adolescent without choice. Furthermore, they were challenged by the judgemental attitudes of service providers or their difficult questions which they

attributed to their cultural or religious beliefs/norms reinforcing abstinence. With this kind of approach (i.e. imposing the services on the young women), some young women asserted their autonomy in negative health behaviours, as evidenced by their reluctance to comply with the service providers' instructions and increased incidences of pregnancies. These findings clearly shows that service providers turned a blind eye to young women's sexual activities in order to maintain their own cultural and religious beliefs, as discussed in Section 7.5.2. Pilkington (2007) asserts that engaging in behaviours defined as risky may be evidence of the young women's resistance to the authority of adults and service providers, and thus a normal function of adolescent development (increasing their own control and autonomy) expressed in negative health behaviours. It is clear that the service providers downplayed young women's power to act according to their own understanding of sexual health, which is often different to the top-down imposed meanings (Spencer, 2013). As such, despite the adults' dominant perspectives, young women framed their own strategies as an effective way to promote their sexual health and self-worth or which were in line with their needs, priorities, preferences and values.

However, the service providers cited several reasons to justify their provision of SRH services to young women. On a practical level, they felt challenged by an increased workload due to the shortage of professional staff. Additionally, they acknowledged their reluctance to hold detailed sexual discussions with the young women and offer them particularly injectable contraceptives. They attributed this to their lack of skills in youth-friendly health services and navigating cultural and religious beliefs. Sexual issues involved matters of great cultural sensitivity and the providers felt that they could be perceived as promoting premarital sex if they engaged in discussions with young women about such subjects.

Chirwa and Kudzala's (2001) study in Malawi also found that the service providers were refusing to provide SRH services to young people due to religious reasons. Similarly, a study about nurse-midwives attitudes towards adolescent SRH needs in Kenya and Zambia revealed that 96% of nurse-midwives disagreed that adolescents should be permitted to gratify their sexual needs, which was rooted in their culture and religion (Warenius et al., 2006). While service providers could be an alternative source of sex and SRH information, their cultural and religious beliefs influenced their role in SRH

promotion in the current study. Instead, they promoted cultural norms (abstinence), particularly when the SRH strategies were against their cultural and religious beliefs, which is contrary to the National SRH and Rights Policy.

It is significant that the current study focused not only on the way in which dominant cultural and religious beliefs placed young peoples' sexual health at risk, but also on how the beliefs influenced service provision with young women resisting service providers' values. Young women in the current study, despite receiving appropriate SRH knowledge, still engaged in unprotected sex, risking unwanted pregnancies and HIV transmission. The common reasons cited by young women for not complying with SRH information and accessing the SRH services from the centres included parent-child relationship, which culturally made it difficult for them to open up on sexual issues and disapproves of contraceptive use among unmarried young people. This could indicate that young women's sexual needs and concerns were not being prioritised in the provision of SRH services (Laverack, 2005).

8.3.1.2.5 The need for integrated services

The current study suggests that young women desire a 'one-stop shop' kind of service that integrates HIV care, SRH and antenatal services. Currently, young women who become pregnant disappear or are discharged from teen club and are seen at antenatal clinic in different health facilities, where they access services along with adult clients. This further exposed the young women to dominant and oppressive power relations with older women as they shared the antenatal services under the same roof. They reported being insulted by older women for being pregnant at an early age and they felt out of place as the clinic is dominated by older, married women. In this context, young women believed that it is important that antenatal services are integrated in HIV management strategy to reduce social reproach and have their own support group for young mothers to share experiences and challenges. They also believed that if they were reviewed by service providers who are more aware of their needs, they could understand their social, moral and sexual terrains, hence enabling them to open up on their pressing sexual issues and freely access SRH services to prevent unwanted pregnancies.

As found in a previous study (Chirwa and Kudzala, 2001), the current study shows that cultural norms act as social control mechanism on young people's behaviours in many societies in order to discourage them from becoming sexually active. Although the providers' technical competence and positive attitudes are part of the national youth-friendly health services (YFHS) and are crucial in effectively attracting young people to use SRH services (National Youth Council of Malawi and UNFPA, 2010), in the current study, the majority of the service providers were not yet trained in YFHS (see Table 6). As such, it could be argued that the definitions and perceptions of quality SRH services between the two groups (the providers and the users) greatly differed. The current study has highlighted that while the young women have a need to exercise their SRH rights, control their sexual health and choose SRH services they needed, the majority of service providers emphasise abstinence and condom use. Service providers' own moral codes were more informed by their cultural, religious and social norms than by their professional training and obligations. The implications of these differences include lack of service satisfaction by the young women, ultimately leading to limited uptake of the appropriate SRH services and consequently poor SRH outcomes. This clearly means that the quality of services on its own cannot guarantee adoption of safe sexual practices by young women because some social, cultural and religious norms upheld by service providers still deny their SRH rights.

8.4 Conclusion

This study has shown that several factors (including social and cultural normative expectations) shape young women's psychosocial and sexual experiences and challenges. Building a positive identity, cultural silence, coping capabilities and caregiving challenges were key issues that influenced young women's psychosocial experiences. Upon finding about their positive HIV status, young women endured sadness due to cultural silences. They strived to fit in their social groups leading them into complex situations where they had little control over their sexual and reproductive health as they sought love and acceptance. Lack of support networks and ambiguity about telling young women about their HIV status were two key challenges that affected the kind of care that young women received from their caregivers. These had a major impact on young women's psychosocial experiences and sexual behaviours.

Socio-economic factors, model of service provision and service providers shaped young women's sexual experiences. Both caregivers and service providers turned a blind eye to young women's sexual activities. Young women's greatest need was to be heard and for the service providers to address their complex practical issues. However, some service providers upheld cultural and religious norms, making it hard for them to talk about relationships, sexual behaviours with the young women or offer them contraceptives. This signifies that the service providers are still falling short in tackling young women's sexual needs, let alone empowering them with the necessary information to enable them to balance rights and responsibilities, and to make informed decisions about their sexual health and contribute to their quality of SRH well-being. This is incongruent with the National SRH and Rights Policy in Malawi, which advocates contraceptive use for everyone aged 15 years and above (Ministry of Health, 2009). These findings have critical policy and practice implications for SRH services for young women who acquire HIV perinatally, as discussed in the final chapter.

CHAPTER NINE

CONCLUSION

9.1 Introduction

This final chapter summarises the study's key findings and interpretations to show its key contributions to knowledge in the field of HIV adolescent health. The implications of the findings for programme development, service provision and future research are described. This chapter is divided into three sections. The first section focuses on the key contributions to knowledge within the two overarching focus areas of the current study – the psychosocial and SRH experiences and challenges of growing up with HIV. The second section outlines the implications of the findings. The final section outlines the study's strengths and weaknesses.

The aim of this study was to determine the meaning of the experiences of growing up with perinatally-acquired HIV for young women aged 15-19 in Malawian context. The study aimed to explore the complexities of young women's lives from the perspectives of young women, their caregivers and service providers. The study further sought to examine young women's challenges in order to understand their health outcomes within the wider socio-cultural and structural context that shaped their experiences and options.

The study addressed the following research objectives:

To explore the psychosocial, sexual and reproductive experiences of growing up with perinatally-acquired HIV for the young women

- To determine the structural factors, perceptions, values and aspirations influencing the young women's experiences as they grow up with HIV to adulthood.

To explore the health, sex and relationship challenges for young women growing up with perinatally-acquired HIV and the impact of the current HIV related and SRH services

- To identify the psychosocial and SRH challenges of the young women as they are growing up to adulthood.
- To identify the issues and challenges encountered by caregivers as they look after the young women growing up with HIV.
- To identify the issues and challenges encountered by service providers as they provide health care to the young women growing up with HIV.
- To assess the impact of the existing health services on the needs of the young women as they grow up to adulthood.
- To identify the most important and realistic strategies in meeting needs of perinatally HIV infected young women as they grow up to adulthood in Malawi.

This study employed a case study approach. Individual in-depth interviews were the method of data collection. Forty-two initial semi-structured interviews were conducted with the three categories of the participants – young women, their caregivers and service providers. Three interviews for each 'case' comprising of a young woman (15-19 years), a nominated primary caregiver and a service provider making fourteen interviews per each category of participants. Ten follow up interviews were conducted with some of the participants regarding issues arising from initial interviews that required clarifications, but were not as structured or detailed as the initial interviews. A repeat interview was conducted with a caregiver (a sister to Ulemu), who became distressed as she was narrating about the nature of relationship with their aunt. 'My story' books which comprised of researcher-generated images depicting different life experiences and events and sentence completion exercise were used to facilitate interviews with the young women as they explained their experiences and needs basing on the chosen images. 'My story' book gave young women more control over the representation of their lived realities, thereby addressing unequal power relations between the researcher and the researched. The book allowed young women to communicate not only key events but also contexts, values and challenges as they explained the experiences in reference to the chosen images.

Since young women are considered persons with diminished autonomy, they are vulnerable to coercion or undue influence, thus the researcher ensured that their participation in the study was informative and non-coercive. Information sheets and consent forms were used in recruitment of the participants. Confidentiality, anonymity and respect for privacy were considered paramount as on-going issues at every stage from data collection to the write up of this thesis, especially in view of the stigma and secrecy surrounding HIV. Retroductive analysis was undertaken to penetrate to a deeper level of social reality by discovering the real mechanisms or structures that led to young women's experiences (Easton 2010). Within-cases and cross-cases analyses were undertaken to produce more contextually grounded, transferable findings. A focus on individual accounts within each 'case' was important to be able to view each case individually within its own context and remain true to the case study approach (Stake, 2006), as reflected in Chapter Four. Cross-case analysis was undertaken to examine how systematically themes and sub-themes (issues) cut across all the cases to identify similarities, differences, relationships and contradictions across the fourteen cases, then cross-case conclusions were drawn, as reflected in Chapters Five, Six and Seven.

9.2 Summary of key study contributions

This section summarises the key contributions to knowledge within the two main focus areas of the current study. The first area was concerned with the psychosocial experiences of young women and how they coped with their complex situations. The second area was on health, sex and relationship experiences and challenges, and how the existing health services impact on young women's experiences.

9.2.1 Psychosocial experiences and challenges in growing up with HIV

- Key contribution 1: Young women endure hidden pain and long suffering on their own, as a result of cultural silence.

