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Sexual and reproductive health service use and resilience among adolescents attending a teen club clinic in urban Blantyre, Malawi

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Sexual and reproductive health service use and resilience among adolescents attending a teen club clinic in urban Blantyre, Malawi.

Blessings Nyasilia Kaunda

1487823

Dissertation submitted in the fulfilment of the requirements for the degree of Doctor of Philosophy in Public Health

The University of the Witwatersrand, Johannesburg, South Africa.

Supervisor	**Professor Lenore Manderson**
Co-Supervisor	**Professor Alister Munthali**
	Dr. Effie Chipeta

Declaration

I, Blessings Nyasilia Kaunda, declare that this thesis is my own original, unaided work. It is being submitted for the degree of Philosophy at the University of the Witwatersrand, Johannesburg, South Africa. It has not been submitted before for any degree or examination at any other university or institution.

Signed  on the 13th of May 2021, in Johannesburg, South Africa.

Dedication

I dedicate this PhD to ALHIV who strive to do well despite the challenges they face in life, and to the mentors, health workers and caregivers who continue to give unwavering support in these unprecedented times. It is admirable to share our lives for a common good. I might not be there for everyone, but I hope we can continue to work together to make a difference in the lives of adolescents in our communities.

Thesis Materials

Original presentations and articles arising from the PhD research work.

I. **Blessings N. Kaunda-Khangamwa** (2020) 'A volunteer for life'. Interactions in resilience and service use research in Malawi. Medicine Anthropology Theory (MAT)7(2):5030.https://doi.org/10.17157/mat.7.2.5030 or http://medanthrotheory.org/index.php/mat/article/view/5030.

II. **Blessings N. Kaunda-Khangamwa**, Innocent Maposa, Rosalia Dambe, Kennedy Malisita, Emmanuel Mtagalume, Lalio Chigaru, Alister Munthali, Effie Chipeta, Sam Phiri, Lenore Manderson (2020) Validating a child youth resilience measurement (CYRM-28) among adolescents living with HIV (ALHIV) in urban Blantyre, Malawi. Frontiers in Psychology. doi:10.3389/fpsyg.2020.01896

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- Working with ALHIV in Research - Workshop Grant support valued at MK300,000 (2019) from Blantyre Health Research Training Trust (BHRTT)

Service Contribution

- Member of College of Medicine Ethics Review Board, The University of Malawi, College of Medicine
- Honorary Lecturer. School of Public Health and Family Medicine. Department of Health Systems Strengthening. College of Medicine. 2018 to date

ABSTRACT

Background

HIV/AIDS remains exceptional in the age of treatment, characterised by huge flows of medication, health information, education, resource supports, technologies, and people across cultures. Such dynamics and complexity raise questions about the everyday lives of people living with HIV (PLHIV), particularly adolescents living with HIV (ALHIV). This thesis is concerned with how these young people, born with HIV and those horizontally infected, manage to maintain their sexual reproductive health (SRH) and well-being despite the blame and adversity associated with the condition. This is known as resilience. An understanding of SRH, service use and resilience is critical to recognise the capacity of individuals, families and communities to navigate available resources and to collectively negotiate for resources to be provided in culturally meaningful ways. Reflecting on resilience places emphasis on the factors and processes in relation to risks and protective supports along a continuum that is complicated by individual, relational, contextual, institutional and cultural issues. Yet little is known about ALHIV service usage, SRH and resilience in Malawi.

I adopt a constructionist interpretive approach to inquire into how ALHIV navigate complexity and negotiate and ensure health, wellbeing and resilience. I attempt to take a critical position, drawing on the in-depth meanings and experiences of ALHIV as they strive to do well. Such applications resonate with resilience -- a concept employed as a heuristic tool centring on a strength-based perspective on processes and experiences that enhance positive outcomes. I utilise a socio-ecological framework to capture the multilevel links and interactions that influence resilience and functional outcomes among ALHIV. In my research, I explored ALHIV experiences, including by attending ART (antiretroviral therapy) and teen club clinics, which were part of the institutional framework designed to foster resilience. Understanding the relationships between service usage and resilience is of great importance to Malawi to

understand the varied pathways ALHIV negotiate for health care, SRH and relational supports.

Methods

In this study, I used a mixed-method approach in a cross-sectional, exploratory sequential design. This is a two-phase method to inform and allow for the modification of the questionnaire and qualitative guides and tools. A qualitative pilot survey was conducted with 42 ALHIV, using cognitive interviews and analysis to ensure that 15-19 year old youth were able to understand and could respond to the questionnaire and qualitative interview guides as intended. This pilot phase was followed by a survey with 406 purposefully selected ALHIV to determine factors associated with resilience and to validate the psychometric properties for the Child Youth Resilience Measure (CYRM-28) tool for ALHIV attending the teen club clinic. To describe and analyse an institutional enabling environment, particularly the adolescent-centred teen club clinic (TCC) model in fostering service use and resilience, I conducted a survey with ALHIV (406), involved 35 health workers in a workshop, and interviewed seven key informants and 144 adults, both "PMKs" (Persons Most Knowledgeable, as identified by young people), and parents/caregivers. Using a case study approach, I illuminated multiple and unexpected pathways that ALHIV took to do well despite experiencing adversity. In-depth interviews were conducted with 26 ALHIV, from which four case studies were selected to present in this thesis to highlight diverse pathways to service users and supports. The 'ecomaps' were added to understand what 'doing well' meant to young people in nuanced ways. The ethnographic approach of this study highlighted how physical and social spaces, places, and discourses enabled ALHIV to embrace the complexities of their experiences, including in relation to SRH, over time. Descriptive and inferential statistics were used to analyse the quantitative findings from the survey, while the framework and thematic analysis were used to guide the analysis of the qualitative data.

Findings

Resilience related constructions are multiple and layered and evolve not only to influence individual capacity but also to enhance family, community and institutional support. Collectively, common elements influence resilience and service use among ALHIV, but the ways they are grouped vary. At the individual level, using a Child Youth Resilience Measure (CYRM-28), I ascertained the three-factor structure and unique components (personal and social skills, caregivers' support, spiritual and cultural support) that inform resilience for ALHIV and appear to influence their attendance at a teen club clinic in Malawi. However, the factorial model challenged the individual and ecological perspective of resilience as dimensions on peer support and education showed low loadings for ALHIV. These observations confirmed that across sub-populations, there are common resilience elements, but the ways they are grouped differ, suggesting the value of further qualitative research.

In line with enhancing our understanding of resilience as a multidimensional and complex construct influencing SRH, service usage and health outcomes, I considered multiple perspectives (ALHIV, caregivers and health-workers, and researcher's roles). This includes an institutional enabling environment, the adolescent-centred teen club clinic (TCC) model, which influences complex interactions and dynamics in fostering resilience among ALHIV. The TCC underscores the potential of institutional factors, processes and policy-enabling environments to ensure positive developments among ALHIV. I also captured ALHIV as multiple service users, who accessed education, community teen club, youth-friendly centres, SRH, HIV care and traditional healing. In analysing this, I stressed ALHIV layers of interest, differing needs, and place interactions for their health and wellbeing. Prioritising the ART and teen club clinic is not unexpected, given the needs for ALHIV and adolescent-centred care. Further analysis using structural equation modelling not only offered unique insights on gendered service use experiences but demonstrated the complex network of correlates and factors that influence the interactions between risks, resilience service use frequency and satisfaction. The desire of ALHIV to reproduce at an early age complicated their

adoption of safe sex negotiation skills, intimacy and SRH care, and likely influenced their lower utilisation of SRH, family planning and sexually transmitted infection services.

Using a case study approach, I reflected on living with HIV as a reference point to understand how young people navigate and negotiate a complex mix of needs. I illuminated multiple and unexpected pathways, including opting for strategic relationships and silence, that ALHIV used to maintain their support systems and not undermine their resilience. The 'ecomaps' were added to personalise ALHIV experiences and strengthen the diagrammatic representation of social and health service utilisation over time. Despite the encouragement of disclosure, openness and the development of self-efficacy as informing resilience, in this current study, 'strategic relationships and silence' were considered to be especially valuable for 'doing well despite adversity'.

Finally, I explored the multiple enabling spaces and places that influence dialogues and positive SRH experience over time. I highlighted the multiple roles of different physical and social spaces and discourses at homes, schools, church, and community and institutional settings, which showcased SRH complexities (informed choices, communication, physical satisfaction, sexual readiness and reproductive preparedness) as ALHIV navigated their status to live positively. ALHIV, parents/caregivers and health workers strive for more open, honest and explicit knowledge sharing and relationships to ensure safety, privacy, choices, pleasure and the provision of SRH services. All acknowledge ASRH as a normative issue that occurs and is influenced by the capacity of young people to negotiate. Diversity norms, values and power relations transformed SRH experiences for ALHIV.

Conclusion

This study stresses the context-specific, multilayered, multidimensional nature of resilience, SRH and service use which are critical for ALHIV wellbeing. I used a public health lens to infer risk and protection factors influencing the outcomes of ALHIV. Living with HIV, even if one is doing well on

antiretroviral treatment (ART), is still experienced as exceptional. I subscribe to a transformative lens and a strength-based approach, and view adolescence as providing space for health exploration and learning.

In this thesis, I note disparities between resilience measures, SRH service usage, frequency and satisfaction among ALHIV, health workers and parents/caregivers, emphasising the need to strengthen collaborative efforts for ALHIV heath. ALHIV are multiple service users with variable knowledge of service provision vis-à-vis access and utilisation in practice. Where knowledge and awareness are strong, there is potential for ALHIV to navigate multiple settings for resource and service supports. This reflects an improvement in accessing services, particularly SRH service use and care, revealing the complexity and fulfilment that ALHIV seek. This is critical for their sexuality. Such recognition accounts for ALHIV as sexual beings, ultimately leading to more open discussions to meet the sex-positive and reproductive needs of both genders. The teen club clinic continues to transform ALHIV biological and social lives, and this ultimately affects their informed choices, empowerment and a sense of belonging.

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Acronyms and Abbreviations

AGYW	Adolescent Girls and Young Women
AIDS	Acquired Immuno Deficiency Syndrome
ALHIV	Adolescents living with HIV
ART	Ante-retroviral Treatment
ARV	Ante-retroviral
ASRH	Adolescents Sexual Reproductive Health
CDC	Centre for Disease Control
CFA	Confirmatory Factor Analysis
CHAM	Christian Health Association of Malawi
COMREC	College of Medicine Ethics Committee
CYRM	Child Youth Resilience Measure
CYRM-28	Child Youth Resilience Measure-28
DREAMS	Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe
DSD	Differentiated Service Delivery
EFA	Exploratory Factor Analysis
EHP	Essential Health Package
EMR	Electronic Medical Records
FGD	Focus Group Discussion
FP	Family Planning
GEAS	Global Early Adolescent Survey
GoM	Government of Malawi
HIV	Human Immuno-deficiency Syndrome
HREC	Human Research Ethics (Medical)
HSSP	Health Sector Strategic Plan
IDI	In-depth interviews
MAT	Medicine Anthropology Theory

MDHS	Malawi Demographic Health Survey
MGDS	Malawi Growth and Development Strategy
NSO	National Statistical Office
OECD	Organization for Economic Cooperation and Development
PEPFAR	President's Emergency Plan for AIDS Relief
PMTCT	Prevention of Mother to Child Transmission
PMK	Persons Most Knowledgable
SADC	Southern African Development Community
SDG	Sustainable Development Goals
SEM	Structural Equation Modelling
SRH	Sexual and Reproductive Health
SRHR	Sexual Reproductive Health Rights
STI	Sexual Transmitted Infections
TB	Tuberculosis
TCC	Teen Club Clinic
TEVET	Technical Entrepreneurial, Vocational Education and Training
UFC	Umodzi Family Centre
UNAIDS	United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNESCO	United Nations Education Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WHO	World Health Organization
YFHS	Youth Friendly Health Service

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The Structure of the Thesis

This PhD submission is structured according to the 'divide and block' format.

SECTION A

Introduction and Literature Review

Chapter one provides a short introduction to the structure of the thesis. In the background, I discuss challenges related to adolescent sexual and reproductive health (ASRH), and policies at the global level, sub-Saharan Africa and particularly in Malawi, including operational definitions guiding this work. This is followed by a literature review in Chapter two, with details on the waves of resilience and central concepts, and how they were operationalised in this thesis. I refer to different interventions, resources and supports for the young people, of which the teen club clinic is one. I refer to a few studies on the construct of resilience in Malawi to situate the research gap. The aim, study objectives, conceptual framework and theoretical underpinnings are presented here.

In Chapter three I present the overall components of and my methodological approach to this PhD. I also present **Paper I**, entitled "A volunteer for life. Interactions in resilience and service use research in Malawi," in which I highlight ethical considerations and reflect on my multiple roles as a researcher, student, volunteer, friend, and aunt, and my personal, academic and ethical dilemmas when working with young people, deemed vulnerable, in the production of knowledge.

SECTION B

Section B is the results section of this dissertation, comprising three published articles and two under review from Chapter four. The co-authors agreed to include the publications as part of this thesis submission. (See Appendix 5).

Chapter four comprises **Paper II,** Validating a child youth resilience measurement (CYRM-28) among adolescents living with HIV (ALHIV) in urban Blantyre, Malawi.

This paper is the first to measure resilience among ALHIV, attending ART and teen-club clinics in Malawi. It confirms the unique components and three-factor structure of the CYRM-28 in resource-constrained countries. The validation of CYRM-28 shows a factorial model that challenges individual and ecological perspectives of resilience, as dimensions on peer support and education show low loadings. The results presented in chapter four heighten the factors associated with resilience at the individual level for ALHIV.

Chapter five, **Manuscript I,** 'Service use and resilience among adolescents living with HIV in Blantyre, Malawi', is focused on the adolescent-centred teen club clinic (TCC) model, and how TCC influence complex interactions and dynamics in fostering resilience among ALHIV. I discuss young people's service use history, intended risks or not and experiences with evidence from multiple perspectives. I underscore the potential of institutional factors and processes and policy-enabling environments to ensure positive developments for ALHIV. Using structural equation modelling (SEM) offers unique insights into the complex network of factors that influence resilience service use frequency and satisfaction.

In Chapter six**, Paper IV**, Adolescents living with HIV, complex needs and resilience in Blantyre, Malawi, I report four case studies reflecting on increasing adversities related to the individual, relational, institutional and cultural experiences. I document composite summaries of the cases as four single stories, offering a 'thick description" and nuanced review of interview data that show how adolescents with complex needs navigate and negotiate for resources in developing countries like Malawi.

In Chapter seven, **Manuscript II,** Spaces and places: Sexual and Reproductive Health and HIV care for adolescents in Blantyre, Malawi, describes how young people's lives are grounded on physical, social, and participatory spaces and discourses that shape their SRH complexities. I acknowledge the divergent spaces as part of a sexual ecology of ALHIV. This approach contributes to a better understanding of complex social processes and relationships that help to transform SRH needs, informed choices and expectations for the future.

SECTION C

In Chapter eight, **Discussion,** I return to the study aims, objectives, conceptual and theoretical frameworks to highlight research findings and key themes. This discussion revises the socio-ecological and constructionist interpretive frameworks that guided this PhD work. The strengths and study limitations are presented in this chapter.

In Chapter nine, **Conclusion and Recommendations**, I summarise how a multidimensional and multilevel approach was employed to help to expound the dynamic processes that support ALHIV to do well and to access services. I consider the implications of the study findings for policies, programmes and indicate areas where future research would be valuable to improve the health and life outcomes of young ALHIV.

SECTION A

CHAPTER ONE

MALAWI, REGIONAL & GLOBAL CONTEXTS

1.0 Introduction



Figure 1.1. Official opening of Umodzi Family Centre (UFC) in Blantyre, Malawi[1].

1.1 Background

U.S. Government Supports Completion of New Umodzi Family Center

[1] Source https://mw.usembassy.gov/u-s-government.

Blantyre, 1 December 2017 – In commemoration of World AIDS Day today, U.S. Ambassador to Malawi, Virginia Palmer, and Malawi's Minister of Health, Atupele Muluzi, together opened the new Umodzi Family Center [UFC] on the campus of Queen Elizabeth Central Hospital in Blantyre. The U.S. Government, through the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and the U.S. Centers for Disease Control and Prevention (CDC), contributed to the completion of the new Umodzi Family Center, a vital Ministry of Health facility in the fight against HIV and AIDS in Malawi.

"The new facility we're opening today, on World AIDS Day 2017, is called the UFC to emphasise the comprehensive and family-focused nature of the new facility. The UFC will be a Center of Excellence in Blantyre where access to critical services will be integrated into a 'one-stop-shop' to include HIV testing and treatment, tuberculosis screening, and targeted reproductive health services. The opening of this clinic marks another milestone in Malawi's outstanding national HIV program. The United States is proud to support Malawi's leadership in the global HIV/AIDS response," said U.S. Ambassador, Virginia Palmer.

The original Umodzi Clinic, established in 2002, was one of Malawi's first Ministry of Health sites to provide access to life-saving ART for people living with HIV. The clinic serves as a referral site for patients from other health facilities within Blantyre and the southern region districts of Chikwawa, Blantyre, Nsanje, Mwanza, Neno, Chiradzulu, and Thyolo.

Story on the opening of the UFC. Reported by US Embassy in Lilongwe, Malawi

(Field notes, 1 November 2018; see Figure 1.1 above)

This opening story is part of the media report that focuses on a clinic as an institutional framework designed to foster resilience. I explore the UFC clinic as offering space and programmes that supports the resilience of adolescents living with chronic conditions. I refer to the interactions of adolescents, health workers within the teen club clinic under UFC throughout my thesis because it forms the 'hub' of my research project on service use and resilience among ALHIV. UFC offers the teen club clinic service model for adolescents living with HIV (ALHIV).

The teen club clinic is part of the adolescent-centered care initiative that caters for social, clinical and health wellbeing. As reflected in the above story, the UFC clinic is increasingly recognised as a growing centre of excellence for HIV care at the district and nationally, with international acclamation. The importance of this has gained momentum with the introduction of 'treatment as prevention' and differentiated service delivery (DSD) focusing on the framework of patient-centred care. There is a need to understand how changes play out in the lives of ALHIV in the fast-moving field of HIV service provision and policy. In this thesis, the focus is on invested resources such as the teen club clinic, with attention to how they contribute to ALHIV service use and provide SRH support to enable young people 'to do well, despite adversities'. This is equated to resilience and well-being.

In this study, I was keen to explore what resilience entails for ALHIV. Specifically, I looked at how individual components and supportive and resourceful environments foster resilience. Resilience-based approaches have the potential to revolutionise SRH, service usage, wellbeing, research and policy:

A lens on resilience shifts the focus of attention from efforts to appraise risk or vulnerability, towards concerted efforts to enhance strength or capability. It also shifts the focus of analysis, from asking relatively limited questions regarding health outcomes, such as what are the linkages between risk exposures and functional deficits, to asking more complex questions regarding wellbeing, such as when, how, why and for who do [social and SRH] resources truly matter. (Panter-Brick & Leckman, 2013, p. 333)

In this thesis, I describe the multiple perspectives of caregiver/parents and health workers, and particularly the experiences of ALHIV with service use. I also provide a counter-narrative to AIDS treatment centres and ARV clinic ethnographies by Biehl (2009) in Brazil and Nguyen (2010) in West Africa; located in settings in which poverty, disease, death, survivorship and structural violence are entrenched (Panter-Brick, 2014). Given ALHIV complex needs, I draw on resilience research and strength-based models to situate young people's social competencies, access and utilisation of care and services, within a specific context and policy agenda.

1.2 Malawi and HIV/AIDS

In Malawi, 34 years after the first positive diagnosis, HIV-associated conditions are still the leading cause of death among 10-19 years old (World Health Organization, 2017). There is an increase in competing factors and complications among ALHIV, both internal and external: taking lifelong medication (Fick et al., 2015); experiencing single and/or double orphanhood (MacKenzie et al., 2017); learning difficulties (Laughton, Cornell, Boivin, & Rie, 2013; Pretorius, Gibbs, Crankshaw, & Willan, 2015); discrimination and stigma (Reif, McNairy, Lamb, Fayorsey, & Elul, 2018; Zgambo, Kalembo, & Mbakaya, 2018); poverty (OECD Development Centre, 2018); early sexual debut and pregnancy(Callahan, Modi, Swanson, Ng'eno, & Broyles, 2017; Eshun-Wilson, Rohwer, Hendricks, Oliver, & Garner, 2019); and poor service use (Bekker et al., 2015). However, not all ALHIV face the same levels of risk or vulnerabilities. I mention the risks, complications and their underlying challenges to give a holistic portrayal of adversities that ALHIV in Malawi experience. Rather than reifying this dominant narration of risks, however, I focus on how these can serve as a space for strength, health and 'wellbeing'. I define wellbeing for ALHIV as having relationships, striving for resilience, the realisation of their potential, and their overall satisfaction with life.

Studies related to service use and the outcome are critical at a time of renewed interest in the challenges of adolescent health and adolescent sexual and reproductive health (ASRH) and sexuality, reproduction and contraception (WHO, 2017a). Promoting ASRH (SDG 3 -- Sustainable Development Goal) contributes to many global goals (SDG 5 -- achieving gender equality; SDG 1 -- ending poverty; and SDG 10 -- reducing inequalities) as they, in turn, contribute to adolescents' wellbeing and wellbeing for all. This is in line with upholding the "Adolescent Health in All Policies (AHiAP)" approach, which ensures inclusivity and the promotion of development support for ALHIV (WHO, 2017a). Hence United Nations Secretary-General, Ban Ki-moon, in speaking to the Global Strategy for Women's, Children's and Adolescents' Health (2016–2030) (Global Strategy), maintained that "[adolescents are] central to everything we want to achieve, and to the overall success of the 2030 Agenda" (United Nations, 2015, p. 5).

There is increasing evidence that targeting adolescents requires addressing challenges on multiple fronts ranging from schools support, active citizenship, the provision of youth-friendly services, and enhancing employment opportunities (OECD Development Centre, 2018; Saul, Bachman, Allen, Toiv, & Beamon, 2018; Toska et al., 2016). In particular, employing positive development or strength-based approaches are critical for enhancing ALHIV resilience and protective factors (caregiver, institutional and policy support) rather than focusing on the primary reduction of risks (WHO 2017a). However, there is a lacuna of information on enabling environments with a positive orientation that are critical for practice and policy. Policies that intervene at critical stages during adolescence can significantly reduce the risks of youth becoming further disadvantaged.

1.3 Policy Context: Global, Sub-Saharan Africa and Malawi

As an outcome of the Cairo International Conference on Population and Development (ICPD) held in 1994, 179 countries, globally, including Malawi, agreed to improve ASRH through age-appropriate health information and access to services under the (MGDS 2017-2022) (Government of Malawi, 2017b). The ICPD, World Health Organization (WHO), United Nations Population Fund (UNFPA), United Nations Programme on HIV/AIDS (UNAIDS), United Nations International Children's Fund (UNICEF), and the Global Strategy for Women's, Children's and Adolescents' Health continue to commit to translating SRHR to improve adolescents' well-being and to ensure transformative change needed to shape and sustain their future(UNICEF, 2017; United Nations, 2015).

Similarly, at the regional level, the 2004 SADC Protocol on Health and the 2006 Maputo Plan of Action (African Union Commission, 2006, 2016; SADC, 2019), in which Malawi is a signatory, have a provision for encouraging universal access to SRH-care services including for family planning) and SRHR (Government of Malawi, 2017a; Government of the Republic of Malawi, 2018). However, the burden of HIV/AIDS continues, and an estimated 37.9 million people including 1.7 million children were living with HIV, worldwide in 2019 (UNAIDS, 2020a). Young women continue to be at risk, and about 6,200 new infections each week are recorded among those aged 15-24 (UNAIDS 2020a). In sub-Saharan Africa, four

in five new infections are among young women aged 15–19 years, and those aged 15–24 years are twice as likely to be living with HIV as men (Barker, Dutta, & Klein, 2017; Global AIDS Update, 2020). As part of increasing resources, programmes, and translation of global trends and policies for countries in sub-Saharan Africa, both global and regional policies have adopted a multidimensional and multilevel strategy. The aim is to continue to reduce maternal mortality and morbidity, infant and child mortality, by ending all preventable deaths of mothers, newborns and children, ensuring combating HIV/AIDS, expanding contraceptive use, reducing levels of unsafe abortion, ending early and forced child marriage, eradicating female genital mutilation, preventing gender-based violence, and ensuring universal health access of adolescents and youth to SRH (WHO 2017a).

Malawi continues to be committed to the provision of integrated and comprehensive SRHR through the following policies: the ICPD Programme of Action, then the Millennium Development Goals, Malawi Government Development Strategy, the Malawi National Reproductive Health Strategy, the Roadmap for Accelerating the Reduction of Maternal and Neonatal Mortality and Morbidity in Malawi, the Malawi Gender Policy, African Union SRHR Policy Guidelines, and the SDGs. Each instrument provides renewed and expanded focus on adolescent health and well-being (Government of Malawi, n.d.-a, 2020; Government of the Republic of Malawi, 2018). Under the Ministry of Health, the Reproductive Health Department since 1997 has employed the Malawi National Reproductive Health Programme Framework to manage SRHR at all levels. The emphasis is on the promotion of informed choice, and safer reproductive health practices by adults and young people, including the use of quality and accessible reproductive health services (Government of Malawi, n.d.-a). Malawi strives to meet the global agendas and related targets within various policies and frameworks as part of getting the HIV epidemic under control, achieving universal health coverage, and highlighting lessons learnt for programmatic scale-out (Chirwa, Kayambo, Oseni, Plotkin, & Hiner, 2018).

As part of acknowledging adolescents' vulnerabilities and needs, and the policies that promote their well-being, Malawi undertakes a multidimensional approach.

This is evident in the adoption and implementation of progressive HIV policies (Chirwa et al., 2018), and overarching policy guidelines on development as guided by the Growth and Development Strategy (MGDS I, II, III) (Government of Malawi, 2017b). The National Youth-Friendly Health Services (YFHS) Strategy explicitly addresses the provision of family planning services to adolescents. Policies such as the National Reproductive Health Service Delivery Guidelines lay out adolescent-specific clinical guidelines for health workers.

The National SRHR Policy and the National Youth Policy support age-appropriate sexual and reproductive health education and information (OECD Development Centre, 2018). The development strategies, including the National Youth Policy 2013 (NYP) and health policies (Health Sector Strategic Plan, National SRHR Policy, 2017-2022), are interrelated, in a complementary way linked to the SRHR 2017-2022 to improve universal access to SRH and the demographic dividend – defined as an acceleration in economic growth due to a decline in the country's mortality and fertility rates, with a subsequent change in age structure (i.e. increase in youth population and people living longer) (Government of Malawi, n.d.-a, 2013; OECD Development Centre, 2018; WHO, 2018, p. viii). Despite highlighting multisectoral support through coordination and implementation for ASRH, outcomes related to gender inclusion, service use and HIV rates remain poor.

Another key SRHR policy issue that must be accounted for and is especially relevant to ALHIV is the YFHS, meant to provide services that are more relevant, equitable, attractive, acceptable, accessible and affordable to young people (Feyisetan, Munthali, Benevides, Kazembe, & Mutombo, 2014; Mwalabu, Evans, & Redsell, 2017). Malawi began to implement the YFHS in 2007 (Feyisetan et al., 2014). The WHO (2006b) defines YFHS as 1) nonrestrictive, meaning that it is free and open to all seeking SRH services, 2) support staff oriented towards providing care to adolescents; 3) appealing facilities, for example, facilities with a discreet entrance, 4) convenient opening and closing hours, including opening after school hours; and 5) comprehensive service provision including clinical and psychosocial support (WHO, 2016b). However, even when 'youth-friendly' services adjust to meet all the needs and preferences of a heterogeneous group of adolescents, still

few adolescents make use of the services. Adolescents continue to request open communication and fear negative attitudes from health workers when they request contraception (Bekker et al., 2015; Mwalabu et al., 2017; Self et al., 2018). The provision of YFHS suggests improvements in some but not all steps of the HIV care continuum, and this may lead to the exclusion of youth from care (Reif et al. 2018).

The global paradigm shift from disease-focused care and healthcare worker paternalism to patient-centred care has revolutionised service delivery for people living with HIV (Kok, Widdicombe, Pilnick, & Laurier, 2018; Mutambo, Shumba, & Hlongwana, 2019). For ALHIV, differentiated service delivery (DSD), also known as differentiated care, is a client-centred approach that simplifies and adapts HIV care to reflect the needs and preferences of young people living with HIV to reduce burdens on the health system (MacKenzie et al., 2017; World Health Organization, 2017). DSD is part of a programmatic shift to improve HIV care delivery and outcomes. It emphasises the *WHO* (clinician, lay providers, peers, clients), the *WHAT* (clinical assessment, antiretroviral therapy (ART) refill, viral load and monitoring), the *WHERE* (i.e. healthcare facility, community, home) and the *WHEN* (monthly, every 2, 3 or 6 months) (Armstrong et al., 2018; Reif et al., 2018). DSD caters for adults, breastfeeding women and adolescents; in this thesis, I focus on the teen club clinic. WHO's core principles for adolescent-specific differentiated care includes family-based approaches, integrated services (SRH services, peer education and support groups) and psychosocial counselling (WHO, 2016a; World Health Organization, 2017). However, most results under the DSD model presented by MacKenzie et al.(2017) have concentrated on showing the potential for treatment outcomes, improved ART service uptake (MacPherson et al., 2015) and adherence (Kim et al., 2017), including higher mother-to-child transmission rates, as reported among HIV-infected pregnant and breastfeeding adolescents compared with HIV-infected adult mothers (Callahan et al., 2017; Reif et al., 2018). To date, there has been little work assessing adolescents' experiences on SRH, service use and resilience within teen club clinic settings.

Adolescent wellbeing is based on both positive and negative physical, sexual, neurological and psychosocial health development (UNICEF, 2017). ALHIV are

increasingly becoming involved in their health and disease management (Dulin et al., 2019; Grimsrud, Barnabas, Ehrenkranz, & Ford, 2017), navigating and accessing youth-friendly health service model-teen club clinics (Feyisetan 2014), recognising the benefits of being on ART, making informed decisions on sexual relationships (Pretorius et al., 2015), and living healthy lives (Bacha et al., 2018; Underwood & Schwandt, 2016). Similarly, more researchers show adolescents doing well, showing low substance abuse, late onset of sexual behaviour, giving birth to uninfected babies, and accessing and remaining on lifelong-treatment (D. Bhana, 2018; Callahan et al., 2017; Ghanotakis, Peacock, & Wilcher, 2012; Pearlstein et al., 2013). It is imperative to work out how adolescents strive to do well despite adversities. ALHIV in Malawi have not been asked what it means to have resilience. In my doctoral research and this thesis, I aimed to identify how services and resources concerned with SRH contribute to positive social and health outcomes among ALHIV.

1.4 Operational Definitions

Some definitions that will frame and guide this thesis are as follows:

Adolescents: Age is one of the key attributes that define the biological processes and differences taking place in young people. Adolescence age demarcations may include early adolescence (10-13years), middle adolescence (15-17) and late adolescence (18-19), as the most convenient ways to define different developmental stages (Chandra-Mouli, Svanemyr, Amin, Fogstad, & Say, 2015; Gottschalk & Ortayli, 2014). However, some adolescents experience menarche (onset of menstruation) below the age of 10. In some contexts, they may be viewed as having come of age; this is reflected in the low age of sexual debut in South Africa, the Gambia and Malawi, which increased health risks of this very young population (Blum, Astone, Decker, & Mouli, 2015; Harden, 2014; Holness, 2014; Mkhwanazi, 2006). Age alone cannot fully identify the multiple aspects of adolescence. I draw on the United Nations Children's Fund definition (Unicef, 2011) of individuals aged between 15-19 years as 'late' adolescents; this age range is the focus of this study.

Differentiated Service Delivery (DSD) refers to a client-based approach that simplifies and adapts services for HIV care in ways that serve the needs of people living with HIV and reduces unnecessary burdens on the health system (WHO, 2016a). For ALHIV, I refer to adolescent-centred care or the teen club clinic, which encompasses a holistic approach central to this thesis.



Figure 1. 2 Differentiated Service Delivery blocks

Source: Family Health International (FHI 2017)[2] and WHO (WHO, 2016a)

The four patient-centred care blocks, as indicated above, were developed under the WHO guide and framework: *WHO* (service providers, mentors, patients), *WHAT* (clinical support, antiretroviral therapy (ART) refill, viral load, monitoring), *WHERE* (healthcare facility, community, teen club clinic, home), and *WHEN* (monthly, every two, three or six months) (see Figure 1.2 above).

[2] https://www.fhi360.org/news/betterhivcare-differentiated-models-care-across-hiv-continuum

WHO (2016) recommends including family-based approaches (parents and other caregivers) and integrating psychosocial support and SRH services, peer education and support groups as part of maximising health and social outcomes (Reif et al. 2017). Family and adolescent centred blocks are cut from the same cloth of 'centredness'; however, the former tends to be paternalistic, while the latter has limited evidence of its effectiveness (Mutambo, Shumba, & Hlongwana, 2020). I use the teen club clinic as an essential intervention under DSD, which takes into account the wide array of ASRH contexts, service user experiences, and ALHIV needs.

Formal support includes organisational or service and care agencies, such as interventions and service providers (also referred to as mandated services), such as child welfare, mental health, juvenile justice, YFHS, clinics and educational support (Ungar et al. 2013). The formal service supports provide space for HIV care and reproductive health care and may include offices and places in public and private institutions, and other professional settings, to ascertain how facilitative environments improve personal and peer support and social skills and outcomes for adolescents. The organisation or service care and the environment are defined as any formal establishment providing training, education or support to adolescents who are younger than 20 years of age. However, I do not merely focus on the presence of organisations that enable adolescents to manage adversity; I also consider their access, satisfaction with services, the quality of interactions, and advocacy, including meanings attached to these services.

Informal/alternative supports: These supports include people in a young person's social network, including mentors, peers, family, neighbours, and members of community organisations and other non-professionals (Blum et al., 2017). I consider informal supports as not only embedded within culturally occurring relationships within the family and community but also spiritual support and cultural pride. Hence there is variability in the use and perceptions of these supports in promoting resilience (Theron & Theron, 2014; van Rensburg, Theron, & Rothmann, 2017). Informal health care supports, such as using traditional healers, pharmacies and non-governmental organisations (i.e., Marie Stopes, locally known

as Banja La Mtsogolo), are critical in this study. They afford opportunities to ALHIV to share ASRH experiences and access relational and support networks for well-being.

Protective factors are independent variables that contribute to positive outcomes including environmental (services and agencies), social (parental or community) and individual factors (self-esteem, abilities, skills) which enable adolescents to overcome challenges (Zimmerman et al., 2013). Most researchers have documented that protective factors and resources can interact with existing risks to influence health-promoting behaviours (van Breda & Theron, 2018). I acknowledge ALHIV descriptions of facilitating factors (protective resources or processes that enable better-than-expected outcomes).

Resilience is broadly defined in different disciplines. There is wide agreement that resilience should be considered along a continuum (with constraining and protective factors) and that it is context-based (Luthar & Cicchetti, 2000; van Breda & Theron, 2018). Bollig (2014) and Kaunda-Khangamwa, Maphosa et al. (2020) explained resilience as personal qualities or as quantifiable aspects that enable one to thrive in the face of adversity. I acknowledge that personal factors play a role in ALHIV resilience. But I go beyond individual factors and focus on processes and interactions that have gained currency in understanding resilience across cultures and sub-populations. This resilience as a multidimensional concept affords a definition which is negotiated between individuals, families, communities and collectives, showing both common and unique trends across settings (Ungar 2016, Ungar & Liebenberg 2011). This thesis is informed by resilience, defined as the capacity of individuals, families and communities to navigate resources and collectively negotiate for resources to be provided in a culturally meaningful way (Ungar 2008). The definition is grounded in a socio-ecological framework and strength-based perspective to understand health and wellbeing outcomes (Bronfenbrenner 1979, Ungar 2008).

Resources are part of the three consensual and broad (assets, contextual and resources) elements of resilience (Zimmermann et al. 2013). While 'assets' are mostly linked to individual-level protective factors or inner resilience processes,

'resources' are linked to contextual and relational components located in the individual's environment (Liebenberg, Joubert, & Foucault, 2017). I refer to resources in the individual as including 1) personal skills (e.g., ability to solve problems, cooperate, and awareness of own strengths), peer support, and social skills; (2) relationships with primary caregivers or for adolescent mothers, with others involved in physical and psychological caregiving, and (3) community resources, e.g., educational, health, recreational and social services facilitating connection to culture, religious and spiritual beliefs, and engagement with and relevance of education (Sanders et al., 2013; Sanders & Munford, 2014).

Relational support is mentioned extensively in this thesis. I use this term to refer to some of the resources that ALHIV consider as nurturing, trustworthy and supportive.

Contextual supports refer to health or social resources, including both formal (hospital, clinics, schools) and informal/alternative (communities, spiritual, traditional healers, cultural) supports. ALHIV experiences and context shape their access to these resources, and conversely, their presence in the community can shape ALHIV experiences and outcomes.

Risk factors can be internal or external variables that increase the chance of negative outcomes in individuals or pose new vulnerabilities among ALHIV. I recognise risk frameworks that are manifest throughout adolescence, including physical, social and psychological dangers and including sexuality-related issues (Zimmerman et al., 2013). My focus is not on predicting negative outcomes (a medicalised or reductionist perspective), but rather on risk processes that enhance positive outcomes (a strength-based perspective) during adolescence (Harden, 2014). The discussion is not only for broadly defined risk factors but, rather, for patterns including negotiating and navigating skills relevant to the SRH related risks and general health outcomes and wellbeing.

Service use, according to Li and colleagues (2015) and to Ungar and colleagues (2013), includes 'patterns', 'histories', 'multiple-use', 'concurrency,' or 'no use experiences' in relation to outcomes. I use the term service use to refer to the self-

reported frequency of social, health and clinical service use and experiences over time. Multiple service users were ‘adolescents’ who reported having used two or more services in the previous year, regardless of the frequency of their use of any of these services. Service use reports among ALHIV, health workers and parents/caregivers expose risks related to social and health matters, access to or availability of resources and supports**.** I discuss perceptions, preferences, treatment-seeking and utilisation of health and social services such as youth-friendly health services (YFHs), community-based clubs, spiritual and traditional healing supports, teen club clinics, schools, detention centres, youth centres, community-based clubs and adolescent clinics. These all support ALHIV access to care, and are designed to deliver forms of support that meet both health and social needs (Biddlecom et al., 2007).

The term *sexual and reproductive health* refers to a state of lifespan wellbeing related to sexuality, reproductive processes, functions and systems. I acknowledge the framing of ASRH as predominantly 'medicalised, reductionist and moralised', creating vulnerabilities for diseases/health risks, broken dreams, stigma and discrimination (Bhana, 2018, Harden 2014). *Sexual health* is “a state of physical, emotional, mental and social well-being related to sexuality: not merely the absence of disease, dysfunction or infirmity” (WHO, 2006a). *Reproductive health* is complementary to sexual health and caters for all matters relating to the reproductive system, its functions, and processes (United Nations United Nations, Department of Economic and Social Affairs, 2017). Sexual and Reproductive Health Rights (SRHR) incorporates four key dimensions including the enhancement of sexual and reproductive rights and promoting sexual and reproductive health. I adopt the widely used SRH definition which combines two distinct but combined concepts of sexual health and reproductive health in relation to processes, knowledge, choice and pleasure. (Fortenberry, 2013; Hensel & Fortenberry, 2013; WHO, 2006a). Guided by Bhana and others (2011; 2016; 2015, 2018) and others (Hensel & Fortenberry, 2013; Mkhwanazi, 2006; Zgambo et al., 2018)**,** I refer to SRH as a guiding paradigm in adolescence. I draw on the public health literature in which SRH is presented as a means of promoting wellbeing and personal relations and not merely the prevention of adverse health outcomes.

Most interventions on family planning and contraception use SRH as a comprehensive framework. However, SRH as a blanket term for family planning or contraceptive use may obscure our understanding of the importance of meeting the contraceptive and reproductive needs of ALHIV. In the context of ASRH and those living with HIV, I was open to the idea that adolescents would use contraception, and these might include any of a range of technologies: condoms, pills, intrauterine devices, male condoms, injectables, implants, vaginal barrier methods, female condoms, and emergency contraception. Sexually active ALHIV may or may not want a family (at the time) and may or may not use contraception. As I argue later in this thesis, services available to them need to take this into account. I define *modern contraceptive use* to describe whether an ALHIV is currently using at least one modern method of contraception. I use the term family planning to describe the use of contraception, without assuming that reproduction occurs particularly in a family formation and in the context of this thesis, family planning need indicates that an ALHIV wishes to stop or delay childbearing and is not currently using any method of contraception.

In the thesis, I depended on secondary data for contraceptive/family planning use. Through interviews, I captured nuanced experiences of ALHIV planning to have children or not, for safe sex, sexual pleasure and whether they had the power to make informed decision to access or not SRH related services and methods.*Sexual behaviours for adolescents* are also commonly framed as a measure, for example, of no sex (abstinence), sexual onset (first sex before the age of 15), with multiple sexual partners, and in relation to representations of teenage pregnancy or abortions and prevalence of STIs and HIV (Boislard, van de Bongardt, & Blais, 2016; Feyisetan et al., 2014; Polis et al., 2017). However, measures or statistical estimates to understand SRH, can focus on one or two indicators, rather than giving a holistic understanding of concepts (Hensel, Nance, & Fortenberry, 2016). In this thesis, I move beyond abstinence, partnered sexual behaviours and barriers to STI care to capture nuances in ASRH experiences across physical and social spaces.

Spaces: I refer to different spaces and places which provide different opportunities to bring together gaps in ALHIV related experiences in the literature, including

enabling individuals and groups to discuss their experiences of sexuality, reproduction and contraceptive use. 'Spaces' were part of the puzzle for this thesis, and I reflect on Abbott-Chapman & Robertson (2015) and Autres & Miskowiec (1984) and others on ideas of particular space as 'positioned in a web of divergent spaces'. I also follow Massey's (2005) notions of 'space' and 'place' as products of contestations, sites of interrelationships, and as being social rather than material, and so shapeless (Massey, 2005). I reflect on spaces and places as material (ecological), dialogical (talks) and transformative (experiences) (Abbott-Chapman & Robertson, 2015; Sudradjat, 2012). I visualise space as heterogeneous, with the potential to transform the lives and experiences of ALHIV.

Wellbeing: Definitions of wellbeing vary, ranging from subjective (optimism, meaningful life experiences) to objective, including material resources (e.g., income, food, and housing) and social attributes (education, health, political voice, social networks, and connections) (Ross et al., 2020, p. 473). McPherson and colleagues (2013, p. 4) refer to psychosocial wellbeing as including emotional wellbeing (e.g. happiness, satisfaction with life); psychological wellbeing (e.g. autonomy, resilience); and social wellbeing (e.g. the opposite of disorder, delinquency, interpersonal violence and bullying). For adolescents' wellbeing, in this thesis, I use a broad, capabilities-based approach and include social and developmental tasks. These include having a voice, a choice, building resilience, access to schools or not, independence, forming relationships, realising their potential, and striving for a satisfying life.

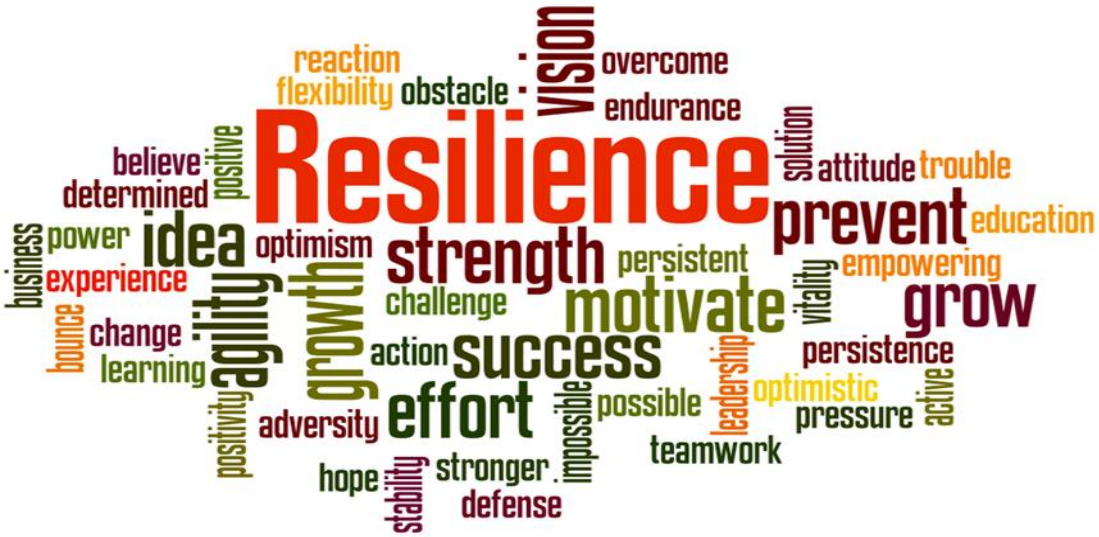
Reflecting on definitions, in the thesis I draw on the works and broad ranges of theories, including but not limited to resilience, development and constructionist interpretive approaches. This is part of contributing to comprehensive approaches and multilevel frameworks to addressing ASRH and wellbeing of adolescents. I will return to the approaches and frameworks in the following chapter, the literature review, in particular sections 2.4 and theoretical notions (2.9) focusing on strengths-based perspectives on SRH. I now turn to the literature, to consider research on SRH, service use and resilience in Malawi and experiences across global settings.

This literature informs my understanding of the research gap and characterises the current evidence base.

CHAPTER TWO

RESILIENCE AND ADOLESCENTS LIVING WITH HIV

LITERATURE REVIEW



2.0 Introduction

Within the social sciences, there is a plethora of literature on adolescence, resilience with gaps and inconsistencies in research findings on 'resilience and HIV'. Literature on sexual or reproductive resilience and strength-based models that show adolescents as visible experiencing sexuality and agency are under addressed. Disparities surround the meanings and experiences of 'doing well' among adolescents living with chronic conditions, of which HIV infection is one of the most common. Empirical studies on resilience have mainly been concentrated in the northern hemisphere on adults and attended to psychological factors, trait resilience, mental issues, depression and resilience measures (Windle, Bennett, & Noyes, 2011). Much is known about adolescents' vulnerabilities and risk factors for poor outcomes (Ungar 2016). The extant literature, exploring the role of protective

factors, resources and processes in relation to ALHIV in low and middle-income country settings, is sparse (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013; Eshun-Wilson et al., 2019). My interest in exploring adolescents doing well, despite adversity, is supported by the international discourse that supports strength-based models that enable them to navigate their environment effectively, relate well with others, perform well and achieve their goals (WHO 2017a). This positive orientation is critical in this study as it modifies our focus to non-pathologising, holistic discourses on ALHIV and their relational supports as they engage with varied forms of services for their wellbeing. Throughout the thesis, I recognise that the ages of 15-19 represent a window of opportunity to explore, support and cater to adolescents' multiple vulnerabilities and complex needs (Rankin 2016, Soeters et al. 2015).

Guiding this chapter is a 'thick description' of the data, and from this the analysis and interpretation of resilience as a concept, process and experiences that exemplifies mixed-methods approaches for a richer understanding of service ecologies and supports (Clifford Geertz, 1973; Maharaj, 2016). In addition, as I illustrate, resilience varies widely by context, culture and time. I elaborate on the concept of resilience as a social construct and include competing discourses (individualism, processes and genes), localising these discourses within a social constructionist perspective and socio-ecological framework. I present an overview of the origins of resilience studies, and to SRH experiences and outcomes, at the global level and in Malawi. The discussion on sexual and reproductive resilience narrows down to consider how a strength-focused perspective is useful to understand adolescent SRH outcomes and wellbeing. I draw on different resources and definitions as part of bringing forth hidden or unnamed factors, processes and pathways to resilience among ALHIV. In the last section, I turn to resilience measurements, focusing on how mixed methods and various resilience scales inform reliable and valid resilience measures across social contexts. The chapter ends with a discussion of the research gap, objectives, and conceptual and theoretical framework that informed the study on which this thesis is based and affords clarity on key concepts discussed in the study.

2.1 The Concept of Resilience and Definitions

Exploring and understanding how ALHIV are able to do well despite adversities such as living with a chronic condition, taking medication for life, poverty, stigma and discrimination, is at the centre of research interest and policy (Eshun-Wilson et al., 2019; WHO, 2017a). What makes it more complicated is that not all ALHIV can manage their hardships fully, are able to conceptualise (let alone realise) resilience, nor understand what risk factors encompass. This warrants an inquiry into what distinguishes ALHIV from others in relation to positive outcomes regardless of difficulties – resulting in resilience-related research and practice. I briefly reflect on the history of resilience as a concept and analysis (using the four waves) to review the scholarship with a particular focus on the global south and especially the Malawi context to situate my PhD work.

What does resilience entail? Resilience is a broad and elusive concept, and encompasses a variety of definitions and operationalisation. The debates on what resilience encompasses continue to grow in prominence in anthropology and cognate social sciences, including public health (Panter-Brick, 2014; van Breda, 2018). This highlights questions on the elements involved and the content and components of resilience over time. For instance, resilience has been defined by various authors as

> ... the process of effectively negotiating, adapting to or managing significant sources of stress or trauma (Windle et al., 2011).
>
> ... a continuum of adaptation, management, success or competence in culturally relevant ways Masten (2011, p. 494)
>
> ... a process of overcoming the negative effects of risk exposure, coping successfully with hardship experiences, or avoiding the negative trajectories associated with risks (Fergus & Zimmerman, 2005, p. 399).
>
> Simply put, resilience refers to successful adaptation in risk settings(Kabiru, Beguy, Ndugwa, Zulu, & Jessor, 2012, p. 13)

These definitions mirror those from earlier research on resilience by Ungar (2005, 2008, 2016) and Luthar (Luthar & Cicchetti, 2000; Luthar, 1990) and broaden their focus to include processes, interactions and contextual resources; this is critical for my research work (Sanders, Munford, Thimasarn-anwar, & Liebenberg, 2017; van Breda & Theron, 2018). Resilience is currently recognised as 1) an interactive process, 2) dependent on individual assets (positive emotions, competence, humour), contextual factors (institutional, relational, cultural) and resources, 3) occurring within an unstable environment (DeMichelis, 2016). It involves acknowledging the interactions and processes that influence 'doing well', including competencies and resources surrounding an individual despite their exposure to risk.

Guiding this thesis is Ungar's (2008, p. 225) definition of "resilience as both the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being, and their capacity individually and collectively to negotiate for these resources to be provided in culturally meaningful ways." Despite resilience encompassing the simple definition of "doing well despite adversity," Ungar's more complex definition is critical. It allows me to explore the complex factors impacting resilience (2008). Hence, resilience is used as a heuristic focusing on a strength-based perspective to enable insights into positive outcomes across ALHIV.

2.2 The Four Waves of Research and Strength-Based Processes

To many resilience is seen as a measure of personal capabilities, including assets such as self-efficacy, competence, optimism and flexibility. This rarely explains the variations in adolescents' behaviour across situations (Garmezy, Masten, & Tellegen, 1984; Theron & Theron, 2010). The focus on individual-based factors, risks or traits characterise the first wave of resilience studies in the 1970s, which were predominantly 'westernised, individualistic and lacking cultural lens' (Madurai et al., 2020; Panter-Brick, 2014). Some studies focused on how children facing mental-related risks, war, and significant disasters managed to handle hardships (Emmy, 2005; Rutter, 1987). Others, such as Werner (2005) on Kauai Island, Hawaii, working with people facing multiple risks such as poverty and

violence, showed that factors such as self-confidence, appealing personalities, and family support enabled children to perform better, thus differentiating between resilient and non-resilient children (Emmy, 2005). I acknowledge that personal attributes continue to play an important role in building resilience as they are part of our everyday lives, hence readily recognisable. In this study, I include individual dimensions as part of deepening our understanding of 'contextual sensitive' attributes that determine resilience among adolescents in Malawi, although I maintain focus on relationships rather than individual personality traits.

The criticism of reliance on individual traits, leading to a list of descriptive characteristics without underlying processes that contribute to 'doing well', led to the second wave of resilience studies, summarised below (see Figure 2. 1). These studies discussed the role of protective factors such as assets and resources, including processes that reduce the effect of risks (Fergus & Zimmerman, 2005; Ungar et. al., 2007). A socio-ecological interpretation of resilience, centring on intervention programme, shifts the focus from predominantly clinical management of practical challenges (Obrist, Pfeiffer, & Henley, 2010; Sanders, Munford, Thimasarn-anwar, Liebenberg, & Ungar, 2015). This shift represents the third wave of resilience studies which has facilitated therapy research and strategies.



Figure 2. 1: Depicting resilience research since 1970s

(Source: Adapted from Liebenberg et al., 2017)

The motivation in this work is on the tensions and interplay between individuals, including multilevel contexts (access to resources, relationships, identity, power,

culture) as emphasised by Ungar and Liebenberg (2011) to deepen our understanding on resilience processes and outcomes. Based on a multilevel analytical framework, development theorists have assessed the trajectories of time (life-course) and boundaries of space, and how these influence resilience outcomes (Panter-Brick & Eggerman, 2012). Hence the focus of socio-ecological interpretation in this study, which envisaged the dynamic role of institutional service provision and usage, in particular, the Saturday teen club clinic, in fostering resilience among young people aged 15-19.

The fourth wave of resilience studies, as discussed by Masten (2011, 2015, 2018), reflects research based on multilevel analysis, biological influences and dynamics of managing risks. This wave discusses the interactional processes spanning across multidisciplinary approaches (the molecular, genetics, interactional supports and modelling) as part of bringing evidence from science into practice (Masten, 2015, Panter-Brick 2014). However, this study did not reflect on biological influences on resilience; rather, as I describe throughout, I focus on multilevel and dynamic perspectives to highlight variations across context, individuals and culture.

2.3 Adolescence, Age, Gender and Resilience

Adolescence is a complex period characterised by well documented biological, developmental, psychological and behavioural changes (UNICEF, 2017; WHO, 2017a). As a developmental stage, adolescence is essentially a period between the onset of puberty and the establishment of independence (Ahorlu, Collins K, Pfeiffer, & Obrist, 2015; Blum et al., 2015; Hudelson & Cluver, 2015). Age and gender are both facilitating factors and barriers to resilience and management strategies (McMaken, 2000; Sokol, 2009). Younger adolescents are likely to have higher resilience scores than older adolescents due to their access to family support (Govender, Cowden, Asante, George, & Reardon, 2017). Older adolescents tend to interact more with peers, and this often heightens their vulnerability (Bernays, Paparini, Seeley, & Rhodes, 2017). Girls report greater resilience and use family and institutional support systems more than boys (Hampel & Petermann, 2005; Theron & Malindi, 2010) and girls communicate more and seek help from others, while boys use aggression, sports, pride, and experiences to manage adversity

(Theron & Malindi, 2010). Age and gender issues are critical and highlight different interactions, relationships to the environment, and access to resources for their wellbeing.

2.4 Adolescence, HIV and Resilience

ALHIV experience more daily living and social functioning adversities compared with peers of the same age without a chronic illness, which leads to low aspirations, poor goals and failures (Betancourt et al., 2013; Donenberg Geri & Pao, 2003). ALHIV face 1) trauma, stigma, violence and poverty which exacerbate poor health and social outcomes related to treatment adherence and clinic attendance (Dulin et al., 2019); 2) record high rates of unprotected sex and teenage pregnancies as they try to meet their sexual needs, marital and reproductive roles (Birungi, Mugisha, Obare, & Nyombi, 2009; Callahan et al., 2017; Eshun-Wilson et al., 2019); 3) low rates of disclosure to sexual partners for fear of rejection (Toska, Pantelic, Meinck, & Keck, 2017); 4) learning difficulties (Laughton et al., 2013; Pretorius et al., 2015); and 5) family breakdown leading to child-headed homes (MacKenzie et al., 2017). HIV/AIDS is also the leading cause of death among 10-19 years old (OECD Development Centre, 2018). The MDHS 2015-16 mentions that about 34% of women in Malawi had experienced physical violence from the age of 15 (National Stastical Office (NSO) [Malawi] & ICF, 2017). Twenty-five percent of sexually active AGYW aged 15–19 characterize their sexual debut as forced (Decker et al., 2018). In addition, rape, among AGYW aged 13-24, has the potential to cause gynecological, SRH problems, HIV, STIs and unwanted pregnancy (Macpherson et al., 2014, Nguyen et. al., 2021). Despite the above challenges, adolescence is a unique and formative time which provides a window of opportunity to explore, support and cater to their multiple vulnerabilities and complex needs (WHO, 2017a).

ALHIV link with relational support within families, alternative care and institutional support for both clinical and social care. However, previous studies suggest that relational support (being closer to parents, caregivers and health workers, and having mentors) was negative, leading to anger, isolation, depression, secrecy and rebellion in both public and private spaces, hence affecting young

people's motivation to do well (Eshun-Wilson et al., 2019; Mattes, 2014). I acknowledge the multiple and competing relational factors, discourses and interactions at varying levels that may affect ALHIV. The benefits of taking ART for ALHIV include 'living healthy lives' (Bacha et al., 2018; Underwood & Schwandt, 2016); managing their behaviour, status and medication (Beckmann, 2013; Bernays et al., 2017); and giving birth to uninfected babies (Callahan et al., 2017; Darroch, Singh, Woog, Bankole, & Ashford, 2016). In a paper which was published this year, Kaunda-Khangamwa, Kapwata et al. (2020) (see Chapter six), I refer to ALHIV using strategic silence and choices to make informed decisions on SRH issues and entrepreneurship, while other adolescents were motivated to uphold educational values (OECD Development Centre, 2018; Rensburg & Theron, 2018). I also acknowledge the positive experiences for ALHIV, such as forming relationships and seeking hospital/clinic support (Bacha et al., 2018; Dahourou et al., 2017). In this thesis, I highlight functional and critical roles and experiences in enhancing ALHIV capacity to make informed decision making, access to institutional support, and forming safe relationships.