The current study provides a new insight that most young women endured the hidden pain, long sufferings and the tragedy of the disease on their own, which was attributed to cultural silence. Cultural beliefs about discussing death and sexual issues (including contraception) with children in many Malawian cultures limited young women's chance of discussing and dealing with their intense feelings and challenges with the caregivers

and service providers. This was exemplified by young women's expression of unspoken grief as they explained their traumatic experiences of feeling neglected and abused for years.

- Key contribution 2: Loss of physical attractiveness generates negative attention from female peers, leading to marginalised and stigmatised experiences.

Almost all young women with visible marks of HIV infection that affected their physical appearance felt more marginalised among their female peers compared to their male counterparts, thus affecting their social identity. The study further adds that social rejection linked to changes in physical appearance was more prevalent from their female counterparts. This could be attributed to social values on ideal qualities and physical appearance for a woman, which collide with the reality of HIV infection. Hence, this presented risks for their sexual health as they sought love, acceptance and personal security in male relationships.

- Key contribution 3: Young women have agency to deal with their difficult situations.

The current study provides a new insight that these young women are active agents in their difficult situations as they build and use strategic relationships, particularly sexual relationships, as an economic strategy to boost their self-image and secure their livelihood. This signifies that young women have the agency and capacity to deal with their social challenges, limits and demands that make up their everyday lives.

- Key contribution 4: There are several factors within the family and health system that may promote resilience, agency and psychological well-being among the young women.

The current study identified that collaborative, positive, adolescent-centred, adolescent-service provider relationships, social capital (strong support networks with caregivers, peers or teachers – emotionally and financially), religious beliefs and access to SRH information and choices are key in promoting young women's resilience, agency and psychological well-being. These factors improved the young women's capacity to achieve their academic and vocational goals and resist peer pressure, thereby reducing their exposure to sexual risks. The literature is silent on the specific components that

make up the significant patient-provider relationships, suggesting that more research is required in this area. The current study further adds that safe and supportive environment, youthful professionals, child counselling and adolescent friendly skills are essential in understanding and embracing the social, moral and sexual issues dominating young women's lives hence effectively meeting their needs.

- ❖ Key contribution 5: Most caregivers need emotional and financial support themselves.

Living with the positive HIV status is challenging for both the young people and their caregivers (Punpanich et al. 2012). The current study provides insight that caregiving coupled with younger age, low socio-economic status, social rejection and personal insecurity overpowered the caregivers' will to care, productivity and economic security. Hence, it diminished the coping abilities for both the young women and their caregivers. Caregivers' inability to provide for the young women's needs increased young women's vulnerability. This clearly shows that most caregivers need support themselves.

9.2.2 Sexual and reproductive health experiences and challenges

- ❖ Key contribution 6: Young women engage in sexual relationships to seek love and acceptance, and to boost their self-image.

Prior studies show that perinatally HIV infected young people engage in sexual activities for pleasure and financial gains (Busza et al 2013, Hodgson et al. 2012, Li et al. 2010, Obare and Van der Kwaak 2010). The current study has extended these findings showing that young women also engaged in sexual relationships to seek love and acceptance and to boost their self-image. The HIV positive status and the visible marks of HIV infection elicited stigmatization by peers and the society, hence affecting young women's social status and identity. As such, they engaged in male relationships for companionship and/or as an economic strategy in attempt to boost their social status and self-worth as young women following the social rejections and loss of parental affection and support.

- ❖ Key contribution 7: The complexity of young women's lives, particularly around socio-economic realities and status, sexual relationships, gender power relations and normative social expectations, diminished their agency, decision making power and choices on sexual issues.

The current study has shown that multiple losses (including the loss of adult support) implied loss of belonging, limited or lost opportunities for young women to secure finances and advance academically. This diminished young women's self-image. Since this made them feel different from their female peers (in terms of socio-economic status and physical attractiveness), they attempted to regain that sense of belonging and sought love and acceptance through sexually attaching themselves to male partners. They also relied on men for material and financial support to boost their social status. However, they encountered gender power inequalities in these male relationships which limited their sexual agency (including bargaining power) and choices in sexual issues. This, coupled with cultural normative expectations, gives male partners a position of power concerning sexual issues and a correspondingly diminished ability among young women to make decisions about safer sex practices. As a result, despite young women having access to appropriate information, it became very challenging to adopt protective measures, to which they were already averse due to their longing for status through sexual relationships.

- ❖ Key contribution 8: Turning a blind eye to young women's sexual activities is a common response by both caregivers and service providers.

The current study has shown how caregivers and service providers turn a blind eye to young women's sexual activities. Both caregivers and service providers complied with their own cultural and religious beliefs, which hindered mutual communication on sexual issues with the young women. Service providers acknowledged that their reluctance was rooted in their lack of skills in youth-friendly health services and cultural and religious beliefs that reinforce abstinence. Most caregivers turned a blind eye to young women's sexual activities in exchange for financial or material gains for they were unable to provide for the young women's needs. In this context, most of them were unable to control young women's risky sexual behaviours, or it could also be a collective collusion to maintain face or a family's reputation.

- ❖ Key contribution 9: Ambivalences in priorities, values, preferences and perceptions affect young women's compliance to adult guidance and access to SRH services.

Prior studies found that status disclosure to a sexual partner can encourage adoption of protective measures (Obare and Van der Kwaak 2010, Birungi et al. 2009, Kadowa and Nuwaha 2009). However, the current study provides a new insight that the attitudes, beliefs and actions of the others, dependence on the male partners for support and cultural and social normative expectations (gender inequalities) compelled young women to keep their status a secret. Despite caregivers and service providers emphasising the significance of abstinence, protective sex and HIV status disclosure particularly to sexual partners, the young women resisted. The study further adds that caregivers were more concerned with protecting their own families from bad reputation, social exclusion and legal repercussions if the male partners discovered on their own. In contrast, the young women feared social rejection and loss of their sources of support which assisted them to cope with their difficult situations and boost their self-worth. These ambivalences in views concerning sex, safer sex and status disclosure to partners signified differences in values and priorities between caregivers/service providers and the young women. These differences in turn affected young women's compliance to caregivers'/service providers' guidance and access to SRH education and services as they perceived other risks.

- ❖ Key contribution 10: HIV is mainly women's responsibility.

The current study has shown that HIV responsibility is mainly placed on young women. Prior study in Malawi (Reniers, 2008) revealed that women are likely to be divorced after their spouses learn of their HIV positive status, due to male dominance in sexual issues. The current study provides a new insight that apart from male dominance, the termination of the sexual relationships by male partners upon status disclosure was attributed to the fact that HIV responsibility was placed upon the female partners. Similarly, caregivers' concern and pressuring of young women to disclose their status to male partners than vice versa, uncovers lack of attribution of responsibility to men but rather placing the HIV responsibility on women.

- ❖ Key contribution 11: All HIV management centres under study still fall short of providing for young women's SRH needs

The current study provides an insight that the HIV management centres under study still fall short of providing what the young women need and an appropriate approach (the services that are appealing and friendly to the young women). Young women felt they were not being heard as individuals. Service providers fail to create an atmosphere in which young women can express their individual concerns and expectations or participate in decision making and have their SRH choices respected. Although peer support groups promote psychological well-being (Johnston et al. 2012, Gately et al. 2007, Koch et al. 2004), the young women strongly felt that some of the universal SRH strategies employed in the centres, like group discussions and offering condoms to every adolescent are not solely appropriate in meeting their individual needs. In addition, those who become pregnant felt that they are discharged from teen club without being given an option for social support or are exposed to dominant and oppressive power relations with older women as they shared the antenatal services in different health facilities.

9.3 Implications of the study

The findings of the current study have several implications for the programme development, service provision and research.

9.3.1 Programme development and service provision

The findings from the current study can inform the practice of HIV care delivery and development of programmes relevant to young women growing up with HIV in diverse ways. These implications include interventions for: (i) the young women, (ii) their caregivers, (iii) the community, (iv) the service providers; and (v) the models of care.

9.3.1.1 Interventions for the young women

The findings revealed that young women are unable to communicate their intense feelings, hidden pains and experiences to caregivers and service providers due to cultural silence. Hence, their intense feelings and agony remained unaddressed within most families and the health systems. Lack of knowledge about young women's

suffering left many caregivers even service providers struggling to deal with the practical psychosocial and sexual issues affecting the young women, leading to poor mental health and SRH outcomes. The counselling services available in the centres are reactive to situations like status disclosure, and/or deviant behaviours as reported by caregivers. These findings have two implications. First, the findings suggest that planned, proactive and on-going individual counselling sessions should be offered to young women to help them cope with loss, sexual rights, gender power roles/norms or a supplementary strategy like individual therapy to effectively help breach the deep-seated cultural silence. The service providers (including teen club coordinators) need to further develop child counselling strategies and skills through continuing education or short training courses to effectively address young women's mental health needs. Young women's expectations of humane responses from service providers to their issues are equally significant. Second, HIV care services need to incorporate mental health assessment from routine screening to thorough assessment and provision of care.

The current study shows that young women engage in early sex for love, acceptance and support. It is evident that in spite of advising young women to disclose their status and refrain from sexual activity or use condoms, they still engaged in unprotected sex leading to unwanted pregnancies. As such, optimal SRH outcomes can be achieved only when young women's perspectives on ideal sexual health services are understood and considered paramount. Currently, service providers emphasise on abstinence, or young women are offered condoms without choice, yet most struggle with condom use with their partners, leading to unwanted pregnancies. The social construction of masculinity and femininity and the socio-economic characteristics shaped the factors that constituted barriers to protective behaviour to a large extent. These findings have three implications.

First, the current study suggests that SRH promotion efforts need to be in line with young women's own perceptions of their sexual health. Ignoring this perception is undermining the principles of empowerment that emphasise the significance of recognizing young women's own concerns (Laverack, 2005), and the SRH services will seemingly be irrelevant to young women. Therefore, service providers need to

understand young women's priorities, values, preferences, expectations and goals in order to design risk reduction programs that are appropriate and mutually acceptable.

Second, the current study suggests that policy makers and NGOs need to be aware of young women's material needs, and get involved in empowering these young women with stable income generating activities or sources of income (not hand-outs). Thus, without empowerment on resource mobilization, guaranteed condom access alone is inadequate to reduce their risks for poor SRH outcomes. Economic opportunities through small scale businesses, academic and vocational achievements in the current study gave young women a position of power to desist being vulnerable and fostered their ability to exercise agency and become resilient. The need to empower the young women reinforces what the then United Nations Secretary-General Kofi Annan emphasised in 2004 at an International Conference in Bangkok (Kofi, 2004), "what is needed is positive change that will give more power and confidence to women and girls. Change that will transform relations between women and men at all levels of society."

Third, the current study suggests that the service providers (including teen club coordinators) need to further develop strategies and skills on resource mobilization and provision of contraceptives to young women through continuing education or short training courses. This in turn enables them to conduct regular trainings with young women to effectively access contraceptives other than condoms and empower them with ideal resource mobilisation strategies.

While caregivers in the current study were concerned about legal repercussions following status non-disclosure, the National HIV and AIDS Policy is interestingly silent on the subject of status disclosure to sexual partners. Instead, it makes reference to the Laws of Malawi in very broad terms, which may be applied to those who may knowingly or negligently infect their sexual partners. The policy points out that "the penal legislation criminalizes conduct that puts the general population at risk of infection such as rape, defilement and other sexual assaults, unlawful wounding and other grievous bodily harm conduct" (Government of Malawi, 2011:7). However, according to Laws of Malawi, though not specific, HIV non-status disclosure in a sexual relationship is an offence under Section 192 of the Penal Code (chapter 7:01), which states that, "any person who unlawfully or negligently does any act which is, and which he knows or has

reason to believe to be, likely to spread the infection of any disease dangerous to life, shall be guilty of an offence at the maximum custodial penalty presently is one year" (Government of Malawi, 2010). Currently, the penalty is being reviewed with an intention of enhancing it, and because the development of the HIV and AIDS legislation has not yet been enacted into law, thus those who violate the provisions of this legislation are unpunished because there are no tools to empower the public institutions delegated with enforcement of the law and health rights in general (Government of Malawi, 2011).

Conversely, building on previous arguments (Bernard, 2010 , Wainberg, 2009 , Open Society Institute, 2008 , UNAIDS, 2008) and from the findings of the current study, it could be argued that criminalizing HIV exposure and/or transmission can increase the likelihood of eroding public health norms that support joint responsibility for HIV prevention. This can further exacerbate stigma associated with HIV, while undermining actions of the underlying cultural and socio-economic factors responsible for the HIV transmission. Therefore, the current study suggests that while the HIV and AIDS legislation is being reviewed, the following critical and ethical issues should be considered: whether an HIV positive woman who is unable to negotiate safer sex by virtue of her age or gender power imbalances sexually transmits the virus to her partner, should she be accused and criminalised? Involvement and robust collaboration of various stakeholders in designing ideal and realistic strategies to assist caregivers meet their own and young women's needs in the broader context, is highly recommended.

9.3.1.2 Interventions for the caregivers

The current study shows that the majority of the caregivers encounter various emotional, physical, social and financial difficulties that in turn influence the care and support they give to young women. In addition, caregivers with low socio-economic status also struggled to control young women's sexual behaviours. Therefore, these findings suggest that caregiving must be acknowledged as a central part of the response to the epidemic. Caregivers require a range of financial, psychosocial, medical and social support themselves as most of them are young, over-stretched with the caring responsibilities, and unable to provide for the young women's needs. There is need to

provide programmes that will build up caregivers' local social supportive networks, and training that will enable caregivers to identify ideal resource mobilisation strategies. This can create economic opportunities for caregivers particularly female caregivers who are themselves struggling with the existing gender power relations.

The current study demonstrates that most biological caregivers, particularly the females, are marginalised and blamed for passing on the virus to their young people or for breaching morality. This finding suggests that the nature and impact of this stigma needs to be acknowledged and addressed in healthcare practice and policy, particularly its ability to influence parental capabilities to support the young women and seek support from the health facilities or communities where necessary. The caregivers need to be assisted with how they can deal with HIV in an adolescent–friendly, age-appropriate way through training or regular joint meetings with the services providers focusing on:

- The complex practical issues affecting young women. These include the normative expectations, different priorities, values and develop realistic strategies regarding risk reduction and economic security among the young women. Instead of distancing themselves from young women's social realities, greater attention to young women's interests, priorities and values (social and medical) is thus crucial to promote their compliance to adult guidance.
- Communication skills around status disclosure and sexual issues with their young women without focusing on blame or shame, and to identify practical issues affecting the young women and refer them appropriately.
- Caregivers' own emotions and fears regarding the young women and balancing the benefits and difficulties of parental disclosure and support or parent-child discussions on challenges within the specific personal, family and cultural contexts.
- Understanding more about factors that influence status disclosure within the family context which may allow for development of family-centred interventions like establishment of family clinics that improve coping capacity within the family unit and beyond.

9.3.1.3 Intervention for service providers

The current study has shown that despite some young women being sexually active and others becoming pregnant, some service providers were still reluctant to discuss sexual issues with the young women or to offer them SRH services, particularly injectable contraceptives. The findings show that cultural normative expectations locate service providers at a critical intersection between cultural and social values which promote sexual abstinence until marriage, and the reality of young women's premarital sex and desire to use contraceptives. These findings have two implications.

First, the study suggests that service providers need to acknowledge that they are key in embracing the young women's complex life, and empowering them to acquire decision making and negotiation power and skills on sexual issues through SRH education and services. Therefore, instead of controlling young women's sexual behaviours and access to the services, service providers need to network and establish collaboration with caregivers. Both service providers and caregivers must realise that young women's health related choices are different from their own and should not be dismissed as wrong or irrational, but rather they should be effectively acknowledged and addressed. Both need to empower young women with the necessary information to enable them to balance rights and responsibilities, exercise agency, make informed decisions about their sexual health and contribute to their quality of SRH well-being.

Second, the study suggests that it is critical that cultural, social and religious norms attached to young women's sexuality and access to SRH services be incorporated in all undergraduate trainings for health professionals and continuing education should be offered to assist all service providers to deal with the realities of adolescent health and the changing picture of adolescent sexuality even in the context of chronic illness. Service providers should be trained or reoriented to undertake their work without becoming 'parents' to young women in order to promote open discussions on sexual issues. What is needed by the young women goes beyond simple provision of SRH services, but includes assisting them acquire life skills such as capability to communicate, negotiate safer sex and the right to make sound decisions.

Another implication for graduate programmes relates to adolescent–provider relationship and counselling training. The findings of the current study indicate that young women benefit from counselling sessions and able to cope positively with their positive status when they have on-going counselling and establish a strong therapeutic relationships with their counsellors. The significance of relationship building implies that this aspect of counselling deserves special attention in both undergraduate and counsellors' training programmes. While some of the undergraduate programmes in health related courses offer counselling skills and related courses that focus on the therapeutic relationship, aspects of relationship-building and counselling skills should be built into other courses in colleges/universities. The inclusion of counselling skills and relationship enhancement techniques in all aspects of health related undergraduate programmes emphasise the significance of individualised, focused and effective counselling sessions in patient care.

Whereas the current study and other studies (Watt et al. 2009, Cotton, et al. 2005, Smith 2005) view religious and spiritual practices as potential resilience factors for coping with positive HIV infection, HIV care services have given the practice less attention. The implication on the service providers is two-fold. First, the current study suggests that service providers need to assess young women's spiritual needs and reflect on how they could be assisted to have their needs met with confidentiality and respect to their individual human dignity. Second, the current study suggests that service providers need to network and collaborate with chaplains providing pastoral care within the health facilities, referring to them young women who may need or benefit from pastoral care services.

9.3.1.4 Implications on models of care

Basing on the National SRH and Rights Policy, WHO's recommendations for adolescent friendly services (WHO, (2012) and the findings of the current study, it is clear that SRH services in all the centres under study still fall short of providing what the young women need (i.e. appropriate care), particularly with regard to services that are appealing and friendly to young women. In this context, the current study suggests that all the health services should be made adolescent-friendly; adolescents should access the services they need to make a positive contribution to their health. The SRH services should be

accessed by all young women from the age of 15 years, as recommended by the National SRH and Rights Policy and be provided in the right manner with respect, without getting the young women into trouble with their parents or caregivers. Young women's values and preferences be respected and confidentiality about sexual behaviour should be protected.

In the current study, several young women were sexually active and five out of fourteen had experienced a pregnancy. The current study investigated their pregnancy outcomes and one young woman has had two children who acquired HIV perinatally (the second child is dead). The findings show that pregnant young women disappear from teen club meeting for fear of being stigmatised by their peers and some service providers. They access antenatal services in other health facilities and reappear at HIV management centres or at teen club after delivery of their babies. Effective prevention of mother to child transmission (PMTCT) is a critical component of antenatal care (ANC) for the pregnant young women to reduce vertical transmission. This study suggests that the current practice of referring young women to other facilities for antenatal services be reconsidered. The ANC should be integrated in HIV management strategy to reduce social reproach as currently young women are being subjected to dominant and oppressive power relations with older antenatal women when they share the services. Service providers should be able to identify pregnant young women early and ensure that they access a full range of antenatal and PMTCT services. The findings also recommend that the National HIV and AIDS Policy and SRH and Rights Policy need to consider young women who acquire HIV perinatally as one of the priority areas in provision of impact mitigation services.

It is evident in the current study that young women encounter several challenges as they access SRH education and services in the centres under study. As such, they pointed out significant and practical SRH issues for the improvement of their SRH outcomes. The seven central issues regarding SRH education and services were identified and these include the need to:

- be heard as individuals, not as a group (like during teen club meetings).
- have their complex practical issues given a priority beyond the medical scope.

- ❖ have their caregivers supported with young women's practical needs, including adolescent sexual health and ideal resource mobilization strategies, rather than just focusing on control of their sexual issues.
- ❖ be provided with an opportunity to make their own decisions regarding their sexual well-being in supportive, trustworthy relationships, and safe and friendly environments, to access services they need in light of their diverse challenges.
- ❖ be reviewed by service providers with adolescent-friendly skills, who can understand their sexual trajectory without judgemental attitudes, thus enabling them open up on their sexual issues and freely access the SRH services.
- ❖ be in contact with specific service providers - suggestive of continuity in care as it can facilitate problem-solving. The young women felt that continuity in care could significantly enable service providers to follow them up on personal and sexual issues, unlike in the current situation, whereby they have to be seen by different service providers, creating disruptions in their care and follow-up.
- ❖ have a separate support group (teen club) for teen mothers to share experiences and challenges of parenthood, and individually or collectively to mobilise resources to reduce their vulnerability.