2.5 Sexual and Reproductive Health

The World Health Organization (WHO, 2006a) defines sexual health as "a state of physical, mental and social well-being in relation to sexuality." As discussed in the previous chapter, reproductive health is defined as “a state of physical, mental and social wellbeing and not merely the absence of diseases or infirmity in all matters relating to the reproductive system and to its functions and processes” (United Nations 2017:1). Reproductive health focuses on methods and services that enable access to accurate information, protection from sexually transmitted infections (STIs), and family planning (e.g. whether or not, and when, to have children). I refer to Epstein and Mamo (2017), who in their work conjoined or used the compound phrase 'sexual and reproductive health’ (SRH) as part of appealing to the multiple spaces that are open to discussion and are heterogeneous and non-stigmatising. I include the quantitative and qualitative exploration of SRH to deepen our understanding of ALHIV experiences across social spaces. For instance, Donenberg and colleagues (2003), discussing personal traits and the potential effect on

sexuality, argued that persons with high esteem delayed sexual activity and ultimately, reproduction. The focus is on positive and respectful approaches to sexuality and reproduction, relationships, and pleasurable and safe sexual experiences free of coercion and discrimination. However, there is inconclusive evidence of positive SRH experiences among ALHIV receiving facility-based support.

2.6 Sexual Resilience

Sexual resilience is defined as an individual's or couple's ability to handle and manage challenges, including the capacity to enter into an intimate relationship or not (Beck & Robinson, 2015). However, most ASRH measurements are recorded as an absence – e.g., never having engaged in sexual activity, never having contracted STI, or never having been pregnant. There is little discussion of 'healthy' sexual behaviours among adolescents. Scholars have coined concepts such as 'sexual readiness,' 'sexual capital,' and 'sexual competence' as relevant to the idea of adolescents taking control of their sexual relationships and behaviour (Biney & Dodoo, 2016; Cox, 2011; Limaye et al., 2012). These concepts provide space to discuss adolescents' preparedness to engage in sex, with the right person, at the right time, with the willingness of both partners and full knowledge about safe sex (Biney & Dodoo, 2016). There is a need to balance adolescents' sexual interests and the laws governing sexual relationships to enable a negotiation space that allows for choices. These might include sexual function, pleasure, delayed sex, fewer incidences of unsafe sex, less infection, and avoiding unintended pregnancies, and informed consent to engage in sex.

2.7 Reproductive Resilience

Reproductive resilience for young women refers to their capacity to adapt or to be competent in preventing or managing pregnancy (Pfeiffer et al., 2017). Pregnancy is conventionally regarded as a health risk among adolescents because it is associated with HIV infection and re-infection, childbirth complications, infant and maternal deaths, school discontinuation and other socio-economic implications (Callahan et al., 2017; de Araújo, Teva, Quero, Reyes, & de la Paz Bermúdez, 2017;

Mwale & Muula, 2018). Hodes and colleagues and Mkhwanazi both suggest that teenagers are often reluctant to delay pregnancy because their lives are enriched when they become mothers (Hodes, Toska, & Gittings, 2016; Mkhwanazi, 2006). A few studies have identified social capital (social supports that have productive benefits, caring caregivers) as providing adolescents with agency, referring to the capacity to make informed choices related to pregnancy (Ahorlu, Collins K et al., 2015). Sources of social capital, mobilisation, and dialogue, including relational support (parents, siblings) and institutional support (nurses, mentors), cater for reproductive preparedness by sharing SRH knowledge, encouraging competency, ensuring knowledge about sexual intimacy and reproduction, and facilitating access to services and the supply of and support for the use of contraceptives (Bhuiya et al., 2017).

Not all relationships with at least one caring, competent and reliable adult ensure adolescents' wellbeing. Parents in Tanzania failed to improve adolescents' sexual and reproductive resilience because they could not discuss sexual matters openly (Pfeiffer et al., 2017). For ALHIV, seeking SRH at both community and clinic levels can cause mixed reactions because of the association of sex with promiscuity, stigma, shame and rejection. These negative attitudes heighten secrecy and make it harder for young people to access appropriate SRH services (Eshun-Wilson et al., 2019; Toska, Pantelic, Meinck, & Keck, 2017). Breaching the culture of silence among orphans in Uganda enhances resilience (Daniel et al., 2009). However, patterns of disclosure, silence-breaking and secrecy change over time, depending on circumstances and context (Daniel et al., 2009; Davis & Manderson, 2014; Manderson, Davis, Colwell, & Ahlin, 2015). In addition, secrets of all kinds exude power (Manderson et al., 2015). Thus it becomes problematic for adolescents to attend to the public health call to disclose one's HIV status in an intimate relationship, adhering to medication because they fear rejection, exposure and social exclusion (Manderson et al., 2015). Pregnancy for ALHIV is a mixed blessing, so harnessing a strength-based focus allows for an exploration of the effects of support systems for adolescents to make healthy SRH choices.

2.8 Adolescence, the HIV Epidemic and SRH in Malawi

In addition to understanding sexuality and reproductive health experiences of ALHIV, regardless of whether they were infected perinatally and horizontally, measuring ASRH outcomes is important for identifying contextual risk factors for adolescents' health. Malawi's current population is 17,9 million, with a median age of 17 years; 45% of the population is less than 15 years (National Stastical Office (NSO) [Malawi] & ICF, 2017). ALHIV aged 15-24 recorded 25% of all new HIV infections in 2019 (Government of Malawi, 2020). Adolescent girls are at extreme risk for poor SRH outcomes due not only to high HIV prevalence but also to poverty, orphanhood, and, as a result of early sexual debut, very early marriages and early age at first reproduction (5% by 15 years and 12% by 16 years) (Lusinje, Phiri, Majawa, & Muula, 2015). Malawi has one of the highest early child marriages in Africa (UNICEF 2019): by the age of 15, nine percent of girls are married, 42% are married by the age of 18; among boys, one percent are married by the age of 15 and six percent are married before they turn 18 (University of Zurich et al. 2018). AGYW face greater SRH related risks than young men, as 47% marry before they reach 18 years, while eight percent of men marry at that young age (MDHS 2015-16). In 2017, Malawi amended its constitutional provision to set marriageable age for both genders at 18 years as part of the initiative to curb early child marriages (Mwambene, 2018).

ALHIV are a particularly vulnerable group for behavioural and developmental reasons, with high risks for transmission of sexually transmitted infections (STIs), antiretroviral drug resistance, and pregnancy (Callahan et al., 2017; Eshun-Wilson et al., 2019). However, Munthali & Zulu (2008) and the results from a survey report on traditional practices by National Statistical Office and colleagues (2019) in Malawi argue that sexual activities and the value of parenthood are encouraged at a very early age through ‘rites of passage’ which create ambiguities in relation to ASRH outcomes.

2.9 Health Service Use and Strength-Based Approaches

Combining the measurement of SRH outcomes with health service usage provides a more context-rich picture of ALHIV health risks. A large part of the literature on ASRH service use has focused on barriers to accessing and utilising services (Chandra-Mouli, Svanemyr, et al., 2015; Feyisetan et al., 2014; Gottschalk & Ortayli, 2014). These include both ALHIV and adolescents without HIV experiencing age restrictions, lack of privacy (Toska, Cluver, Hodes, & Kidia, 2015) and confidentiality, feelings of fear and shame, and negative providers' attitudes (Zgambo et al., 2018). However, few studies have examined and explored how service provision and use contribute to resilience. Positive framing institutions are imperative in decision making and support, and influence access to care for ALHIV including but not only for those on ART (Kok et al., 2018). Understanding service provision and use via a positive orientation are critical for practice and policy.

Adolescents take multiple and unexpected pathways (social supports, routes and courses, according to behavioural or developmental models) to do well (van Rensburg et al., 2017). For example, Rensburg and colleagues (2018) and Sanders and colleagues (2014) claim that the use of mandatory services, defined as formal services/systems (child welfare, mental health services, alcohol and drug services, juvenile justice), facilitate positive outcomes for adolescents facing adversities. Likewise, service use is a protective factor for adolescents' health and can lead to service acceptance, developmental outcomes such as safer-sex behaviours, delayed sexual onset and agency in decision making (Harden, 2014; Macdonald, Verster, & Baggaley, 2017). The same pathways and adversities can lead to broader outcomes (connections to caring peers, adults, developing decision-making skills, competence), thus raising questions about adolescents' choices and use of opportunities.

Adolescent involvement in communities through ceremonies and cultural programming such as rituals, initiation rites, and circumcision ceremonies offer an alternative to negative behaviours and influences (Lydia Wood, Kamper, & Swanson, 2018). Rites of passage and initiation ceremonies are still conducted in

Malawi in various communities, and these provide a context within which to teach adolescents on SRH issues, including how to deal with pubertal body changes and the meanings that adolescents attach to these changes (Feyisetan et al., 2014; Makwemba et al., 2019). According to the Malawian literature, most SRH related outcomes such as experimenting with sex after initiation are tolerated, with girls being advised to stretch their labia because of the understanding that men enjoy pulling them during sexual intercourse (Bagnol, 2011; Undie, Crichton, & Zulu, 2007). The makeshift huts erected outside villages for either boys or girls coming of age provide space for puberty rites which mark the transition into the sexual world (Munthali & Zulu, 2008). Adolescence in many cultures is associated with initiation rites that may enhance pride and a sense of belonging. They do not, however, generally include discussions of HIV risk, care and support. The distinctiveness and significance of menarche in the reproductive process are instrumental in getting communities [including churches] to have organised systems of counselling for girls (and boys) on sexuality issues, even in societies that typically do not have formal initiation ceremonies (Munthali & Zulu, 2008, p. 8). In this research, I needed to consider such alternative spaces that make ASRH issues visible, and so create a supportive and inclusive environment.

2.10 Resilience Measures

Another key requirement in resilience studies is the measures that focus on components and factor structure across settings. Measures of resilience have been predominantly cross-sectional, used mainly with adult populations and involving quantitative procedures in middle and high-income settings, including South Africa (Govender et al., 2017; van Breda & Theron, 2018; Windle et al., 2011). However, the procedures to follow, instruments and dimensions (individual, relational, contextual) to use vary across context, culture and population. Few resilience measures have been validated in African settings, in particular, the CYRM used among adolescents, which includes a Resilience Scale (RS), Child and Youth Resilience Measure (CYRM) and Pathway to Resilience Youth Measure (PYRM) (Pearce, 2015; van Rensburg, Theron, & Rothmann, 2015; Windle et al., 2011). No scale or measurement is considered as superior (Windle et al. 2011), and scholars

continue to question the feasibility to generate reliable and valid measures of resilience.

The CYRM-28 tool was identified as the most relevant measure of resilience for this study. The tool was validated by Liebenberg & Ungar (2011) and has predominantly been used among multicultural youth, with 1451 youth facing adversities in 11 countries (South Africa, Tanzania, Gambia, Israel, Palestine, Russia, India, China, Colombia, USA and Canada) in both the global north and south (Liebenberg & Ungar 2011, van Rensburg et al. 2015). Sanders and colleagues (2017; 2013) used a CYRM as a sub-scale to measure adolescents' perceptions of resilience-promoting resources, including 1) school enrolment and attendance, 2) pro-social behaviour, kindness, and concern for others, including participation in community-level meetings, and 3) risks (individual and contextual exposure to chronic adversity) (Sanders, Munford, & Boden, 2017). The CYRM is relevant to identify individual, community and contextual characteristics of resilience-related patterns, processes, and associations over the life-course for ALHIV.

Qualitative research within resilience studies remains underutilised. Windle and colleagues (2011) and van Rensburg and colleagues(2015) argue for supplementing quantitative survey scores, for strengthening findings and potentially redressing the bias that can emerge when qualitative inquiry is missing. Resilience studies can employ a multimethod approach to generate 'exciting' (Liebenberg & Ungar 2011) data, and to expand the scope and improve the analytic power of resilience studies (Kabiru, Beguy, Ndugwa, Zulu, & Jessor, 2012; Ungar, Liebenberg, & Ikeda, 2012). Ungar and colleagues (2005; 2012) used qualitative methods iteratively, including photovoice, games and talking circles to ensure richer narratives across cultures in Canada. In South Africa, Wood and colleagues (2012) used folktales among orphans to understand their resilience. Both quantitative and qualitative methods are essential to understand the pathways underlying resilience among ALHIV. In the current study I used survey methods combined with in-depth interviews, observations and focus group discussions, with ecomaps used to assess the needs of individuals and families within their ecological life-spaces (Hartman,

1978, 1995).The ecomap is a simple paper-and-pencil simulation that has been developed as an assessment, planning, and intervention tool, and in this study enable us to identify and summarise the informal and formal resources that adolescents negotiated to meet their SRH needs (Bennett & Grant, 2016; Ray & Street, 2005).

As part of a multimethod approach to triangulate the data and strengthen both social and health outcomes, the Global Early Adolescent Study (GEAS) tool was incorporated to provide information for sexual and reproductive wellbeing (Chandra-Mouli et al., 2017). Adolescents from multicultural backgrounds were involved in a 15 multi-country study, conducted in urban areas in low-income countries, and this study informed the GEAS tool developed by researchers from WHO, UNFPA and John Hopkins, Bloomberg School of Public Health (Blum et al., 2017; Mmari et, 2017). The goal of the GEAS is to identify and measure changes in gender norms, health and attitudes towards SRH decisions and well-being among young adolescents aged 10-14 (Kågesten et al., 2016; Lane et al., 2017). The tool includes clusters of questions including 1) family, 2) peer, 3) school (structures, connectedness, communication, expectations) 4) sexual behaviour, 5) empowerment, 6) media, 7) health literacy, 8) community and 9) health systems monitoring and expectations. Hence a modified and validated GEAS tool was used side-by-side with CYRM to strengthen findings on gender, family, peer relationships, and cultural experiences among ALHIV.

2.11 Problem Statement

There is inconclusive evidence on sexual and reproductive health (SRH) service usage and resilience for ALHIV. Biddlecom and colleagues (2007) mention that service use is influenced by multiple and competing social and health factors such as perceptions, preferences and utilisation of health services; and accessibility to youth-friendly health services (YFHS) and adolescents' clinics for continuity of care. The term health service is defined as the provision of both clinical and social support, including information and advice aimed at preventing health problems, or detecting and treating them (WHO, 2001). Yet a large part of the literature on adolescent SRH (ASRH) service use has focused on barriers to accessing and

utilising services (Chandra-Mouli, Lane, & Wong, 2015; Eshun-Wilson et al., 2019; Gittings et al., 2016); for both ALHIV and adolescents without HIV such as age restrictions, lack of privacy (Feyisetan et al., 2014; Munthali, Chimbiri, & Zulu, 2004; Toska et al., 2015), confidentiality, fear, shame, and providers' attitudes (Callahan et al., 2017; Darroch et al., 2016). Few studies examine and explore service provision and use as a component of resilience. Positive framing institutions are imperative in the formation of collective identity and therapeutic citizenship, which influences access to care and adherence to lifelong medication (Kok et al., 2018; S. Russell, Namukwaya, Zalwango, & Seeley, 2016). Understanding service provision and use in a positive orientation are critical for practice and policy.

2.12 Research Gap

SRH management is not centred on condom use and medication alone. Previous studies with adolescent have addressed a range of topics -- sexual behaviours, STI prevention, delays in pregnancy -- but most of these studies have used a lens of risks and HIV prevention (Eshun-Wilson et al., 2019; Toska, Pantelic, Meinck, Keck, et al., 2017). ALHIV in Malawi require care for SRH issues and decision making. Research on ALHIV service usage is limited, and studies conducted in Malawi have focused on poor treatment outcomes and limitations of service delivery for continuity of care (MacKenzie et al., 2017; Ssonko et al., 2017). There is added complexity due to adolescent stages of development, and limited intervention programmes that show adolescents' capacity to transcend risks and address SRH challenges.

Targeted programmatic HIV-focused interventions employing the resilience lens are sparse. For Malawi, there is a growing literature on resilience and interventions informed by the US President's Emergency Plan for AIDS Relief (PEPFAR). The DREAMS (Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe) initiative predominantly focuses on reducing HIV incidence among adolescent girls and young women (AGYW) aged 15-24 (Fleischman & Peck, 2017; Madurai et al., 2020; Saul et al., 2018). The initiative centres on interventions that reduce the impact of structural drivers such as HIV risk, poverty, gender inequality, sexual violence and lack of education to promote health and social outcomes among

AGYW and male partners (Saul et al., 2018; US President's Emergency Plan for AIDS Relief (PEPFAR), 2017). This focus is understandable because adolescents' girls and young women are 14 times more likely to be infected with HIV compared to their male counterparts, highlighting the disproportionately high HIV incidence over time (Brown et al., 2018; Fleischman & Peck, 2017; Saul et al., 2018). Other studies have looked at resourcing resilience in the form of targeted social cash transfers among 13-22 year olds to improve school retention rates and reduce sexually transmitted disease as well as lowering HIV prevalence in Zomba districts, with mixed outcomes (Baird, Garfein, McIntosh, & Özler, 2012; Gittings et al., 2016). There is a large evidence gap that needs to address resilience as a construct that is assumed to improve adolescents' wellbeing.

The adolescent/teen club clinic is an adolescent-centred differentiated care model that appears useful to support ALHIV on ART in terms of retention and adherence (Kim et al., 2016; MacKenzie et al., 2017; MacPherson et al., 2015). Most studies on the care model do not show service use, satisfaction and positive research outcomes in the context of SRH (MacKenzie et al., 2017). There is little work on increasing knowledge and enhancing ASRH service use (Self et al., 2018), pro-social behaviours (Kabiru et al., 2012), 'sexual readiness' (Biney & Dodoo, 2016; Pfeiffer et al., 2017)', 'reproductive preparedness'(Ahorlu, Collins K et al., 2015; Gyan, Ahorlu, Dzorgbo, & Fayorsey, 2016); safe sex, or a decrease in STI (Villa-Torres & Svanemyr, 2015). I focus on the promotion of positive discourses and behaviours that allow adolescents' voices to be heard, empower them to make informed decisions, and enable them to narrate their own stories to achieve important everyday goals.

2.13 Justification for the Study

Previous studies on service use and risks indicate that greater service use and satisfaction result in resilience and functional outcomes (better decision making, resisting high-risk behaviour, increased sense of competence, improved connections with others and service use) (Govender et al., 2017; Sanders et al., 2017). McKenzie and colleagues (2017) identified peer counselling and support and attending adolescents' clinics and teen clubs as promising strategies to improve

adolescents' wellbeing in Malawi. Harnessing the strengths and competencies of ALHIV will advance our understanding of the multiple factors and social meanings, influencing access and service utilisation among ALHIV. These goals inform youth-friendly service practice.

2.14 Aim and Objectives of the Study

The overall aim was to describe and analyse protective factors and resources that influence SRH service utilisation among ALHIV in Malawi. The objectives of the study were to:

1. Determine factors associated with resilience among ALHIV
2. Describe and analyse resilience-promoting resources among ALHIV
3. Describe and analyse formal and informal pathways of adolescent service use that promote positive outcomes
4. Explore SRH ecologies that influence resilience among ALHIV.

2.15 Theoretical and Conceptual Framework

To cater for the multiple sexual and reproductive needs of ALHIV, a combination of technical, constructionist and interpretive approaches, as well as multilevel and interactive processes, are needed. This thesis was informed by the work of several scholars from the northern and southern hemisphere, and their concepts and theoretical frameworks to understand SRH experiences, service use and resilience among ALHIV (Bhana, 2018; Eshun-Wilson et al., 2019; Harden, 2014; Liebenberg et al., 2017; Panter-Brick, 2015; Singh, Both, & Philpott, 2020; Skovdal et al., 2017).

2.15.1 Resilience Theory

As discussed earlier, this thesis builds on three out of the four waves of resilience theory, ecological model and behavioural sciences (psychology and anthropology), to understand resilience within individual and social ecologies. Resilience theory provides the opportunity to look at interactions and processes between protective and risk factors as elucidated in work across disciplines and boundaries by drawing on developmental theory (DeMichelis, 2016; Sanders, Munford, & Boden, 2017),

utilising a socio-ecological framework (Bronfenbrenner 1979, 1986), and focusing on health and well-being (CDC, 2016). The advantage of recognising wellbeing is that allows for a broad range of outcomes to be included in the enquiry: it encompasses functional outcomes, positive emotions (happiness), resilience, good health, social relationships, access to resources, and overall satisfaction with and the realisation of potential in life (CDC, 2016; Kabiru, Izugbara, & Beguy, 2013; Ross et al., 2020).

Resilience theory ensures an analytical approach that incorporates personality or trait-based factors, leveraging on strengths rather than deficits (Rutter, 2012; Zimmerman, 2013). The theory also centres on relationships, resources, and social and environmental influences as a focus of change for adolescents (Fergus & Zimmerman, 2005; Liebenberg et al., 2017). In this sense the theory points to strong social capital as contributing to resilience(Ahorlu, Collins K et al., 2015; Kirmayer, Sehdev, Whitley, Dandeneau, & Isaac, 2009). Hence, there is counter-evidence on the role of trait-based understandings of resilience, including the challenges of doing so in poor resource settings (Masten, 2011, Panter-Brick 2014, 2015). The notion of resilience as a trait tends to blame the individual under study as a victim failing to manifest resilience over time. It maintains psychological factors associated with resilience, while other scholars argue that the same traits can be protective or vulnerable in one context or the other (Kirmayer et al., 2009; Reavley, Bassilios, Ryan, Schlichthorst, & Nicholas, 2015). These debates and critiques around resilience theory are of the essence in this study because they allow me to explore resilience through all dimensions of adolescents' experiences.

2.15.2 Developmental Theory

Developmental theorists have argued for resilience as an interactive meaning-making process within the life course and context (Fleming, 2004; Liebenberg et al., 2017; van Breda & Theron, 2018). Adolescence is a complex period characterised by well documented biological, developmental, psychological and behavioural changes (Timol et al., 2016). I am interested in the capacity of ALHIV aged 15-19 to access services. I use the developmental lens guided by Masten (2011; 2014, 2016, 2018) and Masten & Barnes (2018) to situate adolescence as a

window of opportunity for continual interactions, for the individual and for him or her with the environment, including with other people and institutions, for their wellbeing. Meaning-making guides individual and relational choices, including decisions about engaging with what factors, assets, resources and processes (Liebenberg et al., 2017a). However, meanings attached to the individual, relational assets, and resources change over time. Understanding the shift in attention from one dimension (individual, relational and context) to the other, and understanding the meaningful interplay of support and resources as situations change, have important implications for efforts to promote SRH and service use among ALHIV.

2.15.3 Constructivism and Interpretive Theory

Infusing the socio-ecological understanding of resilience with a constructionist interpretive approach informed by Ungar (2008, 2011, 2016) and Dulin and colleagues (2019) ensures that we look at concepts from multilevel influences and multiple, interacting perspectives. A constructionist and interpretivist orientation focuses on emic points of view and meanings, and examines ways 1) on how co-creation might enable or interrupt resilience processes, 2) how parts of the social ecology influence or not outcomes, 3) how plurality of behaviours and divergent factors, relationships, spaces and networks provide differential benefits to different adolescents, and 4) what hidden resilience strategies have been overlooked (Daniel et al., 2009; Fielden, Chapman, & Cadell, 2011; Manderson et al., 2015). Van Breda (2018) suggests that antisocial activities (also referred to as hidden resilience or "functional but culturally nonnormative substitute adaptations") may be evidence of resilience processes and outcomes when carefully examined from an emic perspective (Ungar 2011, p8). I give ALHIV space and voice to describe protective factors (health resources) and factorial relationships that are "chaotic, complex, relative, and contextual" -- a priority for their wellbeing.

In this thesis, I acknowledge Ungar's (2004; 2007) alternate accounts of resilience definitions (as negotiated outcomes), theory (non-hierarchical, complex), research methods (mixed), risk and resilience factors (multidimensional, constructed, relativistic, dialogical) and the definition of health (a plurality of behaviours, multidimensional and complex). The intent is to capture diverse and context-

specific elements, and experiences that promote discussion on strengths, promotive and constraining factors and resources, to complement prior risk-based research among ALHIV (Kaufman, Cornish, Zimmerman, & Johnson, 2014).

2.15.4 Systems Theory

As part of exploring the factors, dimensions, processes and resilience-related outcomes pertinent to SRH and service use, I focus on complex interactions between individuals and their social ecologies. In resilience and systems theory, this is reflected in the increased attention directed at complex relationships and on institutional support and service provision for vulnerable adolescents (Mueller, Lungu, Acharya, & Palmer, 2011; Pilgrim & Blum, 2012; Sattler & Font, 2016). Systems theory informs Bronfenbrenner's (1979, 1986) initial work on child and human development with nesting structures (micro-, meso-, exo- and macrosystems) and the shift to a systems approach that offers a comprehensive account of contextual influences not only on development outcomes but also on the health and social wellbeing (Bronfenbrenner, 1979, 1986; Liu, Reed, & Girard, 2017). The shifts of focus from individuals to consider the importance of social and cultural dimensions of resilience (Kirmayer et al., 2009; Langham et al., 2018; Panter-Brick, 2015) confirms the variations and allows us to identify that there are "many pathways to resilience" (Govender et al., 2017; Toska et al., 2016).

2.15.1 Conceptual Framework 1

Drawing on terminology from the socio-ecological framework (Bronfenbrenner, 1979) (see Figure 2. 1 below), I adapted the six-level tiers (also referred to as layers) to capture ALHIV's capacities, processes, and interactions as a basis for data collection, analysis and interpretation. The concentric circles represent 'levels' of interaction between ALHIV and their environment. These levels include 1) the individual, illustrating ALHIV at the centre of the circle (age, gender, and ethnicity, risk status), and 2) family (relational support systems, peers, and social networks) which together represent the microsystem in the ecological model. The third circle encompasses the institutional level and includes 3) school (which encourages interconnections, relational support systems, peers, service use, and social

networks); and 4) community (social networks, service use, gender, norms, and traditions) also known as the mesosystem. The fourth and fifth circles are the exo-system and macro-systems which explain the external support through national policies or donor support, programmes and practices: 5) structural (environment, service use, practices, accessibility, and appropriateness), and 6) national (policies and intervention programmes).

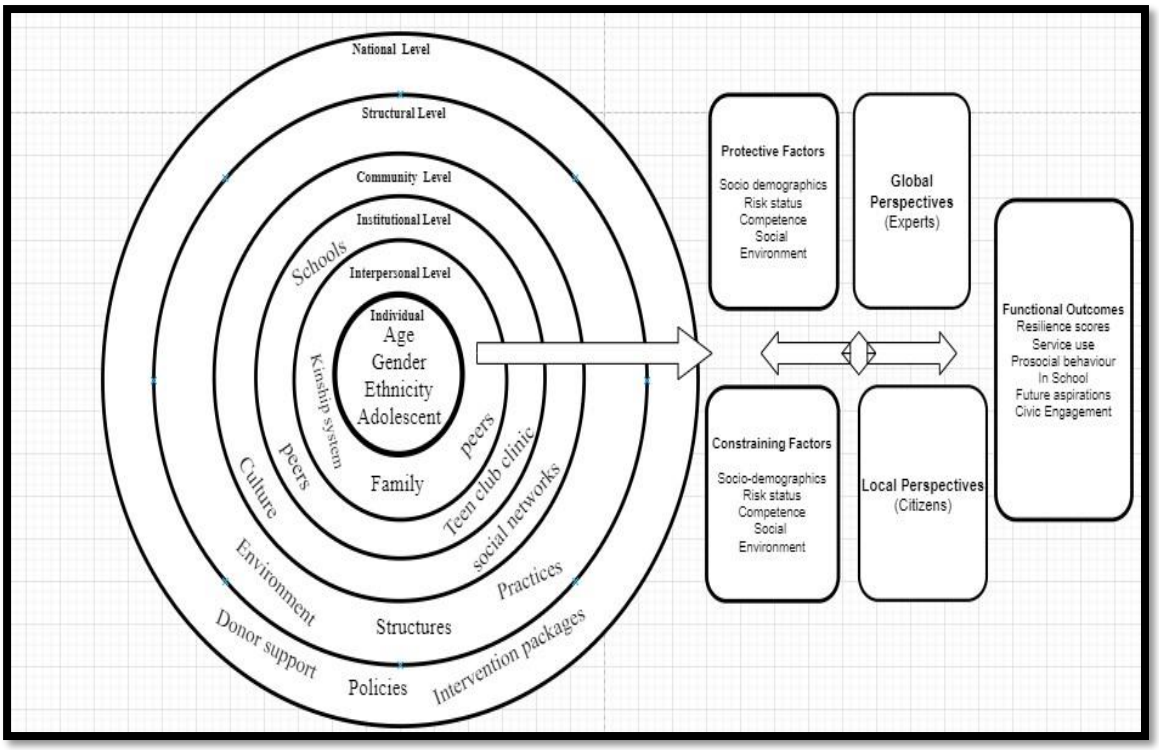


Figure 2. 2: Socio-ecological conceptual framework 1

Source: Adapted from developmental and socio-ecological perspectives (Bronfenbrenner 1979).

Variations in context, interactions and processes, including multilevel social contexts (access to resources, relationships, identity, power, culture), ideally work together to overcome risks (Kirmayer et al., 2009; Luthar & Cicchetti, 2000). Given this multilevel analytical framework, I account for the measure of resilience at the individual level and service usage, trajectories of time (adolescence as a life stage) and boundaries of space and environments, in particular, the teen club clinic and how it influences SRH, service use, and health and wellbeing. The ecological system is relevant for this thesis because I reflect on the interplay between

protective and constraining factors, and global and local perspectives of resilience influencing functional outcomes among ALHIV. The continuous, dynamic analysis enabled me to capture variability across individual resilience dimensions, service use, access to services, and having future aspirations, all of which are examples of functional outcomes.