9.3.1.5 Interventions for the community

The current study shows that there is lack of attribution of responsibility to men, rather than placing the HIV responsibility on young women. This could be attributed to young women's inferior socio-economic position and gender power inequalities. The low socio-economic status, limited decision making power, negative self-image and gender power relations were found to be central to young women's vulnerability and decision making in sexual issues. These structural and contextual issues challenged and facilitated how and why young women made particular sexual choices and seek SRH services. Since these issues are socially and culturally imposed, this study suggests prompt action of various stakeholders.

There is need to map out strategies for increasing awareness of adverse consequences of some normative expectations upon HIV infected young women. Service providers need to network and collaborate with influential community, traditional and religious leaders to gain their support in enhancing community awareness on cultural issues that

impact on young women. There is need to identify positive aspects of the cultural normative expectations relative to HIV infection rather than solely blaming the culture for failing to promote optimal SRH outcomes. Leaders need to be trained in how to mitigate the negative impacts of the other dominant cultural issues (e.g. gender power relations) and how to empower the young women with the practical capacity to mobilise and control their own resources. This training in turn can change the culturally embedded dominating power relations and reinforce young women's awareness of their SRH rights to enable them oppose gender power imbalances, exercise agency and allow them make decisions regarding their SRH. Hence, enabling them to be resilient, develop assertiveness skills to stand for their rights, attain autonomy in accessing SRH services, and recognise their significant abilities thus reducing their vulnerability.

9.3.2 Future research

The current study focused on psychosocial and sexual experiences and needs of young women growing up with HIV. However, the findings suggests further research on the following key areas: (i) experiences of young women accessing non-specialised HIV care, (ii) mental health outcomes in HIV infected young people, (iii) adolescent-provider relationships, (iv) knowledge-implementation gap on condom use, and (v) integration of HIV care, SRH and antenatal services.

9.3.2.1 Experiences of young women accessing non-specialised HIV care

The findings in the current study relate more to young women who were accessing services from the multidisciplinary centres where HIV related health services were readily available and the majority of service providers had received specialised training and experience in the field of HIV and AIDS. Young women who were accessing services in peripheral facilities and other centres without specialised HIV care were not approached because they were hard to reach. Cultural, social and moral norms identified among the cases in the current study are anticipated to be stronger in peripheral (e.g. more rural) areas, and the young women, their caregivers and the service providers in these areas and other centres without specialised HIV care are likely to have different experiences and challenges. More research is needed on the experiences of hard to reach young women, and those receiving care from non-specialist settings.

9.3.2.2 Mental health outcomes in HIV infected young people

Mental health problems were common among young women in the current study. Whether the higher rates of mental health problems (including suicidal ideas or attempts) are due to HIV itself or to social, familial or other factors requires further investigation. Since the current study shows that mental health problems in young women are often under identified, specific research on mental health in HIV infected young women may provide an insight on whether and how mental health influences coping with HIV status.

In addition, there is a need for operational research to explore models of counselling or provision of psycho-social care in terms of its impact on mental health. Most HIV interventions in this context are evaluated against SRH outcomes, whereas this study seems to suggest that mental health outcomes are equally important.

9.3.2.3 Adolescent-service provider relationships

In the current study, young women desired supportive and trustworthy relationships with the service providers in which they would easily access SRH information and services. However, the challenge has been that close relationship between service providers and the young women also hindered close communication about sexual issues. As such, this study suggests that a safe and supportive environment, child counselling and adolescent-friendly skills are essential in understanding and embracing sexual issues dominating young women's lives. However, further research is needed to gain better insight on how these supportive adolescent-service provider relationships can be developed and maintained over time, as the young women adapt successfully to living with HIV and get discharged to adult care. There is also need for operational research to develop and evaluate training materials on communication skills for the service providers in this area.

9.3.2.4 Knowledge-implementation gap on condom use.

The current study has shown that there is a gap between being knowledgeable about risk reduction and applying it in a practical context, which needs to be researched further and addressed within the health systems. Particular focus should be on how the risk reduction strategies (compliance to contraceptive advice and condom use) can be

reinforced in the boarder contexts. In order to develop effective interventions in this area, it may be useful to conduct additional research to further examine men's perceptions and experiences in sexual relationships with HIV infected young women. Further exploration of gender roles (including attitudes, values, priorities and practices) on condom use would increase understanding of the strategies that are important and realistic in reinforcing adoption of protective measures.

9.3.2.5 Integration of HIV care, SRH and antenatal services.

The findings of this study show that young women would like services that integrate HIV care, SRH and antenatal services. As such, this study suggests that there is need for operational research to develop and evaluate news ways of providing integrated HIV care, SRH and antenatal services.

While the findings of the current study cannot be generalised beyond the group of young women whose cases were analysed, the findings are of value to young women, caregivers and service providers providing care to young women growing up with HIV. However, this discussion would not be complete without making note of the strengths and weaknesses that need to be considered for the future studies.

9.4 Study strengths and weaknesses

9.4.1 Study weaknesses

Young women and caregivers approached and recruited in the current study were those who were attending multidisciplinary centres where HIV related health services were readily available, and the majority of service providers had specialised training and experience in the field of HIV and AIDS. Young women who were lost to follow-up and accessing services in peripheral facilities who are likely the most marginalised and most vulnerable to social exclusion and inequalities were not approached because were harder to reach. These were likely to have different experiences and challenges of growing up with perinatal HIV. Nevertheless inclusion of accounts of young women from impoverished families or who lived in rural settings and encountered difficulties visiting the facilities due to financial constraints provided insight into these complexities of accessing the services. The use of a number of research methods also assisted the researcher to ably consider the congruence and complementarity of each participant

group and researcher's field notes with the data from the participants' in-depth interviews provided a comprehensive overview, but more in-depth study of particular groups is needed (Greene and McClintock, 1985).

All participants were from the central region of Malawi (where the researcher lives), which has different cultural and social normative expectations from the other two regions of the country (southern and northern). The central region as a geographical area could have an impact on young women's experiences and health seeking behaviours. It would be interesting to learn the psychosocial and sexual experiences and health seeking behaviours of young women in the southern and northern regions.

The study includes only experiences of young women. Although they cited numerous instances of male beliefs and behaviours, the findings may not adequately represent the male perspectives. It must be noted that the experiences of the young men could be different or could share some similarities. Further studies of young men and the comparison between the males' and females' experiences are recommended for future researchers.

The current study adopted a qualitative case study approach. This aimed to provide a representation of the social reality and a deeper insight into the phenomenon (needs and experiences of growing up with HIV) within its context (Grbich, 1999). The findings provide a rich picture of the small number of young women and are a valuable insight for those seeking greater understanding. Bowling (2009) affirms this point that qualitative methods have an advantage over quantitative methods in situations where maximum opportunity to pursue an exploratory approach is desired and when the issues are sensitive or complex. In contrast to qualitative work, quantitative study seeks to count occurrences, establish statistical links among variables or concepts, and establish findings that can be generalised to the population from which the sample was drawn (Green and Thorogood, 2004). In this context, the views represented in this thesis are not generalizable beyond the group of young women whose cases were analysed (to all young women with perinatally acquired HIV in Malawi). Nevertheless, adopting multiple case study approach, selecting a diverse sample of young women (based on a range of demographic, socio-economic and HIV-related variables) and conducting comprehensive analysis of the whole data set from multiple sources of

evidence allows transferability of the findings to young women growing up with perinatal HIV in similar context. Lack of generalization is a limitation of qualitative research but it may be argued that it is necessary to understand a phenomenon before you can measure it. For example, this study has shown that the stigma that surrounds HIV infection impacted on young women's self-esteem making it difficult for them to access the support and care they desperately needed, and male relationships opened up avenues for young women to access love and acceptance, which boosted up their self-esteem as they grow up with HIV. The qualitative approach does not allow for cross-comparisons between quantifiable factors such as respondents' socio-economic status, or measurements of self-esteem and quality of life. Such a study would require a quantitative approach and would utilise survey-based methods and robust measurement tools. However, whilst such an approach might demonstrate correlations between these factors, it would not provide the depth needed to understand the reality of these young women's lives.

9.4.2 Study strengths

The case study approach enabled discovery of complex processes and structural realities of the young women's lives at individual, family and health facility levels that may not have been attained through other approaches. The approach enabled the researcher to focus holistically on young women as it encompassed all the key individuals involved in provision of their care within the family and the health systems. Hence, multiple perspectives yielded in-depth understanding of young women's psychosocial and sexual experiences of growing up with perinatal HIV.

While acknowledging that in using 'conventional' data collection techniques, young people were sometimes reluctant to discuss their sexuality and avoided direct questions on sexual issues (Busza et al., 2013), the innovative 'my story book' approach designed for the current study encouraged young women's openness on sexual issues. 'My story' books comprising sentence completion exercises and researcher-generated images depicting different life experiences and events, gave young women more control over the representation of their lived realities. The approach addressed unequal power relations between the researcher and the researched, hence yielding powerful and rich data on young women's sexual experiences. Young women were able to communicate

not only key events but also contexts, values and challenges including sexual issues as they explained the experiences in reference to the chosen images.

9.5 Conclusion

This study is unique because it is the first study to determine the psychosocial and sexual experiences and challenges of the young women with perinatally-acquired HIV holistically (within the family and the health systems), based on the underlying structures and mechanisms in real-life contexts. The study has demonstrated a contextual understanding of interpersonal dynamics, mechanisms and structural realities influencing the sexual agency as a cornerstone of adolescent sexual health (particularly among young women growing up with HIV). Disseminating these findings in the HIV management centres, through publications and forums like national and international conferences will inform the policies and health practices on appropriate and realistic strategies of supporting the young women within the family unit and health systems in order to promote optimal mental health and SRH outcomes.

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APPENDICES

Appendix A: Letters of Ethical Approval

Approval from Nottingham University Medical School Research and Ethics Committee

Direct line/e-mail
+44 (0) 115 8231063
Louise.Sabir@nottingham.ac.uk

The University of Nottingham
Faculty of Medicine and Health Sciences

Medical School Research Ethics Committee
Division of Therapeutics & Molecular Medicine
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Nottingham
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16th December 2011

Ms Gertrude Grey Tiwonge Mwalabu
C/o Dr Catrin Evans
Deputy Director & Lecturer PG Studies
School of Nursing, Midwifery and Physiotherapy
B Floor, The Medical School Block
QMC Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

Dear Ms Mwalabu and Dr Evans

Ethics Reference No: C 09 2011
Study Title: Growing up: perspectives of female adolescents, caregivers and service providers regarding needs of adolescents with perinatally-acquired HIV.
Lead Investigator: Dr Catrin Evans, Deputy Director & Lecturer Postgraduate Studies, Dr Sarah Redsell, Principal Research Fellow School of Nursing, Midwidery and Physiotherapy (SNMP).
Co Investigators: Gertrude Grey Tiwonge Mwalabu, PhD Student, SNMP.

Thank you for your letter dated 14th December 2011 responding to the issues raised by the committee and enclosing the following revised documents:

- Application form for ethical approval version number 3.0 131211
- Consent form for use of personal images of participants version number 2.0 131211
- Responses to concerns raised by the Ethics Committee 041111
- Application form for ethical approval version number 2.0 041111
- Information sheet for adolescents version number 2.0 041111
- Information sheet for caregivers version number 2.0 041111
- Information sheet for the Service provider version number 2.0 041111
- Consent form for use of personal images of participants version number 1.0 041111
- Letter of ethical approval from COMREC 011111
- Letter of permission to Baylor HIV Centre of Excellence version number 1.0 041111
- Letter of permission to ministry of Health version number 1.0 041111.
- Letter of permission to partners in Hope Clinic for Pilot study version number 1.0 041111
- Study protocol version number 2.0 041111.
- Consent form for adolescents version number 1.0 050811
- Consent form for caregivers version number 1.0 050811
- Consent form for Service providers version number 1.0 050811
- Guide for observations version number 1.0 050811
- Indicative images version number 1.0 050811.

- Indicative sentence completion exercise in 'my story' book version number 1.0 050811
- Interview guide for Caregivers version number 1.0 050811
- Interview guide for service provders version number 1.0 050811
- Observer information sheet for adolescents version number 1.0 050811
- Observer information sheet for service providers version number 1.0
- Study participant recruitment poster version number 1.0 050811

These have been reviewed and are satisfactory and the study is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethics' Committee approval.

This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

You promptly inform the Chairman of the Research Ethics Committee of

(i) Deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects.

(ii) Any changes that increase the risk to subjects and/or affect significantly the conduct of the research.

(iii) All adverse drug reactions that are both serious and unexpected.

(iv) New information that may affect adversely the safety of the subjects or the conduct of the study.

(v) The attached End of Project Progress Report is completed and returned when the study has finished.

Yours sincerely

Dr Clodagh Dugdale
Chair, Nottingham University Medical School Research Ethics Committee

Approval from College of Medicine Research and Ethics Committee

UNIVERSITY OF MALAWI

Principal

K.M Maleta, MBBS PhD

Our Ref.:

Your Ref.: P.09/11/1124

College of Medicine
Private Bag 360
Chichiri
Blantyre 3
Malawi
Telephone: 01 877 245
01 877 291
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1st November 2011

Mrs. G. Mwalabu
Kamuzu College of Nursing
P/Bag 1
LILONGWE

Dear Mrs. Mwalabu

RE: P.09/11/1124 – Growing up: Perspectives of Female Adolescents, Caregivers and Service Providers Regarding the Needs of Adolescents with Perinatally Acquired HIV Version 2.0 dated September 2011

I write to inform you that COMREC reviewed your proposal mentioned above, which you resubmitted for expedited review. I am pleased to inform you that your protocol **was approved** after considering that you addressed all the queries raised in the initial review.

As you proceed with the implementation of your study we would like you to adhere the amended protocol ICH GCP requirements and the College of Medicine Research requirements as indicated on the attached page.

Yours Sincerely,

Approved by
College of Medicine
- 1 NOV 2011
(COMREC)
Research and Ethics Committee

Prof. J. M Mfutso-Bengo
CHAIRMAN - COMREC

JMMB/ck

REQUIREMENTS FOR ALL COMREC APPROVED RESEARCH PROTOCOLS

1. Pay the research fees as required by College of Medicine for all approved studies.
2. You should note that the follow-up committee will monitor the conduct of the approved protocol and any deviation from the approved protocol may result in your study being stopped.
3. You will provide an interim report in the course of the study and an end of study report.
4. You are required to obtain a continuation approval after 12 months.
5. All investigators must be fully registered with the Medical Council of Malawi.

Approval from Lighthouse HIV Management Centre

LIGHTHOUSE

Tel: (265) 1 758 940 ext 112/1 974 302
Fax: (265) 1 758 705
Cell: (265) 8 88 892 523
Email: samphiri@lighthouse.org.mw

Kamuzu Central Hospital (Area 33)
P.O. Box 106
Lilongwe
Malawi

REF: LH/SP/elk/02587

19th January 2012

Kamuzu College of Nursing
Private Bag 1
Lilongwe, Malawi

Dear Mrs G. Mwalabu,

RE: PERSPECTIVE OF FEMALE ADOLESCENTS, THEIR CARE GIVERS AND SERVICES PROVIDERS REGARDING NEEDS OF PERINATALLY HIV INFECTED ADOLESCENTS

On behalf of the Lighthouse Trust, I approve the above mentioned study to be conducted at the Lighthouse clinic between January 2012 and October 2012.

Any changes to the study protocol affecting participants must be communicated to the Monitoring and Evaluation Department. All study complications should be immediately reported to the Monitoring and Evaluation Department.

You are also advised to acknowledge the input of The Lighthouse Trust in any report or publications arising from this study.

In case the study is not completed within the approved period, you should apply for an extension within shortest time possible.

Yours Faithfully

Dr Sam Phiri, PhD (UK), MSc (UK), Dip Clin Med (MW)
EXECUTIVE DIRECTOR

March 06, 2012

BCM
Baylor College of Medicine

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NANCY R CALLES
BAYLOR COLLEGE OF MEDICINE
PEDIATRICS: RETROVIROLOGY

H-30357 - GROWING UP: PERSPECTIVES OF FEMALE ADOLESCENTS, THEIR CAREGIVERS, SERVICE PROVIDERS REGARDING NEEDS OF ADOLESCENTS WITH PERINATALLY-ACQUIRED HIV

APPROVAL VALID FROM 3/6/2012 TO 2/7/2013

Dear Dr. CALLES

The Institutional Review Board for Human Subject Research for Baylor College of Medicine and Affiliated Hospitals (BCM IRB) is pleased to inform you that the research protocol named above was approved.

The study may not continue after the approval period without additional IRB review and approval for continuation. You will receive an email renewal reminder notice prior to study expiration; however, it is your responsibility to assure that this study is not conducted beyond the expiration date.

Please be aware that only IRB-approved informed consent forms may be used when written informed consent is required.

Any changes in study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participants' safety or willingness to continue in your study.

The BCM IRB is organized, operates, and is registered with the United States Office for Human Research Protections according to the regulations codified in the United States Code of Federal Regulations at 45 CFR 46 and 21 CFR 56. The BCM IRB operates under the BCM Federal Wide Assurance No. 00000286, as well as those of hospitals and institutions affiliated with the College.

Sincerely yours,

JULIE PAMELA KATKIN, M.D.

Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals

Association for the Accreditation of Human Research Protection Programs, Inc. — Full AAHRPP Accreditation

Appendix B: Study Participant Recruitment Poster

ARE YOU A YOUNG WOMAN AGED 15-19?

WOULD YOU LIKE TO TELL US ABOUT GROWING UP?

Young women are needed for a study taking place in this centre.

This study is open to girls aged 15 to 19 years, their caregivers and service providers.

"Growing Up: Needs of Female Adolescents as They Grow into Adulthood"

The purpose of the study is to better understand needs and issues that impact on girls as they grow up to adulthood in order to promote services that are best for them.

IT'S TIME TO DISCUSS ABOUT NEEDS AND ISSUES THAT IMPACT ON GIRLS AS THEY ARE GROWING INTO ADULTHOOD, "ANYONE WILLING?"

The research will be conducted at Baylor and Lighthouse HIV Management Centres

For additional information contact Gertrude Mwalabu at: 09 99930195

or e-mail Gertrude at: mwalabugees2004@kcn.unima.mw.

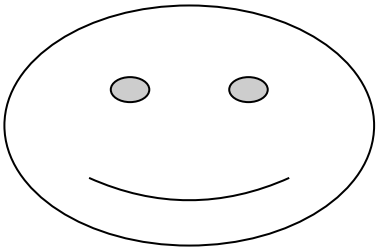
Principal Investigator: Gertrude Mwalabu

University of Nottingham,

School of Health Sciences

Appendix C: Observer Information Sheet for Service Providers

Dear Service Provider



You are being invited to take part in observational study. Before you decide you need to understand what it will involve for you. This information sheet tells you the purpose of this study, what will happen if you take part and about the conduct of the study. Feel free to ask if there is anything that is not clear or if you would like further information. Please take time to decide if you wish to participate.

The aim of this study is to understand the needs of female adolescents are they grow up to adult hood. This will help in promoting health services that will be best for them and help them to keep well and healthy. The study will run for nearly 6 months. You have been invited to participate because you are a health professional providing care, information and support to adolescents in this centre so you are eligible to participate. Your experiences and views on needs of the adolescents growing up with the illness will be of a particular interest for this study.

Participating in this study does not require you to adjust the services you provide in any way. However a researcher will be observing you as you deliver these services and interact with adolescents, in order to determine the range and quality of care, information and support you provide to them. The researcher will take detailed notes on consultation style, professional-adolescent interaction, service provision approach and your interactions with adolescents will be tape recorded. The findings of this study will not have any implications upon you as a health professional but will improve the evidence base for the health practice in the researched area.

Your participation is voluntary and you can withdraw at any time without any penalty. If you do not wish to participate in the study complete the 'opt out' slip and return it to the receptionist.

For more information, contact:

Gertrude Grey Tiwonge Mwalabu

Address: The University of Nottingham, School of Health Sciences

Telephone: +44 07586038037 (UK); 09 99930195 (Malawi – contact during field work)

Appendix D: Observer Opt Out Slip for Service Providers

I have read and understood the observer information sheet

I understand that further information about the study is available from:

Name of investigator: Gertrude Grey Tiwonge Mwalabu

Address: The University of Nottingham, School of Health Sciences

Telephone: +44 07586038037 (UK)

09 99930195 (Malawi – contact during field work)

However I **do not wish** to be observed for this study.

Name of participant: _____

Signature of participant: _____

Signature of investigator: _____ Date: _____

Appendix E: Observer Information Sheet for Adolescents

You are being invited to take part in observational study. Before you decide you need to understand what it will involve for you. This information sheet tells you the purpose of this study, what will happen if you take part and about the conduct of the study. Feel free to ask if there is anything that is not clear or if you would like further information. Please take time to decide if you wish to participate.