2.15.2 Conceptual Framework 2

In Figure 2. 2 (below), I provide a revised conceptual framework; this serves as a unifying framework for this thesis. This framework captures "complex, relative, and contextual" interactions and analysis across individuals and variable focused outcomes, concepts, theory, findings and experiences. The bidirectional arrows showcase resilience processes and emphasises structures and programmes in relation to risks and protective supports along a continuum that is further complicated by interactions across micro-, meso-, exo- and macro-systems affecting ALHIV. The protective and constraining factors relay the key issues under resilience theory, making them the central focus to inform determinants of resilience (Chapter four, Objective 1, Paper II) for ALHIV and others attending the teen club clinic. The nested circles illustrate the multilevel interactions, complex social ecologies, and intergenerational relationships with caregivers/parents and health care workers (Papers II, III and IV).

The interactions within and across the levels afford a description and systematic analysis of pathways of resilience, promoting resources for ALHIV in the teen club clinic setting (Chapter six, Paper IV). Paper II (objective 3) demonstrates an important aspect of systems theory by highlighting multiple service uses among ALHIV and the role that pathway dynamics may play to show 1) the collective strength of relationships of multiple variables, and 2) formal and informal services which adolescents use and which promote positive outcomes.

Paper IV expounded on case studies with two young males and two females whose narratives identified discursive power, 'hidden or strategic initiatives', and processes which ensured their resilience. The complexity of ALHIV negotiations is best demonstrated through strategic silence, choices and relationships that nuance

their experiences of resilience and points of decision-making under caregiver and institutional supports. Objective 4, in chapter seven, captured ALHIV voices and their circumstances in relation to SRH subjectivities and complexities. Spaces and places with positive experiences were analysed within the ecological framework for an in-depth and nuanced framing of ALHIV sexual, reproductive matters, relationships and partnerships.

I extended my analysis and interpretation to a multilevel, dynamic systems model of risk and resilience, to fully identify variability among ALHIV and explore setbacks and turning points in individuals' lives that might promote resilience (Wright & Masten 2015, Masten 2013). Ungar (2004, 2008, 2011) refers to 'hidden resilience' to usefully illuminate strengths and protective factors in addition to adolescents' struggles, offering insights into the lives of children and youth living with HIV. Congruent with developmental, resilience and systems theory, I broadened the tiered and nested experiences of ALHIV, SRH and service use to pathway models that emphasise the value of each part of the socioecological factors and dynamic contexts within which resilience occurs. Such ecologically informed framing, analysis and interpretations are critical to showcasing the potential paths and models, resources and supports, that can maximise resilience outcomes.

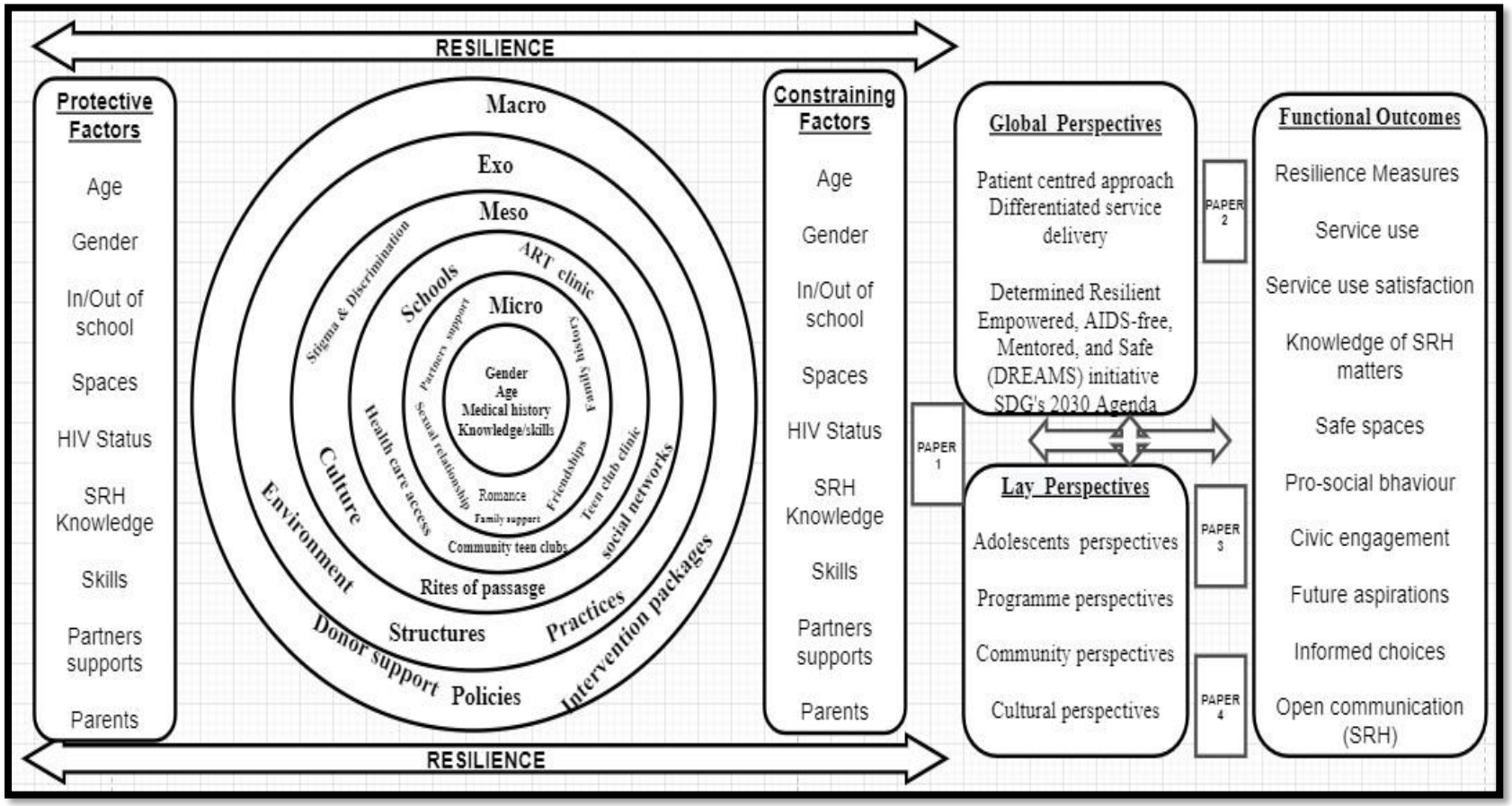


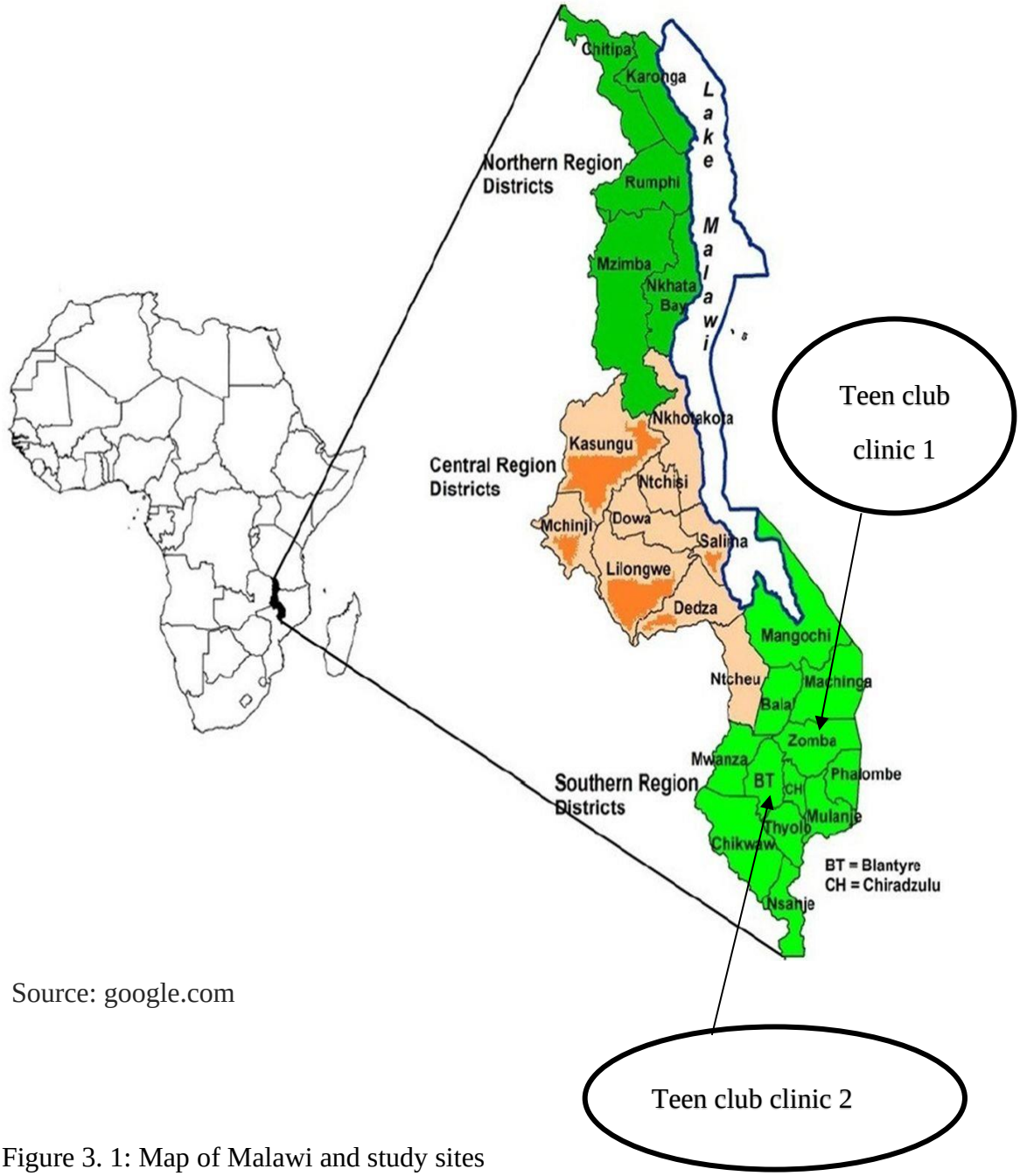
Figure 2. 3: Revised socio-ecological conceptual framework

Adapted from developmental and socio-ecological perspectives (Bronfenbrenner1979)

CHAPTER THREE

ALHIV AND RESEARCH IN CONTEXT

METHODOLOGY



Source: google.com

Figure 3. 1: Map of Malawi and study sites

3.0 Introductions

3.1 Malawi - Country Profile

3.1.1 Socio-Economic Profile

Malawi is a landlocked[3] country, with Zambia to the west, Tanzania in the north and Mozambique to the east and south (see Figure 3.1, map of Malawi, above). Malawi's current population is 17,9 million, with a median age of 17 years, of whom 73% are below the age of 30 and 46% <15 (National Stastical Office (NSO) [Malawi] & ICF, 2017). Malawi is a low-income country, with GNI of US320 per capita (World Bank Report 2019). Recent economic growth shows an improvement, with 4.4% of Gross Domestic Product in 2019, a marked increase from 3.5% in 2018 supported by agriculture production[4] (World Bank Report 2019). The national poverty levels continue to be high, increasing slightly from 50.7% in 2010 to 51.5% in 2016, but extreme national poverty decreased from 24.5% in 2010/11 to 20.1 in 2016/17[5] (World Bank 2019). Efforts to reduce poverty have stalled recently, however, due to drought, floods and most recently, the COVID-19 pandemic (Government of Malawi, 2017b; OECD Development Centre, 2018; UNAIDS, 2020b). The government economic policy currently focuses on five key priority areas aligned to the SDGs and the African Union Agenda 2063: 1) agriculture, water, development & climate change, 2) education & skills development, 3) energy industry and tourism, 4) transport, ICT and infrastructure, 5) health and population. The country continues to depend on external donor aid to meet most of its development needs (Government of Malawi 2017). There is increasing evidence that economic growth affects young people, but differently, depending on needs and resource supports, personal experiences, priorities and aspirations, developmental stages and the context in which they live.

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[3] Malawi's GPS coordinates, 13.2543° S, 34.3015° E

[4] https://www.worldbank.org/en/country/malawi/overview

[5] https://www.worldbank.org/en/country/malawi/overview

Timely interventions and resource supports are critical for placing adolescents at the centre and addressing their challenges on multiple fronts.

3.1.2 Education and Skills Development

Gaps in initial education and skills force adolescents to leave school at an early age, unprepared for work and life. The disparities in educational attainment among youth in Malawi are due to poor social-economic status (living in rural areas, having a mother with no education, poverty) which stops them from attending school because of lack of capacity to pay school fees. Fifteen percent of both genders show a lack of interest to attend school. At the same time, 20% of females experience competing interests and stop schooling because they were pregnant (12%) or wanted to get married (8%) (National Stastical Office (NSO) [Malawi] & ICF, 2017). Researchers on these issues tend to blame adolescents, their differences in status and gender, with the context closely linked to inequalities during adolescence. There is growing evidence that the cash transfer program in Malawi targeting adolescent girls and young women tends to increase educational attainment and reduce teenage pregnancies (Baird et al., 2012; World Bank Group, 2019). As an alternative, I focus on the broader social context and multidimensional strategies, and questions of education, youth-friendly health service, employment, or entrepreneurship to engage the complexity and ambivalence of everyday intimate spaces and resources shaping ALHIV health and well-being.

Malawi supports the intersectionality of development issues (Government of Malawi, 2017). For instance, education, skills training platforms for vulnerable children, and the provision of free primary school education were introduced in 1994. The Technical, Entrepreneurial, Vocational Education and Training (TEVET) programme established in 1999 included scholarships for tertiary education, with the potential for promoting reading, writing, technical, entrepreneurial, and vocational skills and training (World Bank Report 2019). There was an increase in primary school enrollment, so that by 2013, 89% of students had some primary education (OECD 2018). However, only 35% of students complete primary education, which affects the net enrolment rate in secondary school, tertiary and vocational training. Few complete vocational and

tertiary education (2.2% and 1.0% respectively) (OECD 2018). Self-reported literacy (reading and writing in any language) is 71.6 for males and 65.9 for females 15+ years of age. Persistent challenges with regard to high repetition rates and low completion rates (particularly for girls), and poor rates of transition from primary to post-primary levels of education, tend to oversimplify complex social arrangements and blame individual adolescents for being out of school.

Given that almost 50% of the population is under the age of 15, there is a high dependency ratio and low investment in children and young adults, exacerbating financial and economic growth at the country level. As part of strengthening the labour force, the Malawi Growth Development Strategy (MGDS) defined as the percentage of persons aged 15-64 years who are economically active in the total population (Government of Malawi, 2017b), entrepreneurship and vocational trainings are encouraged. TEVET courses, including rural entrepreneurship programmes, are part of the strategies to improve young people in craftsmanship and trades such as carpentry, construction, administrative and technical studies, tailoring and vehicle repair to curb inequalities among young people (Government of Malawi, 2013). There is also a need to identify how adolescents engage to access these different types of resources and supports, so to ensure the diversity of spaces that enable ALHIV to do well despite adversities.

3.1.3 Agriculture, Water, Development & Climate Change

The agriculture sector remains the most important resource and contributes 28% and 80% to the gross domestic product and export revenues, respectively (Government of Malawi 2017). About 60% of youth in rural areas work in the agricultural sector, while others are involved in agro-processing: forestry, fishing, and developing new crop production (OECD Development Centre, 2018). However, the economy is heavily dependent on rainfed agriculture and is most vulnerable to external weather, health and climatic shocks. Other challenges include rapid population growth and environmental degradation, youth involvement and productivity, education, energy, industrial production and transportation (Government of Malawi 2017). The World Bank's programme, Sustainable Energy for All, confirms that energy shortages still stand out, with about 18.02% of the

population having access to electricity in 2018[6]. Investments in agriculture, mainly working with vulnerable communities, young people through entrepreneurship, market, credit and loan schemes, have the potential to enhance community and young people's productivity, which will improve investment and help reduce poverty and hunger (Government of Malawi 2017).

3.1.4 Transport, ICT and Infrastructure

Youth-friendly platforms that provide timely, relevant and accurate information are essential to foster community, stakeholder and adolescents' participation, widespread monitoring and dissemination. The National Sexual and Reproductive Health and Rights (SRHR) Policy (2017-2022) commits to universal access to family planning, SRH information for all, including adolescents (Republic of Malawi, 2009). Similarly, the National Youth Policy (NYP) (2013) envisions "healthy and productive generations of young people" through the provision of comprehensive SRHR and HIV using multiple media (Government of Malawi, 2013). On the other hand, the Youth Friendly Health Service Strategy (2015-2020) (Republic of Malawi, n.d.) calls for harmonisation of education, health and youth policies to improve access to information and resource supports. Adolescents in Malawi access multiple digital platforms, Facebook and WhatsApp groups for SRH needs. However, the uncertainty around the accuracy of the information, privacy, beliefs, values and stigma remain barriers to action (OECD 2018). Integrating technology and SRH has the potential to open communication about sensitive issues on sexuality, increase self-efficacy among adolescents, and support broader community participation (Bailey et al., 2010; Kaunda-Khangamwa, 2020). The review by Bailey and colleagues (2010) recognises the moderate effect of ICT on sexual beliefs, intentions, behaviour and knowledge.

Infrastructure interventions also extends health and social support. The strengthening of transport, ICT and infrastructure is another entry point to ensuring universal health coverage as well as empowerment (defined as the provision of

[6] https://data.worldbank.org/indicator/EG.ELC.ACCS.ZS?locations=MW

comprehensive information, infrastructure, home, community, institutional, economic, and policy support) for all adolescents in reducing adverse SRH outcomes (Blauvelt et al., 2018; Kaunda-Khangamwa, Kapwata, et al., 2020; OECD Development Centre, 2018). However, facilities are often in poor conditions, representing a barrier to access and service use (Addison et al., 2019; Kirmayer et al., 2009). Similarly, some social determinants act as barriers to positive SRH outcomes, includes long distances, high cost or lack of transport to the nearest providers, and adolescents' inability or uncertainty to seek information or care supports. There is evidence, for example, that road construction affects distance and time to health facilities, including access to SRH resources (Blauvelt et al., 2018; Nash et al., 2019). Despite the emphasis by the government to promote multisectoral or cross-sectoral support to improve ASRH, this is not guaranteed due to lack of funding and competing interests to collaborate and ensure translation to the implementation of programmes and services across the country.

3.1.5 Health and Population

SRH issues can have both positive and negative effects on the health and well-being of adolescents. Framing on SRH continues to focus on avoiding danger, death and disease. For instance, early sexual intercourse, combined with low contraceptive use, results in frequent early pregnancies and high fertility rates in Malawi. Thirty-seven percent of sexually active females aged 15-19 reported having ever used a contraceptive method in 2015 (OECD2018). Equally important, 33% of females aged 15-49 discontinue use of contraception within a year (Dasgupta, Zaba, & Crampin, 2015). There is a need to improve young women's knowledge about fertility and making young men aware of their responsibilities, notably having an informed choice and using protection (Self et al., 2018; Zgambo et al., 2018).

As noted earlier, education, health, geography, wealth and gender disparities affect ASRH. Low use of contraceptives is reflected in high fertility, although teenage motherhood decreased from 161 per 100 girls aged 15-19 to 136 between 1992 and 2015 (National Statistical Office Malawi & ICF Macro., n.d.). The overall HIV prevalence in 2019 was at 8.9% among people aged 15-49 (UNAIDS, 2019). The higher prevalence among women than men, at 10.8% and 6.4% aged 15-49

respectively, because more women were being screened for reproductive health services (National Statistical Office Malawi & ICF Macro., n.d.). In 2018, HIV prevalence was 4.9% among young women and 1% among young men (UNAIDS 2019), due to intergenerational sex and early sexual debut. HIV mortality rates in Malawi are high, with around 250 deaths per 100 000 young people compared to 149 at a global level (OECD 2018). Hence the appeals for "collaboration," "bridging the gaps," and "strengthening linkages" between HIV/AIDS and SRH resonate with adolescents' realities.

Malawi is celebrated as having made good progress in its HIV response: the introduction of test-and-treat in 2016 offered immediate treatment to all people living with HIV. It reduced all adult mortality by 35% (WHO, 2016b). Option B+ was introduced in 2011 for the prevention of mother-to-child transmission of HIV (PMTCT) strategy, to ensure that all pregnant women living with HIV have lifelong access to HIV treatment; as a result ART coverage increased from 49% to 85%. This suggests that the UNAIDS 90-90-90 strategy to keep HIV epidemic under control is attainable (Chirwa et al., 2018; Phiri, Tweya, et al., 2017; Tweya et al., 2013). The success is attributed to 1) adopting progressive HIV policies, 2) implementing multisectoral HIV response and support, and 3) high-level political commitment and leadership (Chirwa et al., 2018).

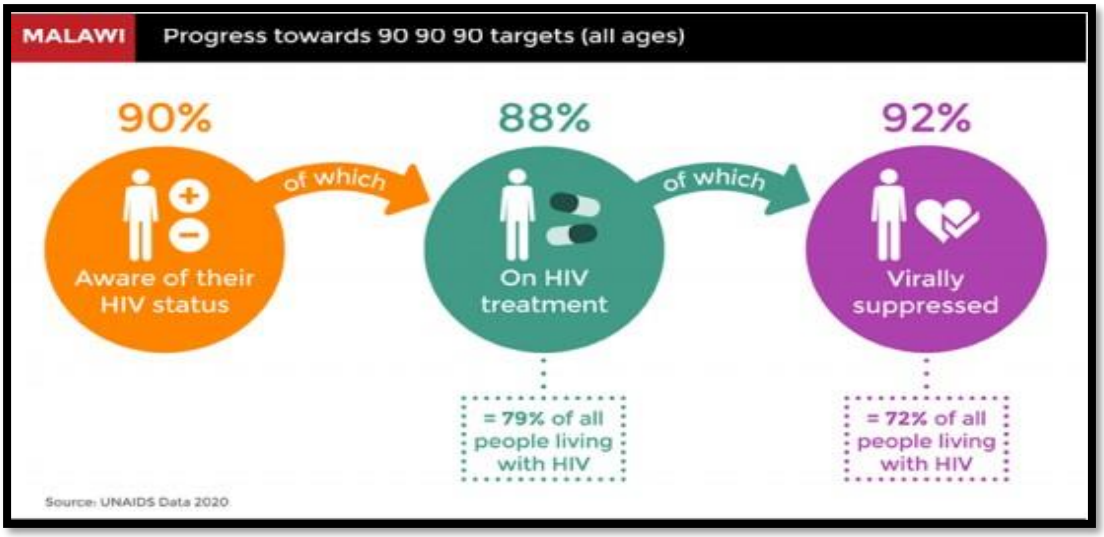


Figure 3. 2: Malawi progress towards 90-90-90 HIV targets.

Source: UNAIDS 2020, Avert 2020

In 2013, Malawi adopted the UNAIDS' ambitious '90-90-90' targets (the three "90s") under the "test-and-treat approach," as a set of goals to help end the AIDS epidemic by 2020. The strategy is that by the end of 2020, 90% of people living with HIV will be diagnosed, 90% of those diagnosed will be on ART treatment, and 90% of those who receive ARTs will be virally suppresed (Davies & Pinto, 2015; Lee & Hazra, 2015). Viral suppression is when the amount of the virus in people living with HIV/positive person blood is reduced to an undetectable level (Kaunda-Khangamwa, Kapwata, et al., 2020; Nachega, Sam-agudu, Mofenson, Schechter, & Mellors, 2018). The targets are essential for all and particularly for adolescents to ensure that there is an almost universal approach to identify people early in their infection; Davies and Pinto (2015) maintain the need for the programme to include the provision of quality care for the retention, suppression and reduction of onward transmission for optimal HIV outcomes. However, despite Malawi surpassing the 90-90-90 targets (all ages) as depicted in Figure 3. 2 (above), adolescents continue to have larger gaps in HIV diagnosis, treatment and viral suppression (Davies and Pinto 2015, Eshun-Wilson et al., 2019).

New HIV infections among adolescents and young women and men (15-24 years) accounted for 9500 and 4000 in 2017, and in urban areas, adolescents and young men continue to perform poorly in terms of ART coverage and viral suppression (see Figure 3. 3 below) (Kaunda-Khangamwa, Kapwata, et al., 2020; Ministry of Health, 2017). Hence, SRH, HIV and viral load suppression disparities persist across gender, geographical areas and sub-populations.

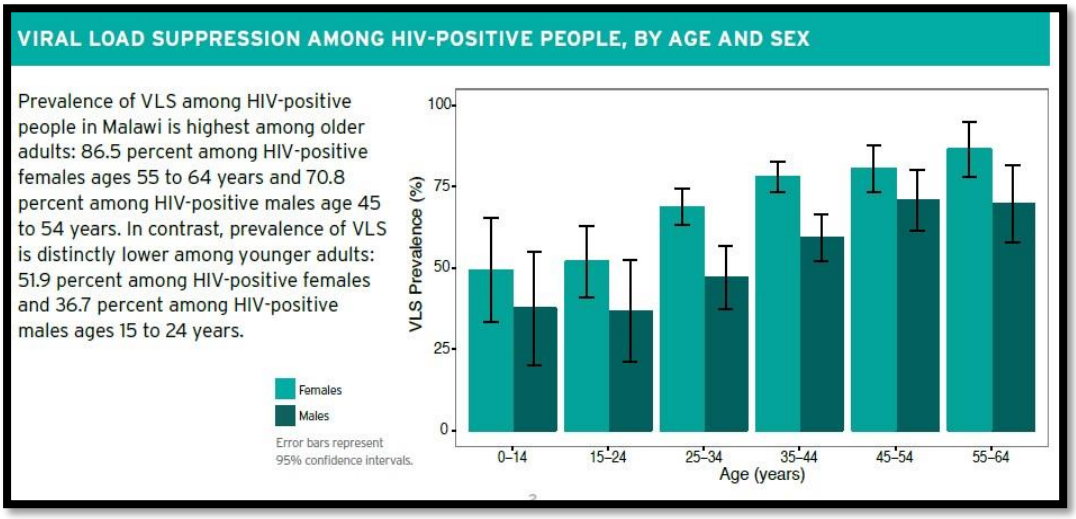


Figure 3. 3: Viral load suppression among 0-64 by age and sex.

Source: Malawi Population-Based HIV Impact Assessment 2015-16 (Ministry of Health, 2017).

3.1.6 Service and Health Care Delivery

The Constitution informs the provision of health services in the Republic of Malawi: “to provide adequate health care, commensurate with the health needs of Malawian society and international standards of health care" (Government of Malawi, 2006). Health services in the public sector are free of charge at the point of use, except for services from private and religious institutions such as Christian Health Association of Malawi (CHAM) hospitals, clinics, laboratories and pharmacies. User fees are waived as part of reaching the dual goal for both HIV/AIDS and SRH programming ‘to end AIDS as a public health threat while aiming for universal access to SRH’ (Kangudie, Guidigbi, Mensah, Bala, & Delate, 2019, p. 1).

What is clear from youth policies and strategies in Malawi is the advocacy for multisectoral and progressive policy approaches on SRH for young people to ensure continued support for information, access to care, family planning for empowerment, development and social wellbeing (Government of Malawi, 2013, 2017b). The multisectoral approach entails united efforts including policy, strategies, stakeholder, donor and adolescent representation and support, with wide-ranging effects: accessing contraception without permission from a parent or a

spouse, improving SRH service provision, and ensuring the quality of care in terms of continuum of care, support and empowerment.

The National Population Policy (NPP 2012, p5), (Government of Malawi, 2012) through advocacy and coordination, guides Malawi's developmental challenges by ensuring the 'structured management of its population dynamics, rapid population growth, high levels of fertility and mortality. The NPP is critical to policy building and contributes to the achievement of various sectoral policies and the larger development plan.[7] The NPP is aligned with an overarching policy, guiding government planning: the MGDS 2017-2022 is linked to the National Sexual and Reproductive Health and Rights (SRHR) Policy 2017-2022, which empowers young people through networks and 'youth aid' for their economic growth and well-being (Rowan, Gesuale, Husband, & Longfield, 2019). The national SRHR policy is aligned to the Health Sector Strategic Plan II (HSSP II) 2017-2022 and the National Youth-Friendly Health Service (YFHS) Strategy (2015-2020) (Government of Malawi, n.d.-a, 2013; Republic of Malawi, n.d.), which promotes the active engagement of adolescents involved in policy formulation, implementation of SRH education and service support (Wigle, Paul, Birn, Gladstone, & Braitstein, 2020). Similarly, the National Youth Policy (NYP) 2013, the National Strategic Plan (NSP) for HIV (2015-2020), and the updated Essential Health Package (EHP 2010) advocate the use of multipronged approaches to addressing challenges facing adolescents. Notably, the NSP and EHP focused on meeting the 90-90-90 targets through identifying critical gaps in the programme and the health system, with the aim of improved health outcomes, protection and patient satisfaction (Chirwa et al., 2018).