The aim of this study is to understand your needs as you are growing up to adult hood. This will help in promoting health services that will be best for you and help you to keep well and healthy. The study will run for nearly 6 months. You have been invited to participate because you are an adolescent accessing services in this centre.

You do not need to do anything different to participate in this study; the plan is for you to access the services without any interference. However a researcher will be observing you as you access various services, behave and interact with professionals, in order to determine the range and quality of care, information and support you receive. The researcher will take detailed notes on the services accessed and the approach. Your interactions with the health professionals will be tape recorded. Your participation is voluntary and you can withdraw at any time without any penalty. If you do not wish to participate in the study complete the 'opt out' slip and return it to the receptionist or the health professionals.

For more information, contact: Gertrude Grey Tiwonge Mwalabu

Address: The University of Nottingham, School of Health Sciences

Telephone: +44 07586038037 (UK); 09 99930195 (Malawi – contact during field work)

Appendix F: Observer Opt Out Slip for Adolescents

I have read and understood the observer information sheet

I understand that further information about the study is available from:

Name of investigator: Gertrude Grey Tiwonge Mwalabu

Address: The University of Nottingham, School of Health Sciences

Telephone: +44 07586038037 (UK)

09 99930195 (Malawi – contact during field work)

However I **do not wish** to be observed for this study.

Name of participant: _____

Signature of participant: _____

Signature of investigator: _____ Date: _____

Appendix G: Information Sheet for Adolescents

GIRLS! IT'S TIME TO DISCUSS ABOUT OUR NEEDS, AS WE ARE GROWING INTO ADULTHOOD, "ANYONE WILLING?"

You are being invited to take part in a study involving young women. Before you decide to participate you need to understand what it will involve for you. Take time to read the following information carefully and talk to others if you wish. This information sheet tells you the purpose of this study and what will happen if you take part. If there is anything that is not clear, please feel free to ask. Please take time to decide if you wish to participate.

What is the purpose of the study?

This study is part of a project the researcher is doing at the University of Nottingham in the United Kingdom. The study is looking at your needs as you are growing up to adulthood. This will help in making health services better for you to help you to keep well and healthy. The study will run for ten months.

Why have I been invited?

You are being asked to participate because you are a young woman between 15-19 years of age. The researcher would like to talk to you if you have been attending this centre for over six months. The researcher would like to hear about your needs and experiences as you are growing up with the illness. Your views on the services offered to you in this centre, will help improve the health services for all young women like you.

Do I have to take part?

It is up to you to decide whether to take part or not. If you decide to take part, you are free to change your mind at any time without any consequences. This would not affect the care you receive from this centre.

What will happen to me if I take part?

If you decide to take part you will be asked to invite your caregiver like a parent or anyone who is taking care of you to participate in the study. After that you and your caregiver will be asked to identify a nurse or a doctor to take part in the study. This should be a nurse or doctor who has been in constant contact with you for over 6 months.

You will be given “my story” book containing an activity and different pictures to assist you in writing your story about growing up to adulthood. The activity will require you complete some sentences and to put stickers on or draw pictures that suit best your experiences and needs of growing up with the illness. You will be given stickers, a pencil, rubber, sharpener and colouring pens in order to do this activity. You will be asked to complete the exercise in the “my story” book at home at your own time and your own pace within the specific period of time. There are no right or wrong answers in writing your story. You will simply write your experiences, feelings and views on the issues that impact on your living with the illness. In case pictures may not best suit your experiences or needs, then you may be required to draw any that suit your situation best in the spaces provided.

Upon completion of the “my story” book exercise you will be asked to take part in an interview. During interviews you will be asked to explain what you have written and the pictures chosen in your “my story” book. If there is a lot to talk about or if you do not wish not to continue with the initial interview, you will be asked to take part in a second interview. During the interview, the interviewer will take notes and with your permission the discussion will be tape-recorded. You may keep the original “my story” book for yourself and the interviewer will have a photocopy of the “my story” book.

What are the benefits of taking part?

There are no immediate benefits for your participation in this study. However your story may help improve the health services given to you and other young women like you. Your story will provide useful information necessary to assist policy makers advocate for the most important and realistic health services that are best for you as you are now growing up to adulthood.

What are possible disadvantages of taking part?

There are no disadvantages or likely dangers to your taking part in this study. However our discussion will involve detailed questions that may focus on personal and sensitive issues. The questions will tackle issues related to your experiences of growing up with the illness and sexual relationships. You will not be forced to answer questions or talk about issues that you would prefer not to discuss. If you feel such questions would upset you, or not wish to continue with the interview, you will be free to do so. This will not have any implications upon you or the care you receive from this centre. On the other hand, we can agree when we can repeat the interview.

What will happen if I do not want to carry on with the study?

If you decide to withdraw from the study after taking part in the interviews, the data will be retained and be used as part of the results for this study.

Will my taking part in the study be kept confidential?

All information collected will be confidential and used for the purpose of this study only. However in situations where you disclose information requiring urgent attention of the nurse or a doctor, or suggestive of abuse or risk for harm, then the interviewer will consult the nurse or doctor for intervention. This will be done to prevent further harm. In addition, data collected will be anonymous. You will be required to invent pseudonyms for your “my story” book to ensure maximum confidentiality and anonymity. The collected information will be stored in a locked filing cabinet at the researcher’s school to restrict unauthorized access to data.

What if there is a problem?

If you have a concern about any aspect of this study or any complaint about the way you have been handled by the researcher, you should ask to speak to the researcher. The researcher will do everything possible to address your concern or answer your questions.

Who is organizing and funding the study?

This study is organized and funded by the University of Nottingham in UK.

What will happen to the results?

This is an academic project that is being carried out as part of the requirement for the completion of my PhD studies at the University of Nottingham in UK. The results of the study will be published in a scientific journal. The anonymous results will further be made available to you, your caregivers and service providers as the participants and to policy makers.

Who has reviewed the study?

The study has been reviewed by my research supervisors: Dr Catrin Evans and Professor Sarah Redsell and the confirmation review panel at the University of Nottingham.

If you would like to take part in this study or discuss this further, please inform any of the health workers in this centre or contact the researcher.

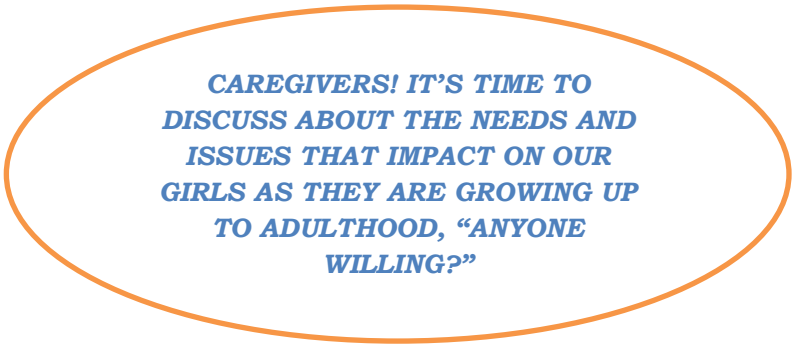
Contact for further information:

The researcher: Mrs Gertrude Grey Tiwonge Mwalabu
Address: Kamuzu College of Nursing,
P/Bag 1,
Lilongwe,
Malawi
Telephone: 09 99930195

E-mail: mwalabugees2004@kcn.unima.mw; ntxggm@nottingham.ac.uk

Thank you very much for taking time to read this information sheet

Appendix H: Information Sheet for Caregivers



You are being invited to take part in a research study. Before you decide you need to understand what it will involve for you. Please take time to read the following information carefully and talk to others if you wish. This information sheet tells you the purpose of this study, what will happen if you take part and about the conduct of the study. Feel free to ask if there is anything that is not clear or if you would like further information. Please take time to decide if you wish to participate.

What is the purpose of the study?

This study is part of my PhD in Nursing Studies which am undertaking with the University of Nottingham. The aim of this study is to understand the needs of your daughter as she is growing to adult hood. This will help in promoting health services that will be best for her and others to keep well and healthy. The study will run for nearly 8 months.

Why have I been invited?

You have been invited because you provide care for an adolescent aged between 15-19 who is interested in participating in this study. Your experiences and views are important to help improve health services to meet the needs of your adolescent as she is growing up to adulthood.

Do I have to take part?

It is entirely up to you to decide whether to participate or not. If you decide to take part, you are free to withdraw at any time and without giving a reason. This would not affect the care your adolescent receives from this centre.

What will happen to me if I take part?

If you decide to participate you will be given an opportunity with your adolescent to identify a nurse or a doctor who has been in constant contact with your adolescent, to participate in the study as well. Your participation is voluntary and you can withdraw at any time without any penalty. There are no right or wrong answers during the interviews, you will simply be asked about your experiences, challenges and views on caring for your adolescent who is now growing up with the illness. The interviewer will take notes and the interview will be tape-recorded.

What are the benefits of taking part?

There are no direct benefits for your participation in this study, however your experiences and views will assist to improve the health services given to your adolescent and other adolescents like her.

What are possible disadvantages of taking part?

There are no disadvantages or foreseeable risks to your participation in this study, however the interview will involve detailed questions on your experiences of raising up your adolescent in relation to other sensitive issues like sexual and reproductive health as she is now growing up with the illness to adulthood. If you feel such questions would upset you, or not wish to continue with the interview, you will be free to withdrawal at any point of the study without any implications upon you or your adolescent or we can agree when we can repeat the interview.

What will happen if I do not want to carry on with the study?

If you decide to withdraw from the study after taking part in the interviews, the tape recording or any notes taken will be destroyed immediately.

Will my taking part in the study be kept confidential?

All information collected will be confidential and used for the research purposes only. However in situations where you disclose information requiring urgent attention of the health professionals, or suggestive of abuse or risk for harm for your adolescent, then the interviewer with your consent will consult the nurse or doctor for intervention so as to prevent further harm. In addition, data collected will be anonymous. The collected

information will be stored in a locked filing cabinet to restrict unauthorized access to data.

What if there is a problem?

If you have a concern about any aspect of this study or any complaint about the way you have been handled during the study, you should ask to speak to the researcher, who will do everything possible to address your concern or answer your questions.

Who is organizing and funding the study?

This study is organized and funded by the University of Nottingham in UK.

What will happen to the results?

The results of the study will form part of my PhD thesis and will be published in a scientific journal. The anonymous results will further be made available to you as participants and to health professionals and policy makers.

Who has reviewed the study?

The study has been reviewed by my research supervisors: Dr Catrin Evans and Professor Sarah Redsell from the University of Nottingham.

For more information, contact:

The researcher: Gertrude Grey Tiwonge Mwalabu

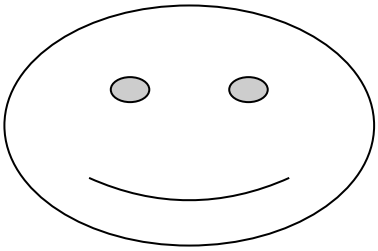
Address: The University of Nottingham, School of Health Sciences

Telephone: +44 07586038037 (UK)

09 99930195 (Malawi – contact during field work)

Appendix I: Information Sheet for the Service Provider

Dear Service Provider



You are being invited to take part in a research study. Before you decide you need to understand what it will involve for you. Please take time to read the following information carefully. This information sheet tells you the purpose of this study, what will happen if you take part and about the conduct of the study. Feel free to ask if there is anything that is not clear or if you would like further information. Please take time to decide if you wish to participate.

What is the purpose of the study?

This study is part of my PhD in Nursing Studies which am undertaking with the University of Nottingham. The aim of this study is to understand the needs of female adolescents as they grow up to adult hood. This will help in promoting health services that will be best for them to keep well and healthy. The study will run for 8 months.

Why have I been invited?

You have been invited to participate because you are a health professional providing health care, information and support to adolescents in this centre. Your experiences in providing services to these adolescents and your views on their needs and experiences as they are growing up will be of a particular interest for this study.

Do I have to take part?

It is entirely up to you to decide whether to participate or not. If you decide to take part, you are free to withdraw at any time and without giving a reason. This would not affect your work in this centre.

What will happen to me if I take part?

If you decide to participate, you will simply be asked about your experiences, challenges and views on providing services to female adolescents who are now growing up with the illness. The interviewer will take notes and the interview will be tape-recorded.

What are the benefits of taking part?

There are no direct benefits for your participation in this study; however your experiences and views will assist to improve the health services given to adolescents in this centre.

What are possible disadvantages of taking part?

There are no disadvantages or foreseeable risks to your participation in this study, however the interview will involve detailed questions on your experiences of providing services to the adolescents which will include sensitive issues like sexual and reproductive health as they grow up with the illness to adulthood. If you feel such questions would upset you, or not wish to continue with the interview, you will be free to withdrawal at any point of the study without any implications upon your work or we can agree when we can repeat the interview.

What will happen if I do not want to carry on with the study?

If you decide to withdraw from the study after taking part in the interviews, the tape recording or any notes taken will be destroyed immediately.

Will my taking part in the study be kept confidential?

All information collected will be confidential and used for the research purposes only. In addition, data collected will be anonymous. The collected information will be stored in a locked filing cabinet to restrict unauthorized access to data.

What if there is a problem?

If you have a concern about any aspect of this study or any complaint about the way you have been handled during the study, you should ask to speak to the researcher, who will do everything possible to address your concern or answer your questions.

Who is organizing and funding the study?

This study is organized and funded by the University of Nottingham in UK.

What will happen to the results?

The results of the study will form part of my PhD thesis and will be published in a scientific journal. The anonymous results will further be made available to you as participants and to health professionals and policy makers.

Who has reviewed the study?

The study has been reviewed by my research supervisors: Dr Catrin Evans and Professor Sarah Redsell from the University of Nottingham.

For more information, contact:

The researcher: Gertrude Grey Tiwonge Mwalabu

Address: The University of Nottingham, School of Health Sciences,

Telephone: +44 07586038037 (UK); 09 99930195 (Malawi – contact during field work)

Appendix J: Consent Form for Adolescents

I have read and understood the participant information sheet

In signing this consent form I confirm that I understand:

1. The purpose of the research project and my involvement in it. ☐
2. My participation is entirely voluntary ☐
3. I may withdraw from the research at any stage without giving reasons. ☐
4. Withdrawing will not penalize or disadvantage me in any way. ☐
5. The observed interactions and interviews will be tape recorded if I accept it to be so. ☐
6. All data are for research purposes only. ☐
7. All my data are confidential and the data will be destroyed within five years after completion of the study. ☐
8. Extracts from the interview may be anonymously quoted in any report or publication arising from the research. ☐
9. If I have questions about the research, or if I would like to see a copy of the final findings of the study, I can contact the researcher by calling her on the number given or write her on the address given. ☐

I understand that further information about the study is available from:

Name of investigator: Gertrude Grey Tiwonge Mwalabu

Address: The University of Nottingham, School of Health Sciences

Telephone: +44 07586038037 (UK); 09 99930195 (Malawi – contact during field work)

I **agree/do not agree*** to participate in this study. (*Delete where applicable)

Name of participant: _____

Signature of participant: _____

Signature of investigator: _____ Date: _____

Appendix K: Consent Form for Caregivers

I have read and understood the participant information sheet.

In signing this consent form I confirm that I understand:

1. The purpose of the research project and my involvement in it. ☐
2. My participation is entirely voluntary ☐
3. I may withdraw from the research at any stage without giving reasons. ☐
4. Withdrawing will not penalize or disadvantage me in any way. ☐
5. The observed interactions and interviews will be tape recorded if I accept it to be so. ☐
6. All data are for research purposes only. ☐
7. All my data are confidential and the data will be destroyed within five years after completion of the study. ☐
8. Extracts from the interview may be anonymously quoted in any report or publication arising from the research. ☐
9. If I have questions about the research, or if I would like to see a copy of the final findings of the study, I can contact the researcher by calling her on the number given or write her on the address given. ☐

I understand that further information about the study is available from:

Name of investigator: Gertrude Grey Tiwonge Mwalabu

Address: The University of Nottingham, School of Health Sciences

Telephone: +44 07586038037 (UK); 09 99930195 (Malawi – contact during field work)

I **agree/do not agree*** to participate in this study. (*Delete where applicable)

Name of participant: _____

Signature of participant: _____

Signature of investigator: _____ Date: _____

Appendix L: Consent Form for Service Providers

I have read and understood the participant information sheet

In signing this consent form I confirm that I understand:

1. The purpose of the research project and my involvement in it. ☐
2. My participation is entirely voluntary ☐
3. I may withdraw from the research at any stage without giving reasons. ☐
4. Withdrawing will not penalize or disadvantage me in any way. ☐
5. The observed interactions and interviews will be tape recorded if I accept it to be so. ☐
6. All data are for research purposes only. ☐
7. All my data are confidential and the data will be destroyed within five years after completion of the study. ☐
8. Extracts from the interview may be anonymously quoted in any report or publication arising from the research. ☐
9. If I have questions about the research, or if I would like to see a copy of the final findings of the study, I can contact the researcher by calling her on the number given or write her on the address given. ☐

I understand that further information about the study is available from:

Name of investigator: Gertrude Grey Tiwonge Mwalabu

Address: The University of Nottingham, School of Health Sciences

Telephone: +44 07586038037 (UK); 09 99930195 (Malawi – contact during field work)

I **agree/do not agree*** to participate in this study. (*Delete where applicable)

Name of participant: _____

Signature of participant: _____

Signature of investigator: _____ Date: _____

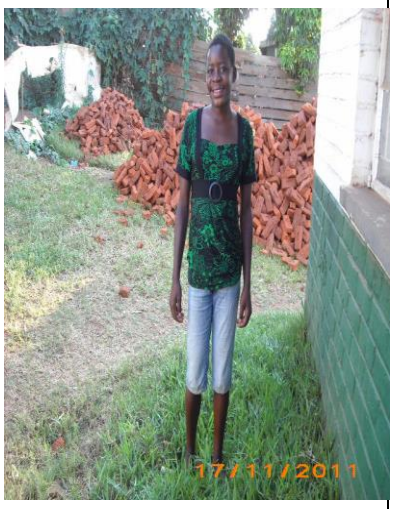
Appendix M: Guide for Observations

1. Consultation style
2. How much independence is given to adolescents in decision making?
3. What kind of information is given?
4. Is choice promoted or not?
5. Do adolescents get a chance to ask questions?
6. Are they asked about 'other' issues relevant to their transition to adulthood?
7. Do providers talk about SRH issues?
8. How do they talk about SRH issues with adolescents?
9. Is it person centred or task oriented approach?

Appendix N: "My Story" Book - Definitive Images and Definitive Sentence Completion Exercise

DEFINITIVE IMAGES

PICTURES DEPICTING DIFFERENT EMOTIONS ON EXPERIENCES OF GROWING UP WITH HIV

		
Am happy	I accepted my condition	Am glad that am alive and I love myself

Am depressed	Am so worried	Am angry with my illness

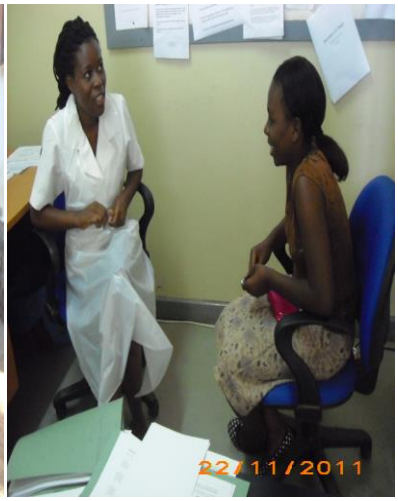
Am so hopeless	I wish I was dead	It's still difficult to accept my condition

PICTURES DEPICTING MAJOR NEEDS/ ISSUES THAT IMPACT ON ADOLESCENTS AS THEY GROW UP TO ADULTHOOD AND ADULT CARE

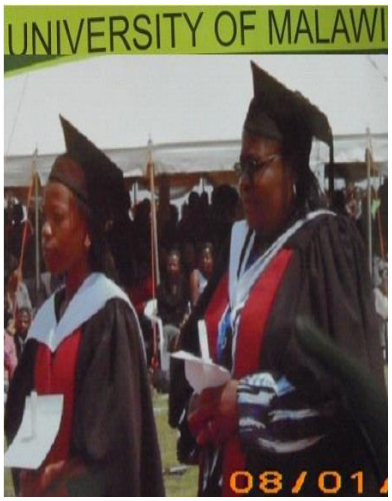
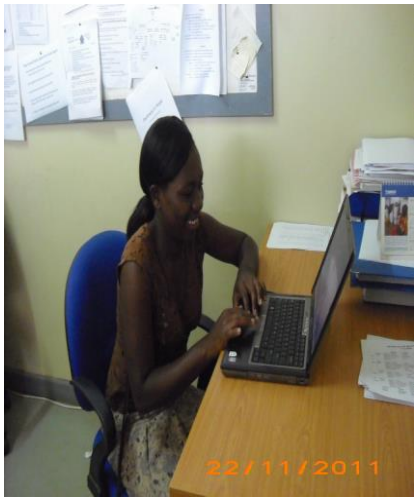
Support from peers	Being loved and accepted by peers	Having a sexual partner