[7] The NPP (2012) has mainstreamed population issues to SRHR policy (2010), National Gender Policy (2003), HIV and AIDS Policy (2003), Policy on Orphans and other Vulnerable Children (2003), The Education Policy (2004), National Policy on Equalization of Opportunities for Persons with Disabilities (2012), National Youth Policy (2005) to enhance adolescents and young people abilities to contribute to national development

3.1.7 Health Service Structure for Adolescents

The structure for adolescent health services in Malawi falls into four levels: the community, primary, secondary and tertiary levels, as illustrated in Figure 3. 4 (below). The services are provided by the public, private for-profit (PFP) and private not-for-profit (PNFP) entities (Government of Malawi 2017). The first point of contact is at the community level, with promotive and preventive care provided through community engagement, door-to-door visits, dispensaries (52), village health clinic (3542) and outreach clinics/posts (4973) by HSAs, focusing on health education, awareness, and the provision of contraception to ensure accessibility to SRH and patient-centred support (Devlin, Pandit-Rajani, & Egan., 2017). The community health service delivery is integrated into existing MoH monitoring & evaluation systems to avoid duplication of resources and efforts (Ministry of Health 2017). Despite sectoral and policy enabling environments, there is a lack of regular coordination, support and integration on SRH and HIV/AIDS (Hopkins & Collins, 2017; Kuruvilla, 2018). The focus is on targeted ministries, sectors, services and/or programmes that can be joined to maximise collective outcomes by offering more comprehensive services amongst the relevant ministries (i.e., between the Ministries of Health; Youth; Gender, Children, Disability and Social Welfare; Ministry of Education Science and Technology-; or Ministry of Agriculture), despite their seemingly interconnected goals (Makwero, 2018; Nash et al., 2019).

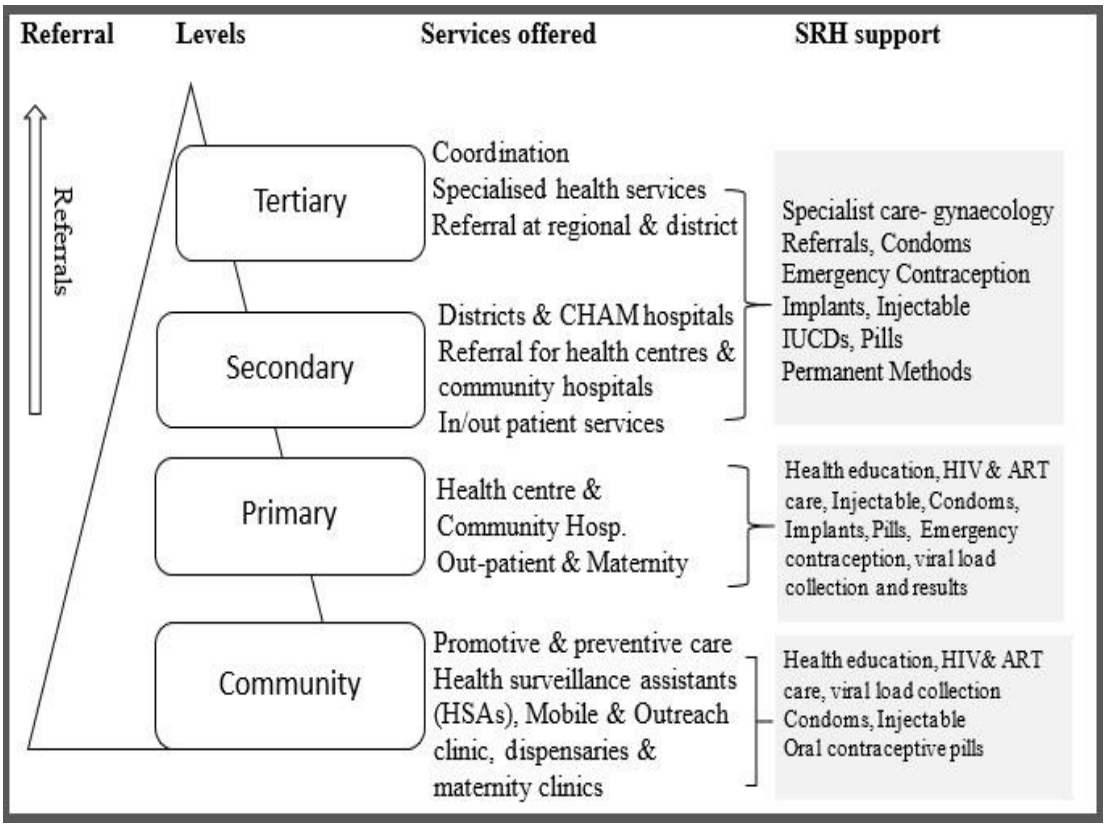


Figure 3. 4: Health service structure for adolescents[8].

The primary level services are where the bulk of health care happens in Malawi. These are largely community initiatives that include community-based distributing agents (CBDAs), health surveillance assistants (HSAs), village health committees, health centres (520) and rural hospitals (56) (Devlin et al., 2017; Makwero, 2018). CBDAs only provide standard methods: condoms, pills, and counselling on specific days at the health centres and clinics, while dispensaries offer health education, injectables and implants. The secondary level includes 24 district hospitals and four tertiary (central) hospitals, providing IUDs and, in some cases, female and male sterilisation. The central hospital serves as a referral facility for district or regional level facilities, and provided integrated (HIV/FP/SRH) and specialist care (surgery, referrals, ANC, PMTCT) (Kanyangarara, Sakyi, & Laar, 2019).

The Malawi health system is also decentralised as a strategy to empower and facilitate the central, district hospitals and community ownership, governance and

[8] Health service structure adapted from Devlin et al. 2017

participation in the delivery of the essential health package (EHP) (Makwero 2018). The Ministry of Health and Population (MoHP) controls family planning and SRH activities and programmes, and these are housed within the Reproductive Health Directorate (RHD). As part of Malawi's FP2020 commitments, the reproductive health office was elevated to the status of a directorate, giving it more decision-making influence (Devlin, Egan, & Pandit-Rajani, 2016). The functions of the MoHP include policy-making, standard-setting, quality assurance, strategic planning, resource mobilisation, technical support, monitoring and evaluation at tertiary health care level and international representation (Government of Malawi, 2017, WHO 2017).

Community, primary and secondary level health services fall under district councils and are run by District Health Officers (DHOs) with the help of District Health Management Teams (DHMTs), and include nursing, environmental and medical officers. The DHOs manage all public health facilities at the district level and direct the implementation, monitoring, evaluation and advocacy for family planning and SRH support services at the primary and secondary level to achieve health and social goals (Makwero, 2018; Wigle et al., 2020). DHOs report to the District Commissioners who are under the Ministry of Local Government. At the technical level, DHOs receive technical backstopping from the Zonal Health Support Offices (ZHSOs) who are under the MoHP. The five Zonal Health Support Offices (ZHSOs) are an extension of the central level and provide technical support to districts. While an established referral system links the four health care systems, the DHO is the leading implementer of clinical care interventions, including delivering ART services through its hospitals and facilities at all levels. It works in close collaboration with donor partners and the CHAM private hospitals and facilities (Government of Malawi, 2017).

Given the need to improve targeting of critical interventions for key and vulnerable populations such as youths and adolescents, much attention is on the provision of services using the broad objective of the EHP and patient-centred care frameworks. The frameworks provide interventions or service delivery, free at the point of access (Sande et al., 2018). There are mixed outcomes on EHP service provision due to

lack of financial and material resources, which affects the coverage of different interventions at different levels of the health care system and geographical location. However, the provision of services for adolescents as a critical sub-population in Malawi offers opportunities to learn about the implementation and effects of intervention programmes. Notably for SRH, the expansion of health service provision and assurance of the quality of care for adolescents, reductions in births, child death rates, maternal mortality, unsafe abortions and ending HIV/AIDS are essential to improve health outcomes and contribute to the national development agenda and demographic dividend (Feyisetan et al., 2014; Government of the Republic of Malawi, 2018).

3.1.8 Zomba District: The Study Setting

Zomba district is situated in the southeastern region in Malawi (Figure 3. 1 above). Zomba has a population of 746,724, with 105,013 living in Zomba City (National Statistical Office, 2019). There are 20 MoH health centres and 10 CHAM health centres; hence most adolescents can easily access services and support at the primary care level. Within the locality, there is one Central Hospital (Zomba Central) and one Mental Hospital (Ministry of Economic Planning and Development, 2017)(Ministry of Economic Planning and Development, 2017). The community hospitals and the health centres are under the responsibility of the Zomba District Health Officer (DHO). In contrast, the central hospital has a separate administration under the hospital director, who manages the allocation of funds, recruitment of human resources and monitoring and evaluation.

The Malawi Demographic Health Survey (MDHS) (2016-17) reported that HIV prevalence in Zomba was 16.8% in females and 9.3% in males aged 15-49 (combined prevalence 13.2%). This is higher than the national HIV prevalence of 8.8%. The prevalence for adolescents is at 7% for 15-24 olds (National Statistical Office Malawi & ICF Macro., n.d.). Adolescents living in Zomba District experience multiple challenges: large numbers of orphans and vulnerable children, early sexual initiation, ART treatment gaps, high rates of childbearing during the teen years, and high school drop-out rates among girls.

My interest in Zomba, a city 70 km outside Blantyre, was to pilot study tools with adolescents attending Tisungane ART and teen club clinic under Zomba Central Hospital (ZCH), a tertiary referral HIV clinic (see Figure 3. 1 above, Teen Club 1 on the map). To address some of the challenges that ALHIV face in Zomba, the Tisungane ART and teen club clinic was established in 2010 as a collaboration between the Malawi MOH, Dignitas International, and the Baylor College of Medicine Clinical Centre of Excellence Malawi. Tisungane is run under a tertiary referral HIV clinic under the Ministry of Health and Population (Mackenzie et al. 2017). The Teen Club model was adapted from the Baylor College of Medicine International Pediatric AIDS Initiative – Center of Excellence Curriculum (BIPAI 2012). BIPAI provides lifelong integrated services and support to HIV patients: testing and obstetric services, prevention and community programmes, including screening for HIV, TB, malaria, hepatitis and cancer (Baylor College of Medicine International Pediatric AIDS Initiative (BIPAI), 2012; BIPAI, 2017). For ALHIV, the BIPAI model employs the 'Teen Club' initiative to run medical and psychosocial interventions as represented by Kim and colleagues (2015, 2017) with treatment groups, camping and prevention campaigns, life skills curricula, leadership and transition of care services as part of ALHIV empowerment, enhancing self-esteem and life skills.

Currently, the Tisungane ART and teen club clinic is run by the Lighthouse Trust in collaboration with the public health service and funded by the Government of Malawi, with the support of various donors,[9] including independent charitable organisations, although the US Centre for Disease Control and Prevention covers the lion's share (Phiri, Neuhann, et al., 2017). Lighthouse is a public trust that since

[9] Lighthouse has varied sources of funding: national and inter- national sources including the Government of Malawi through the MoH and National AIDS Commission with pooled funding including the Global Fund to fight AIDS, tuberculosis and malaria; United Sates of America (The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through Centers for Disease Control and Prevention,CDC); Catholic AID for Overseas Development (CAFOD); Irish Aid through the Rose Project; International Epidemiologic Databases for Evaluating AIDS – Southern Africa; World Health Organisation; University of North Carolina; Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ incl., charities and foundations (Phiri et al. 2017 p5).

2000, has contributed to the Malawi national HIV response (HIV testing services, HTS), facility-based clinical services, and community-based health services, management of integrated initiatives – HIV, TB, hypertension and SRH/HIV) since 2000 (Ng'ambi et al., 2016; Phiri, Neuhann, et al., 2017). It is a Centre of Excellence that supports the quality of HIV care and capacity building. The ART and teen club clinic services are provided within the Zomba district hospital grounds, as a central place with easy access for adolescents who live in the hospital's catchment area.

In this dissertation, I refer to Tisungane ART and Teen Club Clinic because that is where I conducted the initial pilot work. At this clinic, I used cognitive interview processes to adapt, modify and validate the survey questionnaire and interview guides. The pilot study was conducted under the auspices of Zomba Hospital to reduce bias and contamination for the more extensive study. The Tisungane ART and Teen Club Clinic provides similar services to those offered at the main study site in Blantyre. The clinic serves ALHIV on ART with specialised and dedicated clinic time on Saturdays to meet their medical, social and psychological needs. There was provision for comprehensive services ranging from clinical care, counselling sessions, health education, entrepreneurship workshops, sports and games (MacKenzie et al. 2017, Kim et al. 2015).

3.1.9 Blantyre District

Blantyre district is situated in the southwest region in Malawi (Figure 3. 1 above). Blantyre has a population of 1,251,200, of whom 800,264 are living in the city (National Statistical Office, 2019). Blantyre was selected for the main study because of the high HIV prevalence in the city, 17.6% by DHS 2016-17 and 18.2% by MPHIA study 2016 among the 15-49 age group (Ministry of Health, 2017). In Malawi, 4.3% of young women aged 15-24 (about half of whom were based in Blantyre) were living with HIV, compared to 2% of young men (UNAIDS 2019). This study took place in the teen club programme under the Umodzi Family Centre (UFC) ART and teen club clinic at Queen Elizabeth Central Hospital (QECH) in Blantyre (Figure 3. 1 above, Teen Club Clinic 2).

Blantyre is a commercial city with what are regarded as community-level risk factors such as migration, poverty, and high numbers of adolescents with poor SRH outcomes. The city has a large urban population, many of whom experience moderate poverty; the incidence of poverty is highest in Phalombe (83.2 %), with Blantyre City having the lowest levels at 8.0 %, with increased inequalities (0.499 in 2011 to 0.624 in 2017) among those residing in urban areas (National Statistical Office & Ministry of Economic Planning and Development, n.d.). Ethnicity is varied in the city, and although the majority are Mang'anja and Yao, other tribes include Lomwes, Tumbukas, Senas and Tongas. The major religious groups include Christianity (90%) and Islam (8%), with one percent of the population each adhering to Buddhism, Hinduism or identifying as non-religious (Blantyre District Council, 2018). The city reports high levels of unemployment, crime, with rape, defilement and indecent assault on the increase (Blantyre District Council, 2018). Recognising individual, interpersonal, community and societal factors such as migration, poverty and crime, and their interaction with ALHIV, is key to understanding adolescents' experiences, needs and service use in urban Blantyre.

Blantyre District has 28 public health centres and dispensaries, six hospitals, and more than 140 private clinics. Of the 28 health centres and dispensaries, 24 are run by MoH through Blantyre District Council, while CHAM runs four centres. Of the six hospitals, one is a central hospital -- QECH -- run by MoH, one is a community hospital (Mlambe) run by CHAM, and six are private hospitals (Mwaiwathu, Blantyre Adventist, Mtengo Umodzi, Dai, Halima, Shifa and Chitawira) (Blantyre District Council, 2018).

3.1.9.1 Blantyre Teen Club Clinic 2010-2016

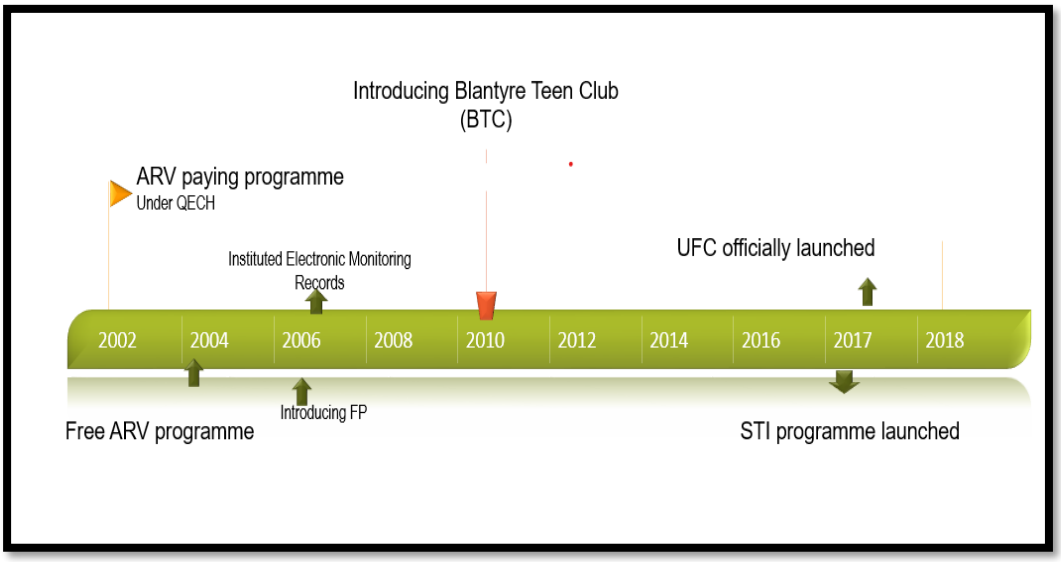


Figure 3. 5: Timeline showing key phases under UFC

The UFC Teen Club Clinic was established as the Blantyre Teen Club (BTC) in May 2010, with support from the University of Malawi, College of Medicine (UNIMA-CoM) and (BIPAI) – Center of Excellence Curriculum (see Figure 3. 5 above). The teen club model and practices were adapted from BIPAI and by 2013, the clinic had 200 ALHIV and 90 caregivers/guardians participating in its programmes (Baylor College of Medicine International Pediatric AIDS Initiative (BIPAI), 2012). PEPFAR and University of Malawi-College of Medicine provided financial support between 2011-2013 and 2014-2016, respectively. BTC's main aims between 2010 and 2016 were to improve ART outcomes by supporting the adolescent and their family. At monthly teen club meetings, teens had peer support and networks to share their experiences, develop life skills, and explore issues of prevention and adherence to medications. During the BTC era, in February 2014, I began to volunteer at the teen club. I refer to BTC as part of highlighting the role of service provision in light of evidence on HIV-related care and support for ALHIV. This is critical to learn the best practices for providing the extra services and social supports for ALHIV transition into adulthood.

3.1.9.2 UFC ART and Teen Club Clinic from 2017

The UFC is part of the regional and national HIV response for enhanced service delivery, training, and mentorship. The centre is a named Centre of Excellence (CoE) under Lighthouse Trust, that is, it is adolescent-centred and monitors and provides comprehensive services to PLHIV in Malawi (Kaunda-Khangamwa, Kapwata, et al., 2020; Phiri, Neuhann, et al., 2017). For ALHIV, UFC offers comprehensive and integrated HIV services: prevention, care, and treatment, including TB screening and management, and referral for patients with advanced HIV (Ng'ambi et al., 2016). The centre provides a "one-stop-shop" for SRH, family planning, and STI care to reduce re-infection while promoting safer contraception methods and PMTCT as part of attaining universal health coverage (Kangudie et al. 2020, Callaghan et al. 2019, Kaunda-Khangamwa, Kapwata et al. 2020). UFC is relevant to my thesis and study setting because it recognises the change in HIV care and support towards universal health coverage and patient-centred care for ALHIV. I reflect on the importance of investing resources and support towards PLHIV and in particular, the ART and teen club clinic services and programmes (Figure 3. 6 below for a snapshot of UFC clinic corridors).

The UFC ART and Teen Club Clinics are located within the QECH grounds, which provides tertiary services to the southern region. The centre was officially opened on World AIDS Day, 1 December 2017 as a promising initiative for improving clinical, relational and psychosocial outcomes. The clinic provides HIV care to about 15,000 PLHIV aged 15-60 and opens from 8 am -7 pm, six days a week. The club currently involves about 3500 young people (ages 10-24) and in Paper III in Chapter five, I provide more information on the differences between ALHIV who receive care in the ART clinic and those who receive care at the teen club. The clinic staff comprises of two medical doctors, 11 nurses, seven clinicians, 27 full-time HIV diagnostics assistants (HDA), and in addition, an extra three HDA as volunteers, 13 health promoters, three clinic aides, one laboratory technician and one pharmacist; these cadres all work on a full-time basis. Twenty-five trained mentors underwent intensive programming on child-centred care. An extra 18 teen mentors who are role mentors support UFC adolescent programmes voluntarily. All

mentors who volunteer during teen club meetings receive allowances in line with Ministry of Health policy. The administration team comprises of one manager, one procurement officer and one assistant, six cleaning staff, four security staff and two ground workers. The M&E team has a manager, senior and junior officers.



Figure 3. 6: A snapshot of UFC clinic corridors[10].

As alluded to earlier, the UFC is located within QECH and is flanked by the Blantyre youth centre to the east, Kamuzu School of Nursing to the south and QECH mortuary and the physiotherapy building to the west and north respectively.

[10] Photos were taken during fieldwork, 7 November 2019.

The centre is surrounded by a brick wall and has three entrances which are gated for the convenience of patients with and without cars. The ground is landscaped with well-maintained lawns, flowers, and trees. The interior of the clinic was built in a rectangular shape, with wide corridors lined with chairs and benches that connect all departments for ease of access and to seat patients waiting for appointments. The clinic has a spacious waiting area with ten long benches and a television on the wall, and five duty stations close to the main entrance (the reception, seating/waiting area, vitals checking and recording spot, two nurses' offices and the entrance to the seminar room). The seating is always welcoming and comfortable, with wooden benches and cushioned chairs with backs facing the television and edutainment posters. Age and subject appropriate role plays were screened throughout office hours.

UFC has 12 consultation rooms (two for TB care, three for HIV rapid testing, two for FP, cancer screening and STI care). Two rooms serve as a laboratory for viral load collection and testing, and another room is used for pharmaceutical services to ensure universal access to care and support. There are four toilets and a kitchen. The courtyard is another core space for ALHIV activities, and the space is analogous to a hole in a doughnut. Passers-by cannot easily view the yard, so allowing privacy, but it is easily accessed through openings along the corridors. The well-maintained lawns cover most of the courtyard where dancing, group interactions and sessions take place. The middle parts have immovable concrete benches and flower beds which are popular during teen club meetings as adolescents place their bags around them. Others sit on them with their feet up, sharing their meals, or having head-to-head talks during health breaks. The courtyard is spacious and can accommodate about a hundred adolescents; however, it is not user friendly in rainy weather, or under extreme summer or winter conditions. In this thesis, I acknowledge and reflect on the modus operandi of teen club spaces and how this space facilitates resilience and positive service usage and SRH outcomes in ALHIV.

3.1.10 Programmes and Therapeutic Resources

The UFC teen club clinic provides specialised and dedicated clinical care and workshop activities on Saturdays and during the school holidays to meet the medical and psychosocial needs of ALHIV. The club is open to ALHIV aged 10-19 years old who are on ART and have had their status disclosed to them. All ALHIV who are identified under 'test and treat' care are referred to the teen club either by clinicians or nurses who confirm with club facilitators that disclosure with parents or trusted caregiver had taken place. As part of enhancing access and support to HIV care, disclosure of HIV status is encouraged. Meetings are spread out monthly, every two months or quarterly depending on age ranges, spanning 8-18 years old and young adults aged 19 and older (this group is also known as Marvelous Youth within the teen club clinic). The colour groups were created for logistical reasons and registration purposes and denote sub-groups defined by colour [grey, green, yellow, blue, orange] (Kaunda-Khangamwa, Maphosa et al. 2020. Kaunda-Khangamwa, Kapwata et al. 2020). The group meetings are usually mixed and can involve anything from 20-90 members unless the club is working on sensitive topics related to sexuality, in which case participants are divided into small groups. ALHIV are requested to attend meetings once every two months for ART refills, clinical care (adherence and viral load checks, counselling) and to participate in group sessions on specific topics ranging from basics on HIV/AIDS, adherence, education and career days. Smaller group sessions and workshops are age-specific and are run to accommodate all adolescents when presenting sensitive topics such as SRHR. The Marvellous Youth sessions meet every quarter and are eligible to those teens who have finished high school or are out-of-school and have graduated from the teen club.

The club is staffed by regular health providers and mentors who have undergone training on pediatric HIV care and intentional programming related to adolescent health curricula, respectively. The mentors are ALHIV who showed good adherence and leadership qualities and were promoted to give guidance, modelling and psychosocial support to peers. However, sometimes the word mentor is used as a blanket term for both clinical and non-clinical health supporters who participate

in teen club activities to ensure adolescent wellbeing. Before every monthly meeting, on the third Wednesday of each month about 15-17 members representing doctors, clinicians, nurses, a pharmacist, nutritionist, monitoring and evaluation staff, lay health workers, and mentors hold preparatory meetings to discuss and draw up the Saturday teen club clinic programme of activities. A typical list of activities includes the designation of roles for those taking care of the registration desk, counselling sessions, refills, health education (role plays, facilitations or presentations), mentors seating adolescents at appointment rooms, maintaining order and facilitating dance sessions and serving food during health breaks and lunch. The doctors, other clinicians and nurses are available to handle those diagnosed with severe illness or STIs, or seeking SRH services such as a loop, Norplant or cervical cancer screening. The mentors coordinate games, dancing and sports activities.

Teen club attendees are encouraged to participate in joint activities except for topics related to SRHR, when younger and older adolescents attend different activities and discussions. For ALHIV, general topics run throughout the year, and these include HIV basics, viral loads, counselling, and public speaking; attendance of these is compulsory but cannot be enforced for members of the clinic. Individual and group activities are central to creating a supportive relationship between adolescents and health providers, and members are encouraged to participate as facilitators or attendees. The one-to-one sessions during diagnosis or counselling sessions allow for privacy and space for participants to share sensitive concerns with nurses, clinicians and doctors. Intentional programming and/or sports activities offer enabling spaces to cater to individual and group challenges and help build the resilience of adolescents struggling to adhere to medication, maintain relationships, or live happily within their community. While group sessions encourage interactive teamwork and support, they can be either a barrier or facilitating factor to continued attendance and participation in the ART and teen club clinic. This is particularly so, when ALHIV aged 18 and above, who have graduated from high school were required transition to adult care, where group meetings are rare.

Workshops and week-long sleep-away camps or retreats are defined as time consciously set aside for reflection, contemplation and isolation. These are held every year to meet the particular needs and goals for ALHIV[11] (Lefebvre & Nicholson-Smith, 1991; Thamuku & Daniel, 2013). For instance, 'Camp Hope'—a residential summer camp and year-round support programme designed for Malawian ALHIV – builds skills and provides psychosocial support to its campers and their guardians. Camp Hope and other retreats are part of a collaboration between Access Health Africa, formerly known as World Camp, with 'SeriousFun' Children's Network, Baylor College of Medicine's Children's Foundation and Lighthouse Trust (Lut, Evangeli, & Ely, 2017). ALHIV are encouraged to maintain good adherence and improve their life skills with mentors and role models with whom they can relate (Mackenzie et al. 2017, Kaunda-Khangamwa, Kapwata et al. 2020). In addition, the retreats enhance ALHIV life skills as they undergo training in leadership, employment strategies and income generation for those transitioning to the adult HIV clinic. Other workshops are held each year to link parents/guardians of the newly recruited adolescents (Guardian /Parent Orientation). Other workshops include parent/guardian sessions for monitoring and evaluation, SRH and entrepreneurial skills sessions. There is monetary compensation, transport reimbursement and snacks shared during the workshop, retreats, teen club meetings and sessions as part of the motivation for attendance (Folayan, Haire, Harrison, Fatusi, & Brown, 2014; Kaunda-Khangamwa, 2020). Allowances for health personnel and mentors are in line with human resource policy for facilitation roles under the Ministry of Health and Population and non-governmental organisational agreement for per diem allowances.

The UFC ART and teen club clinics were chosen because UFC provides comprehensive HIV related care and services in Blantyre. The clinic was conveniently located and had resources that interested me and were relevant to my study. I had prior experience as volunteering in the programme since 2014, as set

[11] http://www.accesshealthafrica.org/camp-hope-1

out as part of my paper on positionality and reflexivity presented in this chapter below. The time spent volunteering facilitated familiarity and provided me with an in-depth understanding of ALHIV lives, and the interactions and processes involved in (non) service use and resilience.

3.2 Study Design

The study used a mixed-method approach in a cross-sectional, exploratory sequential design which is a two-phase method to inform and modify research tools (Creswell 2014) (see Figure 3. 7 below for the graphic summary of research activities and methodology). The study inquiry was based on collecting both qualitative and quantitative data to provide an in-depth understanding of resilience and service usage among ALHV. The design steps were not strictly sequential as I considered meetings and feedback sessions with the panel of advisory committee members as well as field notes and comments from research assistants, health workers, and colleagues. In addition, semi-structured interviews were conducted with caregivers and ALHIV to strengthen methodological rigour (Ungar 2016).

3.3 Sample Size and Study Population

The sample size calculations for this study reflected the number of adolescents attending the UFC ART clinic and the anticipated costs of data collection. The hypothesis was that greater service use and satisfaction with services would result in resilience and functional outcomes such as prosocial behaviours and interaction with family, peers, school, clinic and other institutions.



Figure 3. 7: Research activities and methods graphic summary

Sampling was based on similar processes in studies that had taken place among adolescents attending hospital/Saturday teen clubs in Zomba and Lilongwe (MacKenzie et al. 2017, Kim et al. 2014, 2015). Through the EMR, I purposefully selected adolescents aged 15-19 between January 2015-2019 who were attending the UFC ART clinic. A total of 1099 ALHIV were recorded in the UFC database. In addition, about 254 young people were transferred out, three had stopped attending the clinic, 379 had defaulted, and 57 were reported dead. A total of 406 ALHIV who had been on ART for the past 90 days were eligible to be study participants based on their availability and consenting, as discussed in chapters three, four and five.

As part of maximising the diversity of study participants, for the quantitative survey, I used stratified sampling to identify ALHIV from the Umodzi teen club programme. The strata were based on teen club attendants (full or partial

attendance) and non-attendants. An invitation was sent to all club members to participate in the study, and systematic random sampling was used to draw respondents. A computer-generated list of attendees was used to select every second ALHIV to take part in the survey. In addition, ALHIV were recruited at the health facility level and followed by community tracing to ensure those that are not active due to stopping medication were included in the sample. In Figure 3. 7 above and Figure 3. 8 (below), I provide a summary of the selection of participants and the flow of the mixed methods for the main study, respectively.

From the sample calculation above, I was able to interview a total of 406 ALHIV on ART for the past 90 days and 22 of those who had defaulted within the same period. Follow-up interviews and eco-mapping exercises were held with those who consented to do so as part of enriching ALHIV stories and experiences within the ART and teen club clinic.

Table 3. 1: A summary of research participants

Research Participants	**Total number (N)**	**Research tools**
ALHIV (Zomba)	42	Cognitive interviews
ALHIV (Blantyre)	406	CYRM-28, Service use questionnaire, observations, EMR data and patient files
ALHIV	26	In-depth interviews & Ecomaps
ALHIV	5	FGDs
PMKs	144	In-depth interviews, FGDs & feedback sessions
Health workers (KIIs)	7	Key informant interviews

In the qualitative design, purposive sampling with maximum variation was used among ALHIV caregivers until I reached saturation, that is, when no new information was shared by participants (Creswell 2014). Maximum variation in

participants was desired and this included age, gender and ethnic background to capture the voices and known circumstances of service use, resilience, SRH subjectivities and complexities of ALHIV. Purposive sampling enabled ALHIV aged 15-19 to be identified and selected to yield cases and experiences that were "information rich" (Creswell 2014), providing extended information about how they were living with a chronic condition and striving (and succeeding or not) to do well. The purposive sampling was appropriate for the task, given that adolescents aged 15-19 continue to be disproportionately affected by HIV and the only age group to have experienced a rise in deaths due to AIDS-related illness (UNAIDS 2019). A single setting only was needed to collect primary data to meet the study objectives. Table 3.1 (above) summarises the research participants.

3.4 Phase One (Pilot Study)

The research study implementation process had six components that were covered in three phases. Each phase, and the interviewing guides, built upon previous work to understand the pathways underlying resilience, interactions, programmes and measures that influence service use over time. Figure 3. 7 (above) provides a summary of the research design processes.

3.4.1 Training Workshop for Working with Adolescents

I trained 28 health workers, seven ALHIV mentors, including three research assistants (two females and one male) as part of strengthening their capacity and knowledge on how to work with ALHIV. The health workers, mentors and data collectors were selected based on their experience working with ALHIV during the teen club sessions. Research assistants were youthful, less than 30 years old, and had five years' interviewing experience in health-related research. The training spanned three weekends, allowing time to discuss the study background, the importance of working with adolescents and adolescents as research participants, ethics, and participating in a survey on adolescents' service usage. The last week centred on mentors and data collectors, with attention to survey tools and interview guides to ensure questions were flowing and working as intended. The health workers, mentors and data collectors helped to simplify the questions, while mentors and data collectors coordinated groups taking the survey at central venues

(lecture halls, guardian and teen club sessions) for both the pilot and main study. The mentors and research assistants also managed the group discussions and survey sessions to help ALHIV who had hearing or sight problems.

3.4.2 Component 1. Qualitative Study

In the first phase, the exploratory sequential approach began with the qualitative pilot survey using cognitive interviews and analysis to ensure that 15-19 year olds understood the questions and concepts, and could handle the lengthy questionnaire (Creswell, 2014; Ridolfo & Schoua-Glusberg, 2011). The interviews allowed me to interact with participants, and target cognitive processes to ensure that questions were working as intended (Lippman et al., 2014; Zukerberg & Hess, 1996). Previous studies on cognitive interviewing used 'think aloud' and verbal probing techniques with a group of 5-10 participants to discuss concepts and question-wording formats (Willis, 1999) (see Figure 3. 8).

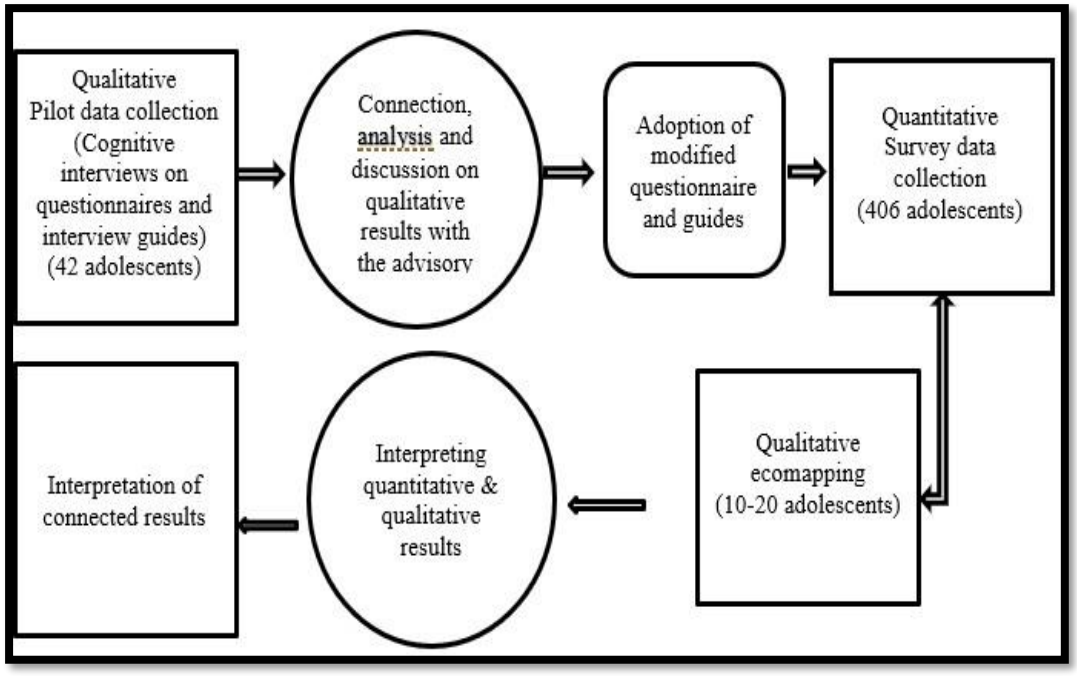


Figure 3. 8: Summary of the research design processes.

The data collection process for the pilot study was undertaken from 1-30 September 2018. I was introduced to the clinic by one of the supervisors under the Tisungane Teen Club Clinic as a student who would be spending time learning about the programme. Adolescents were eager to learn about who I was and what I would be

doing during the sessions. I attended two clinic sessions before the pilot study and contributed to the snacks shared during the health breaks. I spent my time interacting with adolescents, having discussions at random, and responding to different questions that arose during the discussions. During health breaks, I also served adolescents. This was part of the rapport building and aimed to encourage openness and trustworthiness during individual and group discussion sessions.

I worked with the Tisungane Teen Club Clinic staff in Zomba to review the list of ALHIV aged 15-19. The study used purposive sampling to select respondents across ages to represent groups (15, 16, 17, 18 and 19 year olds with seven participants in each group) regardless of the clinic and club attendance, ethnicities and socio-economic backgrounds to participate in the pilot (Appendix 6). Purposive sampling was appropriate for the task, given funding limitations, and the need only for a single source to collect primary data to contribute to questions and processes in the post-pilot study. Figure 3. 9 below provides a summary of participant selection for the pilot study.

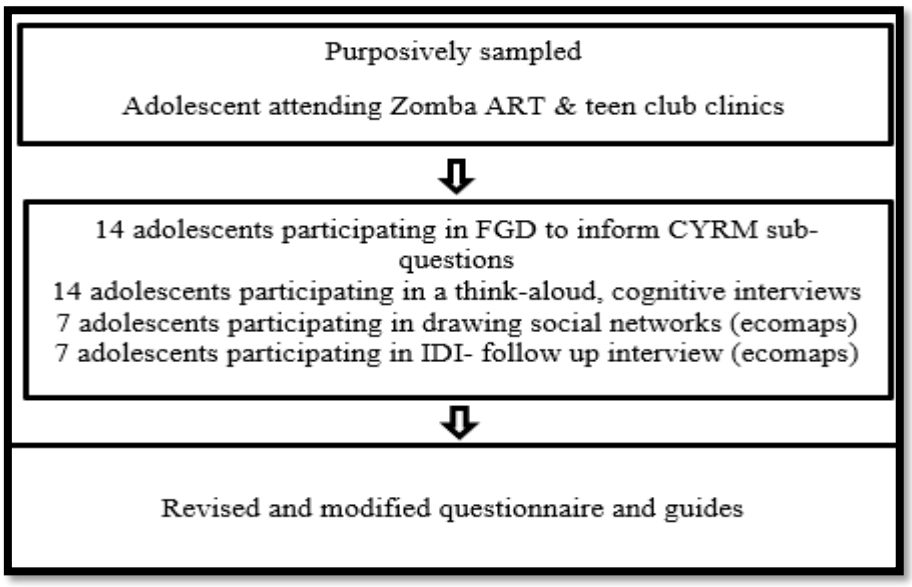


Figure 3. 9: Summary of participant selection for the pilot study

3.4.3 Cognitive Interviews

I held three rounds of cognitive interviews among 15-16, 17-18 and 19 year olds. The interviews were held in a classroom setting and boardrooms to replicate the conditions of administering CYRM-28 survey (n=28), drawing exercise (n=7) and

in-depth interviews (n=7). I employed verbal probing techniques guided by a manual: follow up questions, probes on meanings of resilience, reasons for varied responses, and their suggestions to improve the English and Chichewa (vernacular) interview guides (questionnaire, IDI and focus groups) (Appendix 6, 7 and 7.1) (Ridolfo & Schoua-Glusberg, 2011). ALHIV were allowed to comment verbally throughout the interviews, and I listened and engaged in individual and group discussions on a particular concept or questions until I finished the guides (Blair & Brick, 2010). Sometimes both loud and quieter murmurs and laughter provided me with the opportunity to interject and probe reasons for doing so, and so for discussions and revisions on particular statements in the guides (Willis 1999).

Each interview took between 30-45 minutes for individual adolescents' interviews and 45-75 minutes for group discussions. I conducted all interviews during the pilot phase as I wanted to ensure that adolescents understood the statements in data collection tools and that they worked as intended. Research assistants helped with note-taking during group discussions and transcriptions. The outcomes of the pilot survey included a modified CYRM-28 (Appendix 8, and Chapter three and four, below) to explore the psychometric properties of resilience relevant to ALHIV living in Blantyre, Malawi.

3.4.4 Advisory Panel

The advisory panel is part of adopting best practices to inform resilience research with ALHIV (Folayan et al., 2014; Nyirenda et al., 2018; Theron, 2013). Advisory panels are involved in research in various capacities as presented by Theron (2013): as researchers in community-based participatory research in South Africa, as members of a Community Advisory Group/Board (CAG/ CAB in Malawi to manage the ethical conduct of research (Nyirenda et al., 2017), and to strengthen planning and implementation of HIV/AIDS research (Reidy, Rabkin, Syowai, Schaaf, & El-Sadr, 2018). Their roles are also recognised in resilience research as part of knowledge generation and informing practices in middle and high income-countries (Theron 2013). However, the selection of members of advisory members, roles and participation vary across countries and contexts. In particular, there are challenges in engaging advisory panels in low resource settings like Malawi.

Nyirenda and colleagues (2017) mention knowledge gaps in translating science to people at grassroots levels, and ‘power dynamics’ when different academic disciplines or institutional cultures assume superior positions. There can be imbalances across panel membership and lack of financial support which affects research planning and outcomes. Despite the challenges, community organisations and CABs can significantly improve the commitment of participants, including adolescents.

Hence, invitations were sent to select individuals to join an advisory panel to help with processes to determine appropriate terminologies to use in modifying the survey questionnaire CYRM-28 and Global Early Adolescents Survey (GEAS)-Health Instrument in Malawi. Out of the nine invitations sent out, six experts in adolescents’ health attended the meeting. They provided their views on how to adapt the revised tools: an epidemiologist, a district health office representative, medical anthropologist, sociologist, teen club coordinator and a peer mentor.

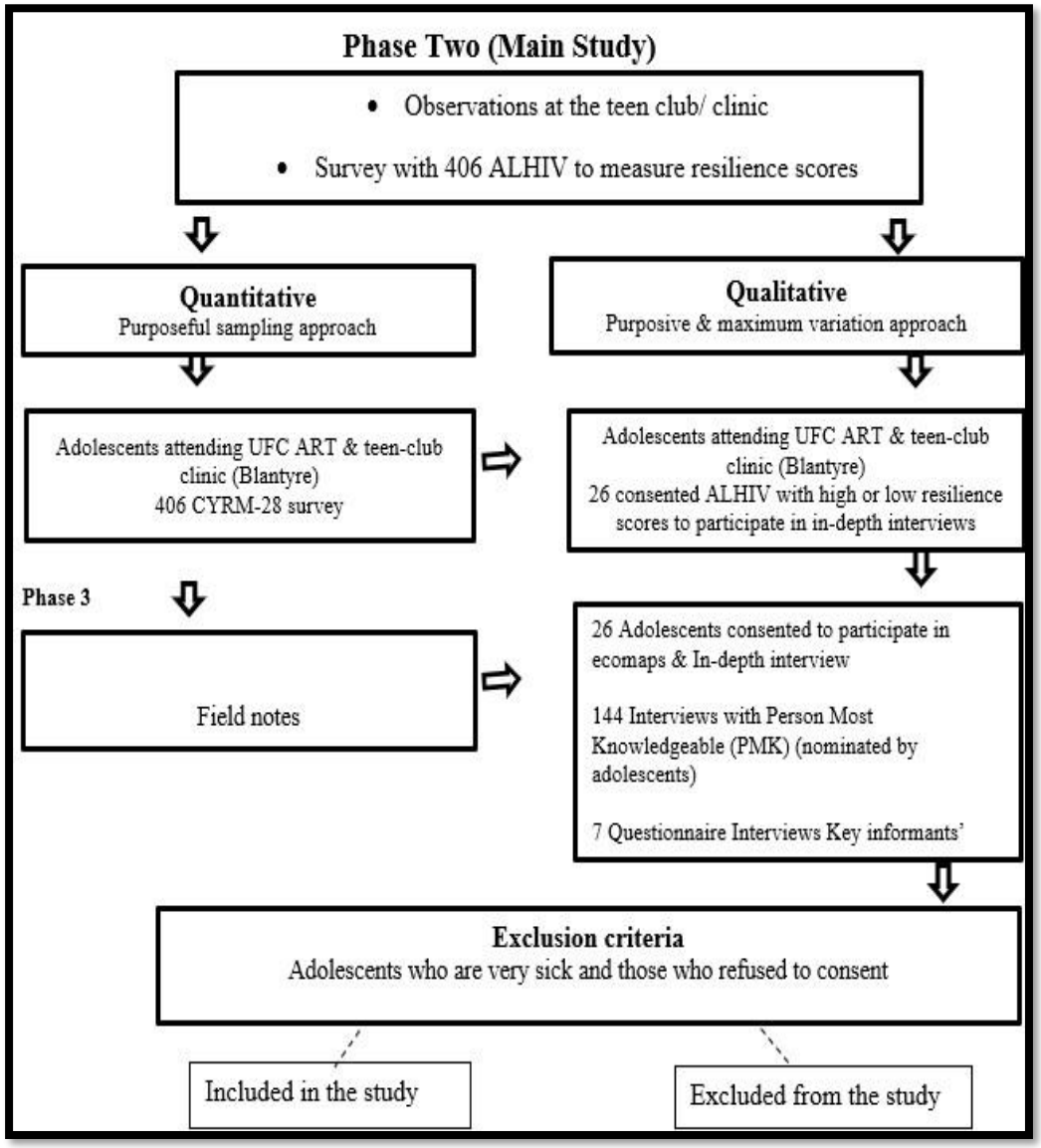


Figure 3. 10: Summary of participant's selection & flow of methods, (main study).

3.5 Phase Two: Main Study

3.5.1 Component 2. Data Abstraction and Records Review

The quantitative part also retrospectively and prospectively reviewed a cross-section of data from the ART and teen club clinic to gain a general overview of the status of ALHIV attending the UFC programme and the indicators of interest for the study (Figure 3. 10 above). There are increasing calls to include age and sex-disaggregated data on adolescents to develop a complete picture of adolescents in a geographical area as well as informing policy and intervention programming (Idele et al., 2014; UNICEF, 2016). The data abstraction sources include programme

records such as the registers, also known as the Health Management Information Systems (HMIS) and the Electronic Monitoring Records (EMR). The EMR is a standard medical and clinical data capturing system placed in a providers' office to track data over time (Douglas et al., 2010). The HMIS registers and EMR records reviews are part of the real-time clinic recording process (Appendix 16), which enables data abstraction from multiple registers and delivery points (UNICEF 2016, Douglas 2010).

I reviewed records of ALHIV who were recruited in the ART and teen club clinic programme between January 2002 to June 2019. The data abstraction period was longer than the period of fieldwork to provide the context and background of PLHIV and ALHIV given the change in policy. The data abstracted from the EMR and ART, STI and Family Planning registers included attendance records and outcomes. The process was two-staged, whereby data were collected on demographics, clinical characteristics of ALHIV and variations of service usage among the adolescents aged 15-19. The abstracted data allowed for information triangulation on the date of initiation on ART, time on ART, records on STI, pregnancy, and provision of contraception. Appendix 16 provides a copy of the data abstraction form.

3.5.2 Component 3. Quantitative Inquiry

Despite debates on how to measure sources of strength and protective factors or resilience among adolescent populations in high- and low-income countries (Govender et al., 2017), various quantitative instruments are available: Resilience Scale (RS), Child and Youth Resilience Measure (CYRM) and Pathway to Resilience Youth Measure (PYRM). No scale or measurement is considered to be superior (van Rensburg et al., 2017), and scholars question their feasibility to generate reliable and valid measures of resilience (Windle et al., 2011). Standard resilience frameworks discuss individual characteristics of resilience over a lifetime, including patterns, processes or associations related to the same (Windle et al., 2011).

The CYRM was most relevant to this study. Sanders and colleagues (2013) used a CYRM as a sub-scale to measure adolescents' perceptions of resilience-promoting

resources, including 1) school enrolment and attendance, 2) pro-social behaviour, kindness, and concern for others, including participation in community-level meetings, and 3) risks (individual and contextual-exposure to chronic adversity). The CYRM-28 helped to identify individual characteristics of resilience over the course of life and patterns, processes, and associations among ALHIV.

To ensure methodological rigour and enrich my understanding of resilience and service use within the specific cultures and context of the ART and clinic teen club, I continued to use quantitative and qualitative approaches in the second phase of data collection. The quantitative inquiry during phase two employed the final questionnaire (a modified CYRM and GEAS-Health Instrument based on pilot results) (Appendix 8). The questionnaire was administered to 406 adolescents aged 15-19 selected through purposeful sampling from UFC ART and teen club clinics in Blantyre (see below and Chapter four).

3.5.3 Measuring Resilience

Resilience was assessed using both quantitative and qualitative methods. The quantitative inquiry determined resilience as a latent variable. It used the CYRM sub-scales with 28 questions, rated using a 5-point Lickert type scale to measure resilience. The CYRM-28 subscales were used to assess the presence of both individual traits and socio-ecological components that are key to resilience processes among ALHIV. The scale captured individual assets (personal through skills, support), relational supports (family, peer) and contextual resources (education, health care, spiritual and cultural support (Ungar 2016, Liebenberg et al. 2011). A copy of the adapted adolescent CYRM-28 questionnaire guide is set out in Appendix 8.

This quantitative inquiry included a paper-based questionnaire that was administered in a classroom set-up in a lecture hall with 15-25 ALHIV in each group's sittings on different days to reach the target population. I led the administration of the questionnaire to 406 ALHIV in lecture theatres at the College of Medicine, during weekends, to maintain privacy and confidentiality. I read out loud the questions and respondents were given a minute to respond to each of the items under the CYRM-28 and other research questions. Research assistants who

were mentors helped those adolescents who had a hearing or vision problems. The interviews took 30-60 minutes, with a health break at 30 minutes when adolescents received a bun and a bottle of juice.

3.5.4 Component 4. Qualitative inquiry: Resilience Measure

Qualitative research within resilience studies remains underutilised. Windle and colleagues (2007) and van Rensburg (2017) argue for supplementing quantitative survey scores to strengthen findings and redress potential bias where the qualitative inquiry is missing. Van Rensburg (2017) argues for phenomenological and quasi-experimental studies to capture depth. In the current study, to understand ALHIV institutional and relational experiences, resilience and service use, multimethods were used to engage ALHIV, health workers and caregivers. The multimethod approach as advocated by Lewin and colleagues (2005) allowed the data collection process to be iterative to capture and compare response patterns among study participants. The term multimethods refers to a combination of two or more methods to investigate a research question or objective. In this current study, the methods used included ethnographic approaches (observation and informal conversations), in-depth interviews and focus group interviews (Appendix 6, 7, 7.1, 9, 10, 10.1, 12, 13, 14 and 15). These methods complemented each other and allowed ALHIV, parents and health workers to be followed up, allowed me to provide feedback sessions, and provided an opportunity for more in-depth explorations of issues that arose through individual interviews.

3.5.5 Ethnographic Approaches: Observations

Ethnographic approaches (participant observation, semi-structured interviews, mappings and focus group discussions) are vital to providing a deeper understanding of local contexts, institutions, processes, meanings and practices in research (Kok et al. 2018, Creswell 2014). Given the sensitive and complex nature of working with ALHIV— a vulnerable target population – previous studies draw on ethnographic inquiry rather than traditional ethnography to shorten the time of ‘being’ in the field to between 6-12 months (Mack, Woodsong, McQueen, Guest, & Namey, 2011; Wray, Markovic, & Manderson, 2007). There is growing recognition of the value of using ethnographic approaches such as observations for

an extended period of time as part of engaging and participating with varied communities, health or social systems to gather nuanced and in-depth experiences on sensitive topics involving vulnerable individual or groups such as ALHIV and caregivers (Nanfuka, Kyaddondo, Ssali, & Asingwire, 2018; Stake, 2006; Wray et al., 2007) An ethnographic approach was essential in this study to provide rich and detailed descriptions about ALHIV behaviours and context, and allowed me to reflect on researchers' positionality and insights (Creswell, 2014; Narayan, 1993).

Participant observation in this study enabled me to be an active member in the field, taking field-notes, interacting, asking questions and having discussions. Participating in meetings and teen club sessions encouraged lengthy interactions, thereby increasing the likelihood of participants behaving naturally in and out of sessions and to freely engage in conversation on personal experiences within spaces and places, and on issues and states of being, such as 'doing well', and health status over time (Morgan, Pullon, Macdonald, McKinlay, & Gray, 2017; Ross et al., 2020). The participant observations aimed to: 1) explore the implementation of ART and HIV care services among ALHIV, how they are structured, organised and delivered; 2) observe the dialogues about SRH service use and other resource supports with ALHIV, caregivers and health workers; and 3) observe interactions and exchanges between ALHIV, health care workers, mentors on SRH sessions during workshops, retreats, interviews, club meetings and at homes. These observations were undertaken as part of triangulating participants' views on both positive and negative SRH-related encounters.

I observed those who attended the ART and teen club each month (age, gender, and ethnicity), and of interactions at meetings. The records on the attendance sheets and the clinic at work were collected over eight months period. At the clinic, I interacted with potential respondents. I sat in on teen club meetings and other sessions to gain knowledge of adolescent experiences when participating in health education on adherence, SRH, basics in information technology, and entrepreneurship workshops. During these observation exercises, I looked at the spaces that adolescents occupied during the sessions, seating plans, the presence of formal speakers, topics shared and interactions with each other, questions asked, and their

reaction to particular topics. I asked questions, showing interest in the responses and allowing others to intervene in the discussions to explore the role of the teen club in fostering or failing to foster resilience (Arias-Pujol & Anguera, 2017). A copy of the participant observation guide is set out in Appendix 17.

In the first six months, observations were done daily. There were many opportunities for engagement in the adolescents 'back to care' room, in TB, FP and STI departments, registration desk, the pharmacy, and interview/diagnostic/HIV testing rooms, including the kitchen where food was shared and staff discussed the integration of programmes. I participated in SRH sessions to gain insiders' knowledge and adolescent experiences when attending SRH workshops. In addition, the clinic corridors and grounds opened up more space for informal conversations and role-playing. I recorded all formal discussions and kept notes of all observations and informal discussions.

3.5.6 Component 5. In-depth Interviews, Key Informant Interviews and Focus Group Discussions.

For ALHIV, to explore the individual, relational and context issues, I used both visual methods such as maps and texts and in-depth interviews, the combination of which offered innovative and interesting ways to present resources and supports that ALHIV use for their wellbeing (Creswell 2014). To demonstrate convergence/divergence, I employed ecomaps (Hartman, 1995; Ray & Street, 2005). An ecomap is an innovative graphic representation or visualisation ("picture") of people or support providers in a person's life, e.g., friends, school relationships, relatives, doctors, neighbours, or church members.

Using ecomaps, I collected detailed data of 26 adolescents with high and low resilience scores, with the method continuing until saturation was reached to extrapolate resilience measures and service use. Adolescents were invited for a second time to my make-shift office, where I continued our conversation and discussed their lives in-depth. The individual-based interviews followed for the second or third time to explore their explanations of their drawings in detail. The data provided detailed ecomaps and rich narration of adolescent service use that supplemented the survey data. In Appendix 10 and 10.1 I show the guide for the

eco-mapping exercise and Appendix 9 for the in-depth interviews. I provide a detailed account of the ecomaps in Chapter six.

IDIs were conducted with ALHIV, health workers and caregivers to talk and describe their life experiences. Most of the issues raised in the survey (service use, resilience, SRH, pregnancy, sex, STIs) were also explored in-depth. The one-to-one interviews were held in my make-shift office, 2km away from the clinic, to provide space for ALHIV to articulate their stories. I encouraged ALHIV to pass by the office any time for both long and short talks and/or to finalise their ecomaps. In addition, during my observations at the clinic, I met other caregivers, who I would request meet me for a quick talk about themselves and their child either at the make-shift office or in the corridors, hence expanding opportunities for data triangulation. There were bottles of water, juice and buns readily available for them to take during the talks. Providing a conducive environment allowed adolescents to phone or send a WhatsApp message to let me know when they might drop by later in the day. \

I chose to use IDIs and FGDs because they offered ways for both individuals and groups to open up during discussions and discuss sensitive issues. For in-depth interviews and focus group discussions, all questions were open-ended with probes, for example, “Tell me about growing up as an adolescent here.” “What kinds of things are most challenging for you growing up here?” “What do you do when you face difficulties in your life?” “How do you describe people who grow up well here?” “What does it mean to do well in your life? (Probe on health, spiritual, physical, mental, emotional, SRH, issues).” (Appendix 7 and 11)

For the five FGDs, I requested adolescent mentors within age groups to coordinate groups of 6-8 persons, who would receive consent forms from me and choose a day that was convenient for them to take part in the discussions. FGDs were conducted with different groups, with six single-gender and four mixed-gender groups of roughly similar ages, for triangulation purposes (Wray et al., 2007). I coordinated FGDs with caregivers whenever I met them during guardian or workshop sessions; I gave them information sheets about the study and invited them for second or third talks whenever they were free. All participants received a bottle of juice and buns during the interviews and transport reimbursement after the interviews.

Most interviews ranged from 30-90 minutes and were held in both Chichewa and English as adolescents tended to express themselves best in a mix of both languages. Digital recorders were used to audio record all interviews and files were stored in Nvivo. I recorded all formal interviews and took notes from all informal talks (see Appendix 9 for a copy of IDI, Appendix 11 for the FGD guide and Appendix 15 for digital recording).

3.5.7 Key Informant Interviews and PMKs

I also interviewed key informants, who were mostly nurses and mentors and PMK (parents and caregivers), about adolescents' lives (risks, opportunities, dreams, service use) for triangulation (Appendix 12, 13 and 14). PMKs and KIs play a significant role in adolescents' lives since they are familiar with their adversities, resources, and opportunities. I held key informant interviews with seven key stakeholders and group interviews with 144 PMKs at various places at night, during workshops, lunch breaks, and weekends when they were not on duty. I used interview guides for discussions which lasted 45-90 minutes for health workers and caregivers. However, I did not follow every question on the guide. Instead, I encouraged participants to have conversations in a relaxed manner. (See Appendix 13 for a copy of the key informant interview).

3.6 Phase 3

3.6.1 Component 6. Fieldnotes

Field-notes recorded in notebooks form a significant part of the data from observations. Creswell (2014) mentions six approaches of taking notes -- as an observer, participant, participant 'outsider or insider', spending more time as an observer than a participant, and vice-versa. The field notes can be captured as text, diagrams, maps or organisational charts. Contextual details or non-verbal actions are all part of data collection, analysis and interpretation (Neale, 2013; Tong, Sainsbury, & Craig, 2007). The note-taking process allows the researcher to describe the observations, interactions and experiences during their field-work. Various researchers and authors use field notes in different ways. Clarke and Bailey (2016) use notes to 'capture threads between visits', new developments and

contextual dynamics. Maharaj (2016) argues for using field notes to facilitate critical reflection and analytical writing and reworking conceptualisation. My documentation and learning process using field notes evolved out of myriad reflections within the ART clinics grounds, make-shift office, school grounds, adolescents' and caregivers' homes, with individuals and groups, and at workshops.

During the eight months of data collection, I moved between participant and observer roles. As a participant, I carried around an A5 notebook of 192 pages and divided each page into two columns to capture proceedings in the field and my reflections as they unfolded. During teen club sessions, meetings and workshops, I wrote short entries and noted my reflections in the notebook. Later at night, I revised my entries and provided in-depth accounts of the observations, interactions and reflections throughout the fieldwork and analysis processes.

For in-depth interviews and FGDs, I scribbled notes as I had a chance to ask for clarifications and feedback on various issues, which provided a more in-depth description of each individual and group discussions as they unfolded. I took time as an observer during clinic working hours, role-plays and workshops. The observed accounts were extended right after the activities when they were still fresh in memory and written up on the same day (Mack et al., 2011). In all my fieldnote entries, my reflections, reactions and questions were documented in the column close to the right-hand side. Reflections created an open narrative that gave a deeper understanding and interpretation of the phenomena under study.

The mixed-method approach in the current study used both quantitative (surveys and data abstraction) and qualitative (observations, in-depth and key informants' interviews and focus group discussions) methods rigorously. The choice of using mixed methods aimed to capture a more complete, holistic and contextual portrayal of the unit(s) under study, with multiple "measures" to uncover some unique results that might be neglected by any single method (Rifkin, 2014). The quantitative surveys, data abstraction of registers and electronic monitoring records (EMR) were employed to establish factors that would explain variations on resilience, associations and measures among ALHIV. The qualitative interviews were used to understand the experiences and meaning of resilience over time. In addition, the

interviews helped me to identify and summarise the informal and formal services that adolescents negotiated or navigated to meet their health and SRH needs. The combination of extensive note-taking, field notes, informal and formal conversations, interviews and group discussions ensured richness of the data to cater for reliability and validity of the data collection process. Data collection for all of the study proceeded simultaneously, but the data were analysed separately. The results of both methods were then converged to answer the research questions.

3.7 Data Management and Analysis

Data were analysed and managed using a combination of methods simultaneously and iteratively. Quantitative study data were collected by the researcher and entered into REDCap by research assistants. The data were managed using REDCap electronic data capture tools which provided space for validated data entry and automated export procedures through STATA version 14.2 in readiness for analyses. I cleaned the quantitative data manually and cross-checked the data for completeness before data analysis. I worked hand-in-hand with the biostatistician to use descriptive statistics to show socio-demographic characteristics of the study population, associations with the variables of interest and latent analysis. Structural equation modelling helped to infer the resilience measure among ALHIV. Multiple regression analysis was done to make further statistical inferences (see chapter four and five for the detailed description).

Qualitative data were stored as audio files, transcribed and translated into English, and stored in NVivo 11. The transcriptions were done by three research assistants and cross-checked by the researcher and supervisors. Preliminary analysis for the qualitative interview was done daily and discussed with research assistants who had a minimum of bachelor's degree and extensive qualitative fieldwork experience. This process allowed me to note emerging themes and data saturation. Despite frequent and cross-cutting themes emerging across individual and group discussions, it was a challenge to ensure data saturation on discussions on the meaning of resilience among ALHIV due to the diversity across the sample of adolescents and life experiences (Lut et al., 2017). However, I held second to fourth interviews with some adolescents and caregivers to discuss their lives in-depth and

draw ecomaps; sometimes I just had informal conversations with participants to learn about what was happening in their lives.

3.7.1 Cognitive Interviews - Pilot Data

I used the constant comparative method (Ridolfo & Schoua-Glusberg, 2011) as an inductive method of analysis to allow for simultaneous comparison of data across and within the three groups of respondents (15-16, 17-18 and 19 year olds). The comparison was made across the respondent and groups for depth. The constant comparative method allowed a better understand the type of information a survey question and interview guides capture including their interpretive processes, intended and unintended responses. The conclusions from the constant comparative analysis were shared with the advisory panel in a workshop and discussed to modify the CYRM-28 questionnaires and interview guides in readiness for the post-pilot survey and interviews.

3.7.2 Measures: CYRM-28/GEAS Survey Data

Data from the self-administered survey (modified CYRM and four subscales from GEAS-health instrument) were entered into STATA for further analysis. The initial analysis enabled the description and summaries of socio-demographics, gender and age disaggregated data. The review of records collected descriptive data and clinical characteristics on date of initiation on ART, time on ART, records on STI, pregnancy, and contraception disbursed. The second phase of data analysis employed inferences from the data, with a combination of latent analysis, structural equation modelling, bivariate and multivariate analysis to identify associations between age, gender and resilience scores (individual, contextual risks, functional outcomes).

The key outcomes variables are resilience, risks and service user experiences. For Chapter Four, the resilience-related variables are measured as a latent variable and used latent analysis, a sub-set of structural equation modelling to identify response patterns among ALHIV (Collins, 2010). The validity and reliability tests, model fit, and SEM were run to find scores and identify any relationships between variables, scores across ALHIV(Sanders, Munford, Thimasarn-anwar, et al., 2017; van

Rensburg, Theron, & Ungar, 2019). In this chapter, I describe how I adapted and validated the CYRM-28 among ALHIV in Malawi (Kaunda-Khangamwa, Maposa, et al., 2020). In Chapters four and five, I provide detailed quantitative analysis and presentation, which resulted in Paper II and manuscript I respectively.

All statistical analysis was conducted using STATA version 14.2. I used inferential statistics: Spearman Rank-Order to find correlations for service use, risk and resilience across ALHIV age groups. I also used multiple regression to isolate any relationships that answer our research objectives. Significant relationships used multiple indices: 1) chi-square (χ^2), degree of freedom (df), 2) Tucker-Lewis Index (TLI), 3) The Comparative Fit Index (CFI), 4) Root Mean Square Error of Approximation (RMSEA), 5) Standardised Root Mean Square Residual (SRMR), and 6) RMSEA with 90% confidence interval, for instance, those with alpha above 0.60, $p<0.1$. A biostatistician helped me to handle the statistical data analysis.

3.7.3 Data from In-depth Interviews and Focus Group Discussions

Framework analysis enabled me to make sense of qualitative data in both the preliminary, middle and final stages of the data analysis plan (Creswell, 2014; Srivastava & Thomson, 2009). Ritchie and colleagues (1994) have discussed a framework analysis that entails 1) familiarisation; 2) identifying themes; 3) indexing; 4) charting; and 5) mapping and interpretation (Ritchie, Spencer, Burgess, & Bryman, 1994). The five steps enable both hand and computer-based coding using NVivo 11. After the familiarisation stage, when transcripts were read more than four times, emerging themes were analysed through constant comparison and feedback sessions during fieldwork and workshop meetings or teen club sessions. I had comprehensive field-notes and transcripts and undertook paragraph coding and indexing to identify the portions and sections supporting various themes and quotations (Creswell, 2014; Srivastava & Thomson, 2009). I went further to chart the data using flip charts and feedback sessions in workshops to inform the different manuscripts for my studies.

Mapping and interpretation continued to be an iterative process for themes for each ALHIV individual case from the 26 in-depth interviews, five FGDs and seven KIs, including field notes entries (Ritchie et al., 1994). More detailed analysis for

qualitative work is presented in Chapter six, with case studies and ecomaps to visualise ALHIV resources and supports, and in Chapter seven to understand a dynamic and fluid construction of space and place which is key for ASRH experiential learning and experience (Abbott-Chapman & Robertson, 2009; Massey, 2005).

The case studies in the form of stories contributed to my understanding of resilience among ALHIV. I employed a multiple case study approach as have been defined by Yin since 1994 (1994, 2009) and linked it with the concept of 'complex needs' to challenge the way we think in explaining resilience.

> A case is defined as "a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clear and the researcher has little control over the phenomenon and context" (Yin 1994, p 13).

Since I do not have control over the activities within the teen club settings, I refer to multiple-case studies, with four case studies to explain 'how' and 'why' particular experiences and supports (institutional and relational resources) result in both positive and negative outcomes among ALHIV (Ungar, 2012; Yin, 2009). By including visual data in the form of ecomaps in the case studies, I sought to enrich my findings and present ALHIV surrounded by supports and resources (Appendix 10, 10.1, 19).

The paper in Chapter seven uses data from participant observation, field-notes and in-depth interviews, and group discussions. In this chapter, I adopt an anthropological approach to look at social and sexual ecologies that enable resilience among ALHIV in the context of SRH. The study included multiple level spaces, places and relationships: homes, schools, community activities and teen club clinic -- as enabling spaces that support SRH positive social and health-related outcomes for ALHIV. The interactions and dialogues ensured SRH and experiences to be highly visible, as an open topic of discussion with ALHIV voices heard and making informed decisions.

With the quantitative data, descriptive analysis and inferential statistics helped to show patterns of service usage, risks and resilience measures across the 15-19 age groups. The broad themes that emerged from the qualitative data included resilience-related experiences, and navigation and negotiation of formal and alternative supports, and institutional resources to meet ALHIV health, social, spiritual needs. The themes and inferential statistics were compared continuously with the literature, discussed with supervisors, members of the advisory panel, some mentors, and in workshops to strengthen the validity of the research findings.

The following article, entitled ‘A volunteer for life’: Interactions in resilience and service-use research in Malawi, was published in *Medicine Anthropology Theory* (MAT). This was an attempt to acknowledge my multiple roles, respond to the complexity of reflexivity. I then return to ethics considerations to maintain the best interest of ALHIV and finalise this chapter on methodology.

POSITIONALITY AND REFLEXIVITY

Paper I

Kaunda-Khangamwa B.N (2020a) ‘A volunteer for life.’ Interactions in resilience and service use research in Malawi. Dissertating Essays. *Medical Anthropology Theory* 7 (2): 5030.

https://doi.org/10.17157/mat.7.2.5030 or
http://medanthrotheory.org/index.php/mat/article/view/5030

3.8 Introduction

This was an attempt to acknowledge my multiple roles, and so respond to the complexity of reflexivity, defined as a critical reflection of researcher’s roles, positions, thoughts and decisions when engaging in research (Naveed, Sakata, Kefallinou, Young, & Anand, 2017). My positionality and reflexivity are presented as a short methodological paper where: 1) I discuss the pleasure and challenges of my multiple roles as an insider/outsider dilemma; 2) the increasing use of WhatsApp as a conventional form of interaction and chow this changes fieldwork space; and 3) the ethical implications of working with adolescents attending a teen club clinic. I reflect on my roles as a student of medical anthropology and public health, 'friend', 'aunt' and 'volunteer' to contribute to discussions on working with young people, deemed 'vulnerable,' in the production of knowledge. I also make a few suggestions on what researchers working with adolescents may consider in fieldwork. This is not intended to be prescriptive but to account for the privileged/difficult situation of having to constantly navigate and redraw boundaries of their relationships with research participants.

This paper was published in *Medicine Anthropology Theory*. The format and references have been amended to comply with the thesis.

Abstract

In a time of renewed interest in the challenges of adolescent sexual and reproductive health (SRH) and service use, increased scholarly attention paid to fieldwork and knowledge production is critical. I describe the pleasure and challenges of engaging with multiple perspectives, spaces, places, and roles at a family centre in Malawi to understand the complexity of the interactions and relationships related to my doctoral fieldwork. This work is part of a large mixed-method study that explores SRH, service use, and resilience among adolescents living with HIV and attending a teen-club clinic in Blantyre, Malawi. Drawing from resilience theory and experiences of reflexivity, I reflect on my roles as a student of medical anthropology and public health, a 'friend', an 'aunt', and a 'volunteer'; on my occupation of diverse spaces (clinics, homes, school grounds, digital); and on my use of multiple methods (including participants' observations, individual and group interviews, workshops, feedback sessions, and fieldnotes), which make up the data collection, analysis, and interpretation processes. The reflections contained in this essay advance our understanding of the implications of the methodological considerations and ethical questions underscoring approaches to adolescents' research.

Keywords: adolescents, ethnographic approach, reflexivity, teen club clinic

* * *

Social media tagline

Adolescents living with HIV strive to do well despite their adversities for today, tomorrow, and for the next generation! @BlessGift5



Figure 3. 11: Umodzi Family Centre, Blantyre, Malawi[12]

On a rainy Tuesday night in January 2019, I received a WhatsApp message from Keto, a 17- year-old young man, at around eight in the evening. 'I need to see you,' it said, 'I just need someone to talk to.' The text was followed by twelve heavily crying emojis. Keto was not taking his anti-retroviral medications as required. He explained that he felt very alone in a house full of siblings who did not take medication; now, he was forced to attend the monthly teen club clinic. 'I am taking a break. For the next month, I will not take my meds,' he stated. That was the beginning of more than 1,000 hours I spent chatting with adolescents on WhatsApp as part of my fieldwork.

Between November 2018 and June 2019, while working on my PhD (entitled 'Sexual and Reproductive Health Service Use and Resilience among Adolescents Living with HIV [ALHIV] and Attending a Teen Club Clinic in Urban Blantyre, Malawi'), I conducted an eight-month mixed-methods study to understand ALHIV access to health services. The key challenge of my research was to try to understand how young people with life-long conditions such as HIV strive to do well despite adversity; that is, how they aspire to and exercise resilience. This challenge was born out of my volunteer work in this exact clinic three years prior to starting my

[12] Photo taken by the author during fieldwork, 1 December 2018

doctoral studies in 2017. Now, spending time in the clinic in Blantyre under a different mantle, I was faced with the question of how we as ethnographers negotiate the transition from being a volunteer to a researcher in a group of young people.

As a volunteer, my role involved serving refreshments during break times and facilitating discussions scheduled for teen club meetings and workshops. Sometimes, I merely sat and conversed with young people, giving time and support within or outside the clinic. Now in the context of my doctoral research, I asked myself how I could keep up with the dialogues that took place exclusively through the WhatsApp messaging service and how these dialogues could constitute a research method. In addition, on such an informal and intimate platform I needed to negotiate boundaries between 'researcher', 'friend', and 'volunteer' while maintaining my research goal as well as the adolescents' best interests. As a medical anthropology and public health student, researcher, and previously a volunteer, I now write this article to contribute to discussions on the methodological challenges of navigating transitions between shifting roles when working with young people deemed 'vulnerable' in the production of knowledge.

From other work on ALHIV (Hodes et al., 2018), street youths (Theron & Malindi, 2010), and ARV clinic ethnographies (Nguyen 2010), I knew that building rapport with those I wished to interview was critical. I aimed to understand how various interactions and encounters at home, in school, at the clinic, and within the community informed young people's use of services to enhance wellbeing over time. Our discussions continued at participants' homes, university lecture halls, seminar rooms, teen club meetings, and in my makeshift office. Sometimes we talked as we walked down the street, in the school grounds, or along clinic corridors. The chats' topics spanned from well-wishing to educational funding, weddings, family conflicts, and funerals. These discussions offered my interlocutors—young people, caregivers, and health providers—opportunities to reflect on how adolescents negotiate and exploit varied resources to support their wellbeing.

I had to keep cultivating both old and new relationships. Aged 15–19, some adolescents referred to me as an 'aunt', regarding me as an elder and an authority.

Most called me by my first name, which helped reduce the distance between us and facilitated our ability to have open discussions about their lives. To a few, I became an older friend, a confidante, a personal support person that they had never had before. As alluded to by Nguyen (2010) and Biehl (2009), forming friendships generates richer data illuminated by bolstered rapport through open and in-depth discussions with the same participants in varied social spaces.

Trying to balance my different roles vis-à-vis these adolescents, bearing in mind power relations, and ensuring that no-one was left behind, we agreed to set up a closed WhatsApp group. More adolescents joined, some requesting private one-to-one conversations when they felt the need to talk. Some ALHIV complained that I paid more attention to those with phones (and thus able to use WhatsApp) than those without. Others felt I did not give their parents or guardians enough time and support. The chat messages covered far more than I had anticipated; the highly frequent exchanges, which occurred throughout the day and night and included both individual and group discussions, gave me exceptional insight into their circumstances. It dawned on me that the presence of a researcher arouses curiosity and provokes the consideration and expression of various identities, relationships, and experiences among interlocutors.

Consequently, I began to hold meetings and group discussions with parents and guardians on Sunday afternoons. However, by the third month of data collection, fewer invited participants were turning up because of the farming season. Two more WhatsApp groups were formed with adolescents' parents, guardians, and health workers during the study's debriefing workshops and guardian sessions. Rules and administration were discussed within the groups to keep order. I tried to play a minimal role in the chat groups and let participants share their voices and their everyday experiences (Narayan 1993). The text chats were reasonably private and so questions naturally arose on how I was going to incorporate these into my research narrative.

It was a challenge to maintain the newly formed ALHIV group chats, as such interactions quickly evolved into friendships that required more open and frank talks. Many of the adolescents who I'd regularly meet 'emptied their heavy hearts',

laughed heartily, or asked to be referred to a nurse or specialist. While I was happy to engage in these chats, I was still a researcher; such sudden and dramatic transitions raised ethical issues regarding what might be used as data; and whether my interlocutors were always aware that 'auntie' or 'friend' was simultaneously someone doing research. To adapt, I continued to take notes as key ethnographic data. I expanded my descriptive and reflective notes and transcripts on those ALHIV and caregivers who had consented to meet for multiple interviews. In the successive meetings, we reviewed the notes and discussed experiences to inform themes for further analysis.

Yet my roles were blurred not only in relation to the youth themselves. Some caregivers/relatives of the adolescents would send me messages or call to ask for contributions to school fees or request referrals to social welfare services. Some believed that I knew their young kin 'better' than them and booked appointments or stopped me in clinic corridors accordingly, often to discuss their concerns about young people having sexual relationships, drinking, or accessing pornography. These conversations were often intense, and so there was a need to balance my desire for 'research saturation' so as not to compromise my wellbeing (Wray, Markovic, and Manderson 2007). I constantly had to remind myself to comply with ethical guidelines and to offer equal opportunity for all to participate in the research while protecting their confidentiality and safeguarding their identities. I referred ALHIV and caregivers to dedicated mentors, teen club study coordinators, and programme managers for their best interests. This was one way of managing the increasingly blurry lines between my roles.

Working with multiple groups (ALHIV, their caregivers, and health workers) provided space in which participants representing different interests could reflect on their life experiences. I learnt that some parents had been subjected to confessional statements by group members (e.g., 'Hello, my name is [. . .] and I have HIV') before starting Sunday meetings despite not being comfortable with disclosing their status. Others appreciated the therapeutic dialogues (Moyer, 2015). This discrepancy highlighted the need for constant communication with caregivers to improve relationships and trust. Adolescents were able to relay some of their

worst fears and, through expression, magnify their autonomy and foreground any existing tensions related to their wellbeing (particularly with regards to meaning and decision making). Twelve months after I finished my fieldwork, I still receive calls in the middle of the night and messages that need responses, as well as referrals to clinic staff or specialists. My role as a volunteer continues. It seems I was never a student researcher; in the eyes of my participants, I was always a volunteer at the teen club clinic.

As my account shows, the boundaries between volunteer and researcher roles can easily become blurred due to sustained periods spent interacting, interviewing, and building relationships during fieldwork. To address this challenge, I underwent a period of critical and public reflection on myself, an example of reflexivity, in an attempt to acknowledge my multiple identities and roles as a volunteer, researcher, confidante, and student (Narayan, 1993). To a large degree, some experiences were beyond my control, illustrating the thin line between insider and outsider roles. I had to navigate the beliefs of caregivers and ALHIV that my presence meant significant changes and support would follow. It can be suggested that even though being a volunteer made my integration into the clinic and relationships a lot easier, in some instances, particularly when I refused a request for help, my role as a researcher was put into question.

This is why I held regular debriefing sessions with research assistants, supervisors, and the advisory panel; it was important to discuss my methodological challenges. I reinforced my role as a researcher by continuously attending and giving feedback sessions on my research in the weekly clinic planning sessions, as well as the guardian and teen club clinic sessions. In addition, during in-depth and group discussions, I resorted to giving realistic responses, refusing to provide false hope. I offered referral support to participants who wished to speak with a dedicated nurse or counsellor within the teen club clinic.

I have provided in these Field Notes some of my insights on navigating the boundaries between the shifting roles and relationships that may be occupied by researchers working with ALHIV. I have taken particular care to draw attention to the challenges and opportunities one may face when working with adolescents over

an extended period in different capacities.

3.9 Ethical Considerations

Ethics approval came from The Human Research Ethics Committee (HREC) of the University of the Witwatersrand (Appendix 1) and the College of Medicine Research and Ethics Committee (COMREC) in Malawi (Appendix 2) Ethics considerations were recognised at all levels, during study design, data collection and analysis (Embleton et al., 2015; Folayan et al., 2014) (Appendix 5,6, 12, 15 and 18 include the information sheets and consent forms).

When working with vulnerable minors such as ALHIV, there is a particular need for ethical responsibility. The ethical considerations that guided this research included dealing with raised expectations, respects for all persons, avoiding doing harm, protection of privacy, and always maintaining confidentiality (Schweiger & Graf, 2019). The research assistants and I stressed the purpose of the study and to make sure ALHIV, parents and health workers understood the research to curb issues related to monetary or service benefits. In cases of discomfort or distress caused by any question in the guide, the participant was informed of their rights to refuse to answer, and the researcher ensured that ALHIV were supported to speak with a dedicated nurse or counsellor of the Umodzi Teen Club. However, there was tension, as some ALHIV did not trust health workers.

3.9.1 Informed Consent

People participated voluntarily. Informed consent in either English or Chichewa, the dominant local language (Appendix 18), was either written or verbal when using a digital recorder or provided with a thumbprint for people who could not write. Assent for adolescents under the age of 18 (minors) was sought for study participation. Parent or caregivers gave consent for all minors. I also sought permission to write notes and use a digital recorder (Appendix 15) for an information and consent form. Consent forms described the benefits of participating as contributing to the knowledge base on adolescents' resilience and SRH. No remuneration was given to respondents, but a transport allowance of MK 1000 (US$1.50, ZAR 20) was provided to adolescents travelling to a central venue to take part in the survey.

3.9.2 Confidentiality

Participants' confidentiality was considered at all times. Confidentiality cannot be guaranteed during interviews and constant communication and reminders not to share discussions during interviews with outsiders was emphasised. There was a risk of a breach of confidentiality among members of the teen clubs (caregivers, ALHIV and health workers), as they knew each other by sight. However, questions of confidentiality during interviews and group discussions were no greater than interactions at the HIV clinics and the teen clubs. Given the protection of privacy, issues raised by caregivers'/health workers about ALHIV or vice-versa were not shared, unless both parties agreed to meet and discuss in-depth. Data collection, surveys and qualitative interviews were held at neutral venues such as make-shift offices, boardrooms, and lecture halls to maintain the confidentiality of participants. Identifying information was de-identified and kept in a password locked computer, with no access for those indirectly involved in the study. All participants, schools, villages, and clinics were assigned pseudonyms, and other identifying information was removed.

3.9.3 Protection of the Vulnerable Population: ALHIV

As mentioned above, the teen club/health workers' team, mentors, three research assistants, Zomba and Blantyre counselling, and a nursing team, underwent a two-day training workshop (Working with Adolescents Workshop) to strengthen their capacity and gain comprehensive knowledge on how to manage vulnerable adolescents and potential distress during the research study. I was aware that asking SRH related questions may trigger stress or evoke unpleasant memories related to HIV risk status, family history, sexual assault, and stigma. One young woman reported that she was raped, while three others mentioned that they were pregnant. Others would come to my office and just cry, and when I referred them to the nurse in charge, they would refuse and remind me that I had promised to keep their issues confidential. A few boys complained of stress at their homes and all these cases were discussed in-depth with the participants and with their agreement, they were referred to health workers and mentors for support. I maintained that ALHIV lives must be respected and sometimes kept quiet not to breach confidentiality, while I

upheld the right for safety and wellbeing of ALHIV at all times. (Embleton et al., 2015; Folayan et al., 2014). I continued to provide my contact details for ease of reference and referrals whenever ALHIV were ready for counselling sessions.

I held regular debriefing sessions with research assistants, supervisors and the advisory panel to cater for researcher distress. This was due to interviews that were sensitive and intrusive which asked ALHIV re-tell moments when they were taken advantage off by others, stigmatised in their own homes or at schools, or failing to meet high expectations (monetary and resource supports) of health workers and caregivers (Wray 2007). I respected the time they took to talk about their lives and opened the space for second or third interview sessions to give them a voice and maintain the rights of participants, their safety, and wellbeing.

3.9.4 Limitations

SRH issues among ALHIV are sensitive issues, and respondents may have felt obliged to adjust their views and lie about their behaviour. Adolescents might have felt embarrassed or fearful to talk about sex, pregnancy, and HIV-related issues. To limit social bias, interviews were held away from community members who might eavesdrop on discussions.

Quantitative study questions were read to participants at a central venue (UFC Clinic and College of Medicine, halls). Thus, confidentiality was not possible (since participants saw each other), but pseudonyms and identifiers were used in interviews and quotations in all publications. There was an emotional risk for ALHIV participants who had reported to be pregnant or who had impregnated a girl, causing accidental disclosure during feedback sessions with health workers or caregivers at the facility level. Health workers used their discretion to share more information during SRH sessions at teen club clinic meetings. The research team emphasised during the consent process that participants could withdraw their consent to participate either partially or fully at any time, and that they could refuse to answer questions that made them uncomfortable, without fear of repercussion. Most ALHIV who had reported that they were pregnant or had made a girl pregnant failed to turn up for their second nterviews, but the fact that some ALHIV had revealed their pregnancy status should be seen positively.

SECTION B

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter of the results section introduced Chapters four-seven, in which I present the five articles that are part of this PhD. To give an overall picture of SRH service use, I refer to data that were reviewed and collated from the Electronic Medical Records (EMR), family planning and STI registers to show the trends of contraception and family planning methods used by ALHIV in the previous year. While the quantitative findings cannot show any associations, they raise questions about whether 'apathy, indifference or not thinking about it' could be related to the ALHIV low turnout in accessing SRH related services or systemic factors. The findings pointed me towards conducting more in-depth interviews and comprehensive analysis in order to identify enabling factors and barriers to accessing SRH resource supports for ALHIV, as I discuss in chapters five and seven. Objectives and summaries of the published articles precede the chapters. I made modifications to the presentation of the papers by revising journal-specific requirements such as revising the format of headings, styles of citations, declarations, and acknowledgements. The publications are presented in this thesis with the permission of co-authors. The final list of references were integrated at the conclusion of the thesis.

A retrospective review using Electronic Medical Records (EMR) of adolescents' SRH service use was conducted as of 1 January 2018 to June 2019 to capture the quantitative accounts of various SRH service usage across age groups and gender for ALHIV. I refer to findings from a review of data on files for the family planning and STIs registers, from EMR and paper-based registers. The EMR is a standard medical and clinical data capturing system placed in a providers' office to track data (service used) over time (Patel et al., 2018). The registers and EMR are endorsed by the Ministry of Health, Malawi ((Douglas et al., 2010; Government of the

Republic of Malawi, 2018). In Table 4. 1 below, I set out the key variables that were considered through the registers.

Table 4. 1: Key SRH variables collected as part of triangulation.

Instrument	Variables
EMR Data	Age, gender, pregnancy outcomes, number of children alive, contraception use &discontinuation, spousal support
Family Planning Register	Age, sex, pregnancy outcomes, number of children, contraception use & discontinuation, spousal support
STI Register	Age, gender, HIV/art status, service use, male circumcision, varied type of STI & stage (genital ulcers, warts, urethral/ vaginal/discharges, lower abdomen pain, swellings, syphilis etc), contraception shared and referral services.

I developed the data extraction tool following the column headlines in the registers to manage data collection. The data extraction processes were coordinated by me and data officers working on the same register to allow constant comparisons and data quality. The EMR and register reported data on 15-19 year olds and included: methods of family planning, inconsistent condom use, STIs, and pregnancy. Our initial hypothesis was that we could link the ART and Teen Club Clinic dataset, EMR, FP and STI data to provide the next level of triangulation. However, with sporadic entries in the various registers, we failed to link the ALHIV data, particularly for males, and so needed to treat the four sets of data as separate to understand patterns of SRH service use among ALHIV. Hence the data were conflicting and did not support an in-depth analysis nor enable me to find associations. However, the descriptive statistics gave a brief account for SRH service usage and gender issues as part of triangulating self-reported experiences and forms of institutional supports.

4.1 Contraceptive Use

Out of 6,873 women alive on ART who visited the facility between November 2018 to June 2019, 1,678 were using contraceptives, representing 24% (Figure 4. 1). Contraceptive use between adolescents aged 15 – 19 was lowest at 5% (15/279) as compared to other older women 20 years and above (see Figure 4. 1 for the summary of contraception use among PLHIV). In chapter three, I provided a comprehensive description of SRH related sessions and support that ALHIV go through on a monthly basis. The findings on contraceptive (non) use indicate that knowledge of different contraception methods does not translate to uptake. It is evident that even the few ALHIV who show interest to use contraception actually do not adopt it. However, if or when they do, they do not access the different forms of contraception available at the teen-club clinic. As indicated in Figure 4. 1 below, available data on contraceptives such as the injection, male condoms, loops demonstrate a growing acceptability of contraception by women.

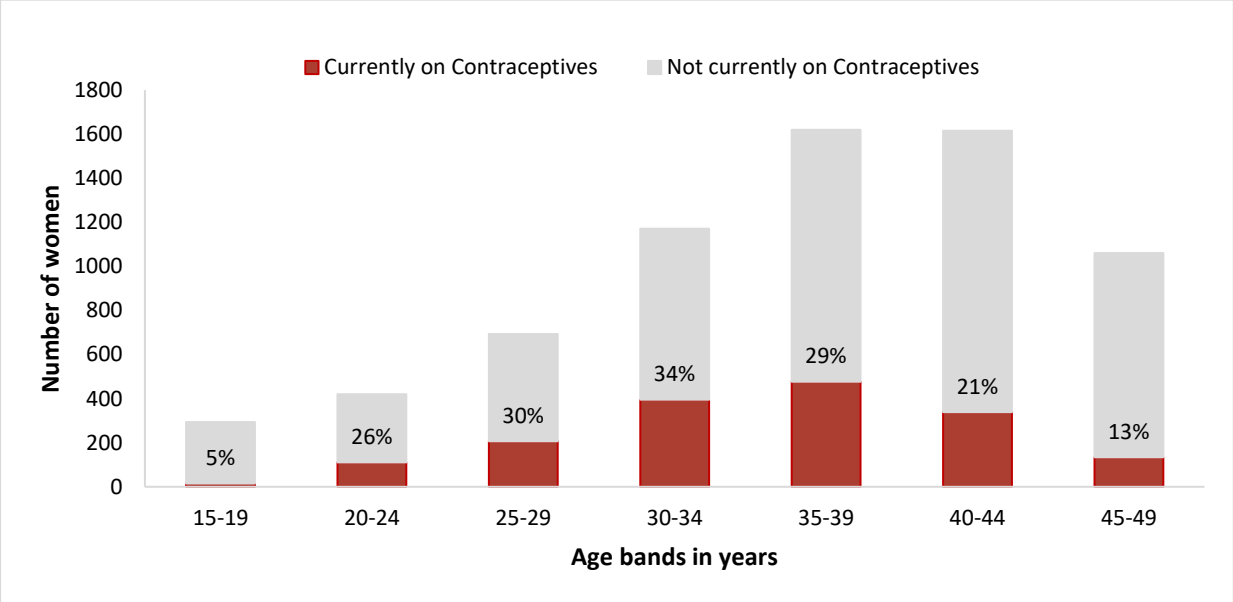


Figure 4. 1 Contraceptive use among women accessing ART.

4.2 Type of Contraceptives

Contraceptive use was highest among women aged between 30 to 44 years old and lowest among adolescents aged 15-19. The most commonly used and preferred methods of contraception were Depo-Provera and male condoms, as shown in Figure 4. 2 (below).

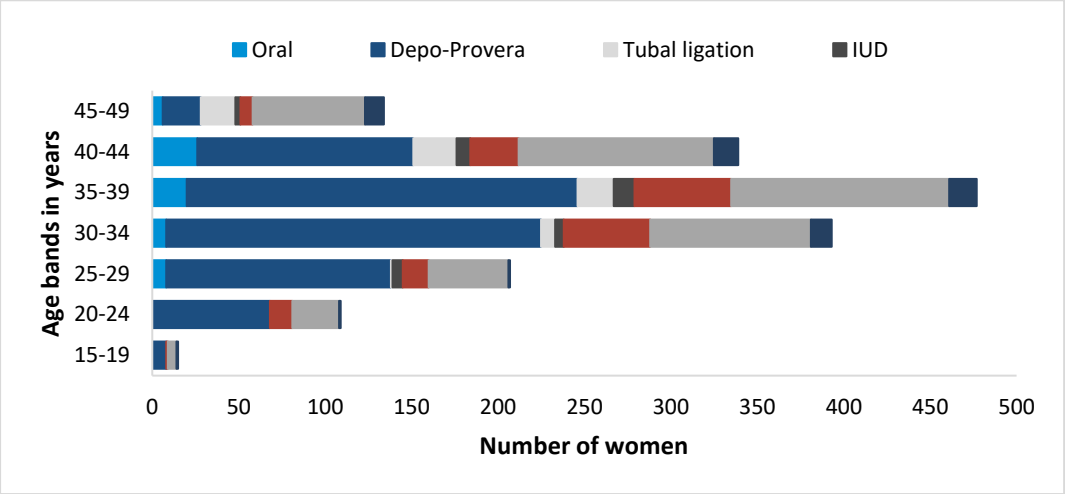


Figure 4. 2: Type of contraceptives used by women on ART.

Reasons for Not Using Contraceptives.

The reasons provided for not using contraceptives were following spouse's wishes, afraid of side effects, apathy, and not thinking about using contraceptives, as shown in Table 4. 2 (below).

Table 4. 2: Reasons for not using contraceptives (N=169)

Age band in years	Apathetic % (n)	Spouse wishes % (n)	Afraid of side-effects % (n)	Never thought about it % (n)
15-19	3.4 (2)	5.6 (1)	0.0 (0)	7.8 (7)
20-24	8.5 (5)	11.1 (2)	0.0 (0)	10.0 (9)
25-29	23.7 (14)	16.7 (3)	50.0 (1)	16.7 (15)
30-34	18.6 (11)	27.8 (5)	50.0 (1)	21.1 (19)
35-39	16.9 (10)	27.8	0.0 (0)	22.2 (20)

		(5)		
40-44	20.3 (12)	11.1 (2)	0.0 (0)	11.1 (10)
45-49	8.5 (5)	0.0 (0)	0.0 (0)	11.1 (10)
Total	**100 (59)**	**100 (18)**	**100 (2)**	**100 (90)**

4. 3 Sexually Transmitted Infections for PLHIV

The participants who were tested and were positive for STIs were mostly 25 years or older and only two below the age of 15 were reported to have had STIs (Figure 4. 3 below). For the participants who were interviewed, the majority who reported to have had STIs were females who were not pregnant, mostly 25 years or older, followed by males not circumcised (MNC). The few ALHIV who were recorded complained mainly of vaginal discharge and warts. The absence of 15-19 year old males with an STI (Figure 4. 3 below), which can be attributed to health systems factors or individual decisions not to seek care and support from the teen club clinic.

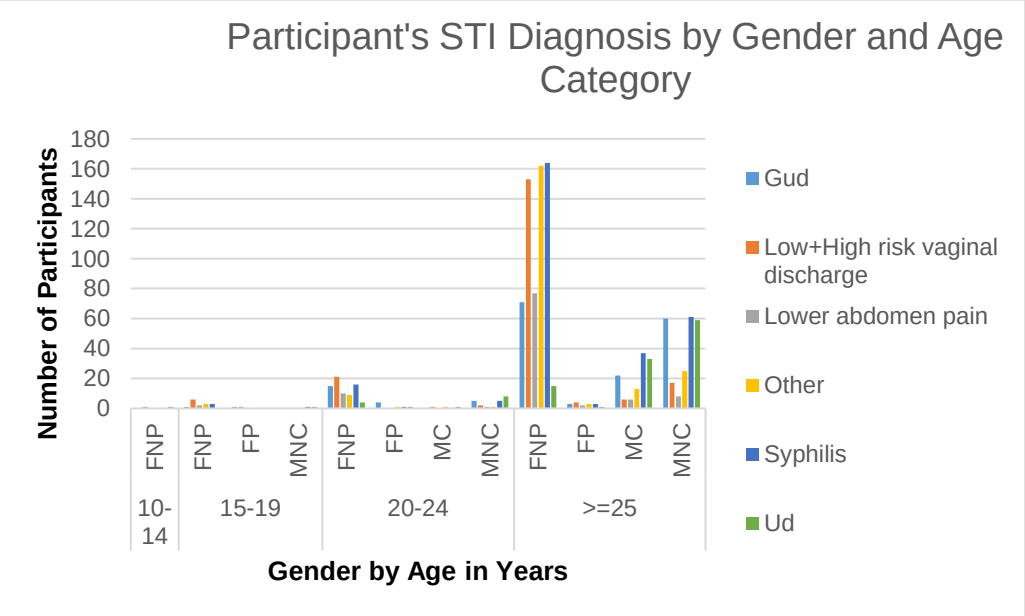


Figure 4. 3: Participants' STI Diagnosis (0-64 years old) by gender and age category

Key: (FNP- female non-pregnant, FP-female pregnant, MC-male circumcised, MNC- male non-circumcised) GUD-genital ulcers disease, other (genital warts, scrotal, inguinal, balanitis, conjunctivitis), UD-urethral discharge.

Given the limitations of depending on quantitative data alone to measure ALHIV contraceptive and family planning methods use, role of sexual partners to provide rigorous SRH service use evidence, I turned to qualitative research. The consequent multidimensional assessment of resilience and SRH service use is evident throughout the thesis and is predicted by both the capacity of individuals and their social and physical ecologies to facilitate positive experiences which are culturally meaningful to ALHIV. I highlight the presence of positive discourses on sexuality, reproductive preparedness, open discussion on SRH, positive and pleasure approaches, and relational support for health and wellbeing.

THE RESILIENCE MEASURE

Paper II

Kaunda-Khangamwa BN, Maposa I, Dambe R, Malisita K, Mtagalume E, Chigaru L, Munthali A, Chipeta E, Phiri S and Manderson L. (2020) Validating a Child Youth Resilience Measurement (CYRM-28) for Adolescents Living with HIV (ALHIV) in Urban Malawi. *Frontiers in Psychology* 11:1896. doi: 10.3389/fpsyg.2020.01896

4.4 Introduction

This chapter addresses **Objective 1**, to determine factors associated with resilience among ALHIV, and aimed to examine the factor structure and psychometric properties of the CYRM-28 in a resource-poor setting.

I determine the resilience of ALHIV from a strength-based perspective. I acknowledge that ALHIV resilience is well understood as a fluid and dynamic concept; hence as adolescents develop and progress in their lives, their resilience continues to change depending on situations and circumstances. To capture this, I employed quantitative methods to determine the dimensions: individual, relational and contextual factors that inform resilience for ALHIV. I considered the dimensions in relation to age, gender and level of schooling to understand the underlying processes involved.

As part of the methodological rigor to test the interrelationships within the resilience construct as a latent variable, I had to validate and adapt the Child and Youth Resilience Measure (CYRM-28) for ALHIV. I look at an in-depth understanding of interactions between individual dimensions (personal skills, peer support and social skills), relational support (caregiver physical and psychological support) and contextual dimensions (spiritual, education and culture) in the examination of resilience among ALHIV in Malawi. I adopted a socio-ecological perspective of resilience and used CYRM-28 to account for differences and cross-cultural influences on the context to measure resilience. I undertook multi-staged data collection (cognitive and focus group interviews) and analysis (framework and SEM) to confirm the wording and psychometric properties of CYRM-28 among

ALHIV. Both exploratory (EFA) and confirmatory (CFA) approaches were employed to determined possible dimensions of resilience, the sub-scales and confirm the validity of resilience as a multidimensional construct. The CYRM-28 has good reliability, validity and adequacy scores, which render it useful as a self-report resilience measure among ALHIV in Malawi. Findings from this chapter provided the basis to understand the relationships and processes involved in resilience-related outcomes in paper II and III.

4.5 Abstract

Resilience as a strength-based notion, measured across cultures, age groups, and sub-populations, contributes to understanding health and well-being. Yet, there is limited evidence of how the construct performs in resource-limited countries. We explored the psychometric properties of the CYRM-28 and validated the scale with adolescents living with HIV (ALHIV), a key sub-population. The participants included members of an advisory panel and 406 ALHIV, aged 15–19 years, attending an antiretroviral therapy and teen club clinic in Blantyre, Malawi. This study employed a mixed-method study using an exploratory sequential design. The advisory panel discussed the CYRM-28, and select ALHIV then translated it into Chichewa, pilot-tested it using cognitive interviews and back-translated it for clarity and appropriateness. The resultant CYRM-28 was tested using a survey with purposefully selected ALHIV. The overall median score was 123, with an interquartile range of 110–130. Minimum and maximum scores were 53 and 140. Cronbach's alpha of 0.863 and Kaiser–Meyer–Olkin measure (0.866) confirmed internal consistency and the sample size adequacy, respectively. Bartlett's tests of sphericity ($p < 0.001$) informed factor analysis. Exploratory factor analysis determined possible dimensions of resilience and the sub-scales. The confirmatory factor analysis (CFA) confirmed the construct validity and supported a three-factor model consistent with the conceptualisation of resilience as a multidimensional construct. Structural equation modelling was applied to perform CFA to measure model of resilience. Multiple fit indices showed a good fit for the model. The CYRM-28 has good internal consistency, test and re-test reliability, and moderate convergent validity which render it useful as a self-report resilience measure to inform and evaluate interventions for the health and well-being of adolescents in Malawi.

* * *

4.6 Introduction

Resilience describes doing well despite adversities. Resilience can be understood along a continuum where risks and protective factors interact, with individuals trying to reduce the effects of challenges or threats. Ungar defines resilience as "the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being, and their capacity individually and collectively to negotiate for these resources to be provided in culturally meaningful ways" (2008, 225). This definition encompasses multiple socio-ecological factors that influence positive outcomes over time. These are individual (cognitive skills, self-management), relational (peer, family, community support), and contextual (education, health, social services) (Obrist et al., 2010)). The inclusion of socio-ecological factors in this study is critical for a nuanced understanding of resilience.

Globally, resilience researchers have used a variety of instruments to capture self-reported accounts of social well-being and health. Windle et al. (2011) and Henley (2010) identify that the most frequently used resilience tests and scales are COPE Scale, Rosenberg Self Esteem Scale, The Connor–Davidson Resilience Scale (Pearce, 2015), Child Youth Resilience Measure (CYRM) Resilience Scale (RS) (Sagone & Caroli, 2014) and Antonovsky's Sense of Coherence Scale (SOC) (Windle et al., 2011). No scale or measurement is considered as superior, and there is a continuous debate on their feasibility, reliability, and validity in different settings (DeMichelis, 2016). However, the scales are biased toward personal constructs for adults and children in high-income countries, and there has been little work conducted in low- or middle-income settings (van Rensburg et al., 2015, 2017).

Studies on resilience with adolescents have predominantly focused on mental health, often with a single focus such as the role of peers, family, school, or community-based resources to improve both social and health outcomes (Betancourt et al., 2013). Ungar and Liebenberg (2011), however, discuss the significance of multiple formal and mandated interventions (mental health, education, child welfare, and the justice system) to foster resilience.

Similarly, Betancourt et al. (2013) and van Breda and Theron, both working in sub-Sahara Africa, discuss the interplay between individuals and contexts, including access to resources, in understanding resilience (2013; 2018). The Resilience Research Centre[1] recommends the use of CYRM-28 to capture contextual and cultural elements considered relevant to develop a valid measure of resilience (Ungar, 2016).

There have been several attempts globally to validate the CYRM-28, including in Canada (Liebenberg et al., 2012), New Zealand (Sanders et al., 2017), Australia (Langham et al., 2018) South Africa (Govender et al., 2017; van Rensburg et al., 2019). In the global north, there is variability in the factor structure correlations and relationships that measure resilience among youths (Pritzker & Minter, 2014). In South Africa, studies have been conducted on the analysis of resilience as a culturally and contextually entrenched construct among Sesotho-speaking youths (Van Breda and Theron, 2018), street youths (Malindi, 2014) and adolescents living with HIV (ALHIV) in KwaZulu Natal, using a factor structure analysis on youth experiencing sexual risks (Govender et al., 2017; van Rensburg et al., 2019). The aforementioned studies and Jia & Vijver (2015) offer a rigorous cross-cultural adaptation process and psychometric analysis to reduce bias and allow for comparability of scores across cultures or populations. However, methodological limitations within the CYRM include failure to load on one factor or sub-samples, and over-reliance on exploratory factor analysis (EFA) rather than confirmatory factor analysis (CFA) for validation (Ungar and Liebenberg, 2011; Liebenberg et al., 2012). In addition to methodological limitations, findings on unique factors such as *ubuntu* and *batho* (community interdependence) as a source of resilience warrant further inquiry to understanding concepts underlying resilience measurements among adolescents (Liebenberg et al., 2017; van Breda & Theron, 2018).

Ensuring that CYRM-28 measures are appropriate for ALHIV in Malawi is critical to identify factors and processes that characterise resilience in key sub-populations. Literature on resilience and HIV has particularly been informed by USAID programs under PEPFAR (United States President's Emergency Plan for AIDS Relief) (Fleischman & Peck, 2017). This includes the DREAMS (Determined,

Resilient, Empowered, AIDS-free, Mentored, and Safe) initiative, which focused on reducing the incidence of HIV among adolescent girls and young women aged 15–24 (Brown et al., 2018; Saul et al., 2018)). The DREAMS initiative centers on interventions that reduce the impact of structural drivers, such as HIV risk, poverty, gender inequality, sexual violence, and lack of education, to promote health and social outcomes among young women and male partners (Saul et al., 2018). Other studies include resourcing resilience through targeted social cash transfers to 13–22 year olds, in Mchinji to improve school retention(Gittings et al., 2016) and in Zomba district to reduce the risk of sexually transmitted infections, including HIV (Baird et al., 2012). These studies did not measure resilience *per se*, and so far, there has been no assessment of the CYRM-28 factor structure among adolescents living with HIV in the country. An understanding of the resilience construct among this subpopulation will enhance the monitoring and development of relevant interventions to improve well-being and livelihoods of ALHIV.

The CYRM-28 Factor Structure

Despite the value of using CYRM-28, there is increasing evidence on the conflicting results from factor analysis, showing variability on the structure and scores, including the underlying construct (Liebenberg et al., 2012, 2017; van Rensburg et al., 2015). In their work with youth in Canada, Rensburg and colleagues used a 5-point Likert-type scale with three sub-scales (individual, relational, and context), and a 28-item list with response options ranging from “not at all” to “a lot” (Liebenberg et al., 2012). On the other hand, a study with youth in New Zealand used four sub-scales and a 28-item list, with four measuring spirituality, seven items on individual resources, seven items on family resources, and ten items on social and cultural resources (Sanders et al., 2015). The South African structure of CYRM-28 used with Sesotho-speaking youths combined social/cultural and communal/spiritual as one sub-scale, with less emphasis on individual sub-scales. Hence, resilience measures vary across context, sub-populations, and socio-cultural groups, warranting further investigation on validation processes, results, and interpretation (Windle et al., 2011; Jia & van de Vijver, 2015).

4.6.1 Materials and Methods

4.6.1.2 Study Design

Data reported in this article derive from a non-interventional mixed-method study. The study employed an exploratory sequential design, with a two-phase method to inform and modify research tools. The study conformed to recommendations for using CYRM-28, which included employing a six-member advisory panel to inform research study processes, site-specific questions, and the adaptation of the scale for ALHIV in Malawi (Ungar, 2016). The original version of the CYRM was translated into Chichewa, the dominant language in the study setting, and this version was validated for survey use among ALHIV. Routine programmatic data from registers (attendance, gender, ages, in and out of care) from 2010 to 2019 informed the characteristics of the study participants and settings, and the discussion section of this article.

4.6.1.3 Study Setting

The study was conducted among ALHIV attending an Adolescent Teen Club at the Umodzi Family Centre (UFC) within Queen Elizabeth Central Hospital (QECH) in Blantyre, the major commercial city of Malawi. The QECH serves as a referral hospital for the south-west zone of the country. Adolescents attending the teen club, described in the next section, come from urban, peri-urban, and rural areas surrounding Blantyre. All adolescents testing HIV positive from these areas are counselled and offered enrolment in the UFC and other health centers and facilities surrounding QECH. Adolescents who need hospitalisation are admitted to in-patient wards and are referred to UFC for HIV testing, confirmatory tests, and support. Before an adolescent is discharged, he or she receives another counselling session and is invited to join UFC or to attend an antiretroviral therapy (ART) clinic close to their home. As of June 30, 2019, the UFC ART clinic registry had a total of 14,160 people, of whom 3500 were adolescents aged 10–24.

The Teen Club Program

The UFC teen club program is a Lighthouse Trust, Youth Friendly Health Service initiative, managed by UFC and supported by bilateral partners. The club model was adapted from the United States Baylor College of Medicine International Paediatrics AIDS Initiative (BIPAI) in partnership with the Malawi Ministry of Health (Baylor College of Medicine International paediatric AIDS Initiative (BIPAI), (Baylor College of Medicine International Pediatric AIDS Initiative (BIPAI), 2012; BIPAI, 2017)(Baylor College of Medicine International Pediatric AIDS Initiative (BIPAI), 2012; BIPAI, 2017; MacKenzie et al., 2017) Adolescents aged 10–19 are eligible to participate in the club programs after disclosure which entails their acceptance of their HIV diagnosis, its implications, and their disclosure of this to significant others. Adolescents are prepared to transition out of the teen club program from around 20 years of age. Currently, teen club services adhere to a "test and treat" policy and provide differentiated service delivery in terms of service intensity, frequency, location, and health worker support. The emphasis is on a patient-centered care approach to HIV care (Chihana et al., 2018; Prust et al., 2017).

To strengthen the clinical, psychosocial, and resource supports, various activities are scheduled throughout the year. Lighthouse Trust manages these activities with support from the Ministry of Health, local non-governmental organisations, and PEPFAR under the Centers for Disease Control and Prevention (Moody et al., 2018; Phiri, Neuhann, et al., 2017; Prust et al., 2017). The teen club is held on Saturdays and provides comprehensive programming for those aged 10–19 years under three pillars: (1) Clinical Care, including screening and management of opportunistic infections, ART monitoring including side effects and viral load, nutrition screening and treatment, TB screening and treatment, and referrals for specialised care; (2) Psychosocial Support: adherence counseling, peer support, mental health screening, coping with stigma and discrimination, livelihoods, and future planning; and (3) Sexual and Reproductive Health services: education and contraception administration (Kim et al., 2014; MacKenzie et al., 2017).

4.6.1.4 Study Participants

The study involved ALHIV, attending the UFC ART and teen club clinic during the study period, with signed informed consent from parents/caregivers and assent from those aged 15–17 years, and informed consent from those aged 18–19 years. The study pool purposefully selected young people aged 15–19 because of the continued disproportionate effects on this group from HIV and the only age group to have experienced a rise in deaths caused by AIDS-related illness (UNAIDS, 2019). Participants included those attending (or not) the ART clinic and UFC teen club, in and out of school, pregnant or not, and included both those born with HIV and those horizontally infected. People excluded from the study included those who were critically ill and those aged below 15 or above 19 years.

4.6.1.5 Sampling

Sampling was based on similar studies conducted with adolescents attending Saturday teen club clinics in Zomba and Lilongwe, in Malawi by Kim et al.(2015, 2017) and MacKenzie et al. (2017). Through the electronic medical records, we purposefully selected adolescents aged 15–19 between January 2018 and June 2019, attending the UFC ART clinic. Through the UFC database, a total of 1099 ALHIV were identified and invited to participate in the study. Follow-up revealed that 254 had transferred out, 3 had stopped attending the clinic, 379 had defaulted, and 57 were reported dead by October 2018. A total of 406 ALHIV who had been on ART for the past 90 days were eligible to participate (see Figure 4. 4).

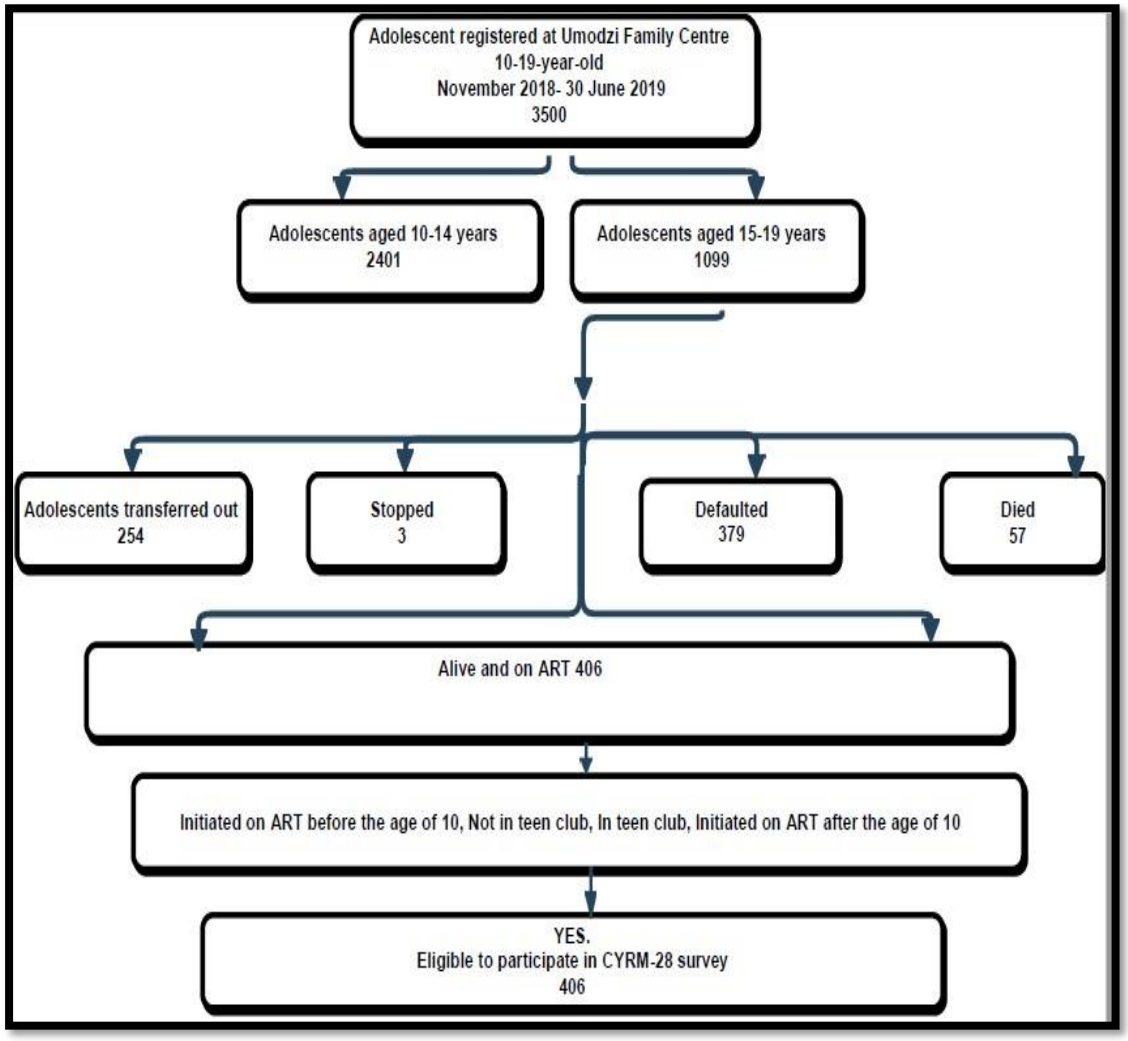


Figure 4. 4: Summary of the study sample

Recruitment Processes

All adolescents attending the UFC ART and teen club clinics were invited to take part in the study when they presented at the clinic reception. The support staff and adolescents' mentors working at the ART clinic gave out letters of invitation written in vernacular, Chichewa. They explained the study objectives briefly to all adolescents aged 15–19, over 8 months (November 2018–June 2019). Adolescents were given a chance to be recruited as they would normally visit the clinic for routine follow-up and attend the teen club every month or two. There were two different letters of invitations for adolescents aged 15–17 to attend, with their parents signing the consent form while they signed an assent form; those aged 18 and 19 provided a written consent form.

4.7 Instruments, Measures, and Procedures

4.7.1 Site-Specific Questions

Consistent with the CYRM manual regarding site-specific questions to capture context, relevant questions were conceptualised during the pilot survey and shared with the panel of six advisors as part of triangulation (Ungar, 2016). There were 11 questions, including statements on life experiences and adolescents' knowledge of service use, for example: "Being an adolescent is challenging," "I can handle difficulties in my life," "I have knowledge of sexual and reproductive health," and "the teen club clinic provides support." The 11 site-specific items were measured on a 5-point Likert scale, ranging from 1 (not at all) to 5 (a lot) (Appendix 8.1).

4.7.2 CYRM-28

The adapted version of the CYRM-28 (Liebenberg et al., 2012) was administered to measure ALHIV resilience. Resilience is a latent variable that comprises 28 items with eight components (individual: personal and social skills, peer support; caregiver physical and psychological and context: spiritual, education, and cultural), which provide insights to three subscales (Ungar, 2016). The individual sub-scale has 11 items that are divided under (1) personal skill with (5 items), peer support (2 items), and social skill (4 items); (2) the relational sub-scale considers physical and psychological caregiving with 2 and 5 items, respectively; and (3) the context sub-scale focuses on spirituality (3 items), education (2 items), and culture (5 items) (van Rensburg et al., 2017). The following are some examples of statements under individual personal skills – "I am able to solve problems without hurting myself or others"; caregiving – "My caregiver stands by me during difficult times"; context – "I enjoy my community's traditions" (Ungar, 2016).

In this article, we concentrate on adaptation processes and changes to the wording of the CYRM-28 items. These modifications are consistent with the manual to ensure context relevance and familiarity with competing measures (van Rensburg et al., 2015, 2017). The items are measures on a 5-point Likert scale, ranging from 1 (not at all) to 5 (a lot) with higher scores (≤140) representing increased resilience

(Ungar and Liebenberg, 2011). A summary of these 28 items within their sub-scales is set out in Appendix 8.

Data Collection

Data collection occurred in two phases. The first phase was a pilot and pre-test study, using cognitive interviews with 42 participants to determine if ALHIV understood the questions and underlying concepts in the CYRM-28. The interviews were held in Zomba (70 km from Blantyre) at Tisungane teen club, Zomba Central Hospital, as a rapport-building activity; we targeted cognitive processes to ensure that the questions worked as intended (Zukerberg and Hess, 1996; Ungar, 2008).

Previous studies on cognitive interviewing have used "think aloud" and verbal probing techniques with a group of 5–10 subjects to discuss concepts and question-wording formats (Blair & Brick, 2010; Zukerberg & Hess