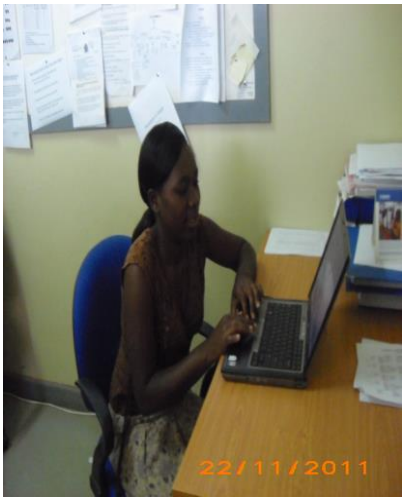
Counselling	Family support	Support group

Contraceptive use	Taking Drugs	Type and approach of health services

		
Pregnancy	Relationship with caregiver	Relationship with service providers

PICTURES DEPICTING FUTURE ASPIRATIONS AND PRIORITIES

		
Continue with my education	Go to university	Have a job

		
Get married	Have children	Remain single but have a job

PICTURES DEPICTING INDIVIDUALS YOU WOULD TELL YOUR HIV STATUS

My friends	Service providers	My family members

DEFINITIVE SENTENCE COMPLETION EXERCISE IN "MY STORY" BOOK

Major themes:

- Experiences of growing up with HIV infection
- Major needs/issues that impact on adolescent as they grow up to adult hood and adult care. May include:
  - ✓ Sexual and reproductive health
  - ✓ Disclosure of HIV status
  - ✓ ART adherence
  - ✓ Psychosocial support
  - ✓ Future aspirations and priorities.
  - ✓ Other medical issues

NB: Have a look at the pictures and choose those that best match your responses to the questions to be completed and use the space provided to write your response or create an image that suits your response best.

If you cannot read or write, *the researcher will explain to you how* you should just put stickers on images that best match your responses.

A. Experiences of growing up with HIV infection (Use yellow stickers for images depicting your responses)

Questions	**Responses**
Tell me your story about growing up with HIV (an adolescent will be asked to explain more about the response during interviews). - What makes you say that?	

How do you feel about having HIV? (Put stickers on images that depict your responses) What do you think makes you feel like that?	
How does having HIV effect your: - relationships with peers - relationships with family members - future plans If the relationship is affected or not affected, what do you think are the possible reasons for that? How about the reasons for the effects you have mentioned upon your future plans?	

B. Major needs/issues as you grow up to adulthood and adult care (use green stickers for images depicting needs/issues)

Questions	Response
What might be your major challenges or difficulties of living with HIV as you are growing up to adulthood (Put stickers on images that suit your major challenges or create images). What are your reasons for choosing these images?	

Who do you like to talk to about your condition? (Put stickers on pictures that suit your preferred individuals). Why talking to the people chosen? Why not talking to the others about your condition?	
What do you hope for in the future? (Put stickers on pictures that suit your future desires or create images). Do you think your condition influenced you in any way in regard to images chosen? If so how? If not, why not?	
What helps you to cope up with living with your condition? (Put stickers on pictures that depict on issues that help you to cope or create images) How does that help you cope up with your condition?	
What do you think are the most important and realistic strategies in meeting your needs? Why do you think so?	

Appendix O: Interview Guide for the Caregivers

Introduction

Thank you very much for agreeing to participate in this study. As I had discussed with you earlier, I am interested in exploring your experiences of raising up a young woman growing with the illness. I will be asking you to look back and identify her needs as she is growing up to adulthood with the illness. You don't have to answer all of the questions. Only answer what you feel comfortable with. Anything you say will be completely confidential and will be anonymously reported.

Do you have any questions about the interview or the research?

Demographic information

Gender	
Age	
Number of children and their ages	
Years you have been caring for the adolescent	
Parental status	
Education background	
Residential area	
Marital Status	
Date of interview	

Experiences and challenges of caregivers / Needs of the female adolescents

1 Can you tell me what it is like to look after an adolescent who is growing up with the illness?
    - Can you expand on your response
    - What do you think about it?
    - Do you have any worries and anxieties about raising up a young woman growing up with HIV?

- If yes, can you tell me about your worries and anxieties?
- How do you plan to handle your worries/anxieties?
- If no, why not…….
- How comfortable/confident do you feel about discussing issues related to your adolescent who is growing up with the HIV with the:
    - ✓ Adolescent herself
        - ➢ Which issues? Why? *(probe for each issue)*
        - ➢ At what age? Why? *(probe for each issue)*
    - ✓ Health providers?
    - ✓ Family members?
    - ✓ Your friends?
- If not comfortable, which issues and why not? *(probe for each issue why not)*

2 What are your main issues/challenges of looking after a young woman growing up with HIV? *(ask the caregiver to explain for each)*

- What have you done so far about them? (*ask the reason for each action*)
- If you have not done anything about the issues, why?
- How do you plan to handle the issues/challenges that you have not done anything about?
- How have the issues/challenges influenced your:
    - ✓ care for your adolescent
    - ✓ attitudes towards the experiences and needs of your adolescent
    - ✓ relationship with adolescent
    - ✓ Relationship with other family members, friends and the community.
- Please share with me what people in the community do to or say about female children/girls growing up with HIV?
- Are there any other uses of ARVs apart from prolonging life?
- How did you assist her to cope up with her status?
- Who else is involved in provision of care to this adolescent?
- How do you maintain confidentiality of her status?

3 In your views what would you say are the major needs/issues that affect your adolescent as she is growing up to adulthood and adult care? (*probe even for those that are health related)*

- Can you describe any particular need/issue that affects your adolescent that you have found it difficult to deal with?
- What do you think are the consequences?
- How do you assist your adolescent not to become pregnant?
- If your adolescent is found with condoms, what would you think about that adolescent? What will be your reaction?
- If the service providers ask for your consent for your adolescent to access contraceptives, how would you respond?
- At what age do you think female adolescents initiate sexual act?
- Who do you prefer could discuss sexual and reproductive issues with the adolescent? Why? At what age?

4 How do you support your adolescent regarding living with HIV and SRH issues? *(probe more on what is done and its effect on the adolescent)*

- Who has so far provided assistance in regard to this?
- Can you tell me the type of the assistance provided?
- What do you think could have been done better and how?

5 Which strategies do you think are the most important and realistic in meeting the needs of your adolescent as she grows up to adulthood and adult care?

Is there anything else you would like to add on your views about female adolescents growing up to adulthood in general?

Concluding remarks

Thank you so much for sharing your experiences with me. If you have any further queries do feel free to get in touch with me through the number I have provided.

Appendix P: Interview Guide for the Service Providers

Introduction

Thank you very much for agreeing to participate in this study. As I had discussed with you earlier, I am interested in exploring your experiences in providing care to female adolescents growing up with HIV. I will be asking you to reflect back at your experiences and interactions with the adolescent and identify her needs as she is growing up to adulthood with the HIV. You don't have to answer all of the questions. Only answer what you feel comfortable with. Anything you say will be completely confidential and will be anonymously reported.

Do you have any questions about the interview or the research?

Demographic information

Gender	
Age	
Professional status	
Working experience: • in HIV management • with HIV infected adolescents • in adolescent health particularly SRH.	
Period of seeing this adolescent	
Any relevant adolescent health training	
Residential area	
Marital status	
Date of interview	
Time taken	

Experiences and challenges of service providers / Needs of the female adolescents

1. Can you tell me what it is like to provide care to an adolescent growing up with HIV?
    - Can you expand on your response
    - What do you think about it?
    - Do you have any worries and anxieties about providing care to this adolescent growing up with HIV?
    - If yes, can you tell me about your worries and anxieties?
    - How do you handle your worries/anxieties?
    - If no, why not…….
    - How comfortable/confident do you feel about discussing issues related to her status as she grows up with the HIV with the:
        - ✓ Adolescent herself – which issues and at what age? Why?
        - ✓ Fellow health providers?
        - ✓ The guardian/parent?
    - If not comfortable/confident, specify which issues and why not?
2. What are the main issues/challenges of providing care to this adolescent as she is growing up with HIV?
    - What have you done so far about her as a service provider?
    - How does this HIV management centre plan to handle the issues/challenges that you have not done anything about?
    - How have the issues/challenges influenced the:
        - ✓ Care provided the adolescent in this centre?
        - ✓ Attitudes of staff towards the experiences and needs of this adolescent?
        - ✓ Relationship of staff and the adolescent?
        - ✓ Relationship of staff and adolescents' guardian/parent?
    - Please share with me what people in the community do to or say about female adolescents growing up with HIV?
    - Apart for being medication to prolong life in HIV infected people, what else have you heard people use ARVs for?
    - What challenges does she encounter and how have you assisted her?

3. In your views what would you say are the major needs/issues that affect this adolescent as she is growing up to adulthood and adult care?
    - Can you describe needs/issues that affect the adolescent that you have found it difficult to deal with?
    - What do you think are the consequences?
    - What issues do you comfortably discuss with the adolescent?
    - What are the guiding policies in this centre concerning accessibility of condoms or contraceptives to these adolescents?
    - What has been your experience? How about with this adolescent?
    - What challenges do you have in discussing sexual issues with this adolescent?
    - At what age do you think female adolescents initiate sexual act?
    - Have you ever had female adolescent collecting condoms in the consultation room? If yes why do think it is easy for them collecting condoms? If not why do you think it is difficult for them collecting condoms?
    - What strategies have you put in place to prevent her from being pregnant?
    - What strategies are put in place to prevent the secondary transmission of the virus?
4. How do you support female adolescents regarding living with HIV and SRH issues?
    - What do you think could have been done better and how?
    - How does the facility assist adolescents to disclose their status to their sexual partners?
    - If an adolescent has no caregiver, how do you handle such cases?
5. Which strategies do you think are the most important and realistic in meeting the needs of your adolescent as she grows up to adulthood and adult care?

Is there anything else you would like to add on your views about female adolescents growing up to adulthood in general?

Concluding remarks

Thank you so much for sharing your experiences with me. If you have any further queries do feel free to get in touch with me through the number I have provided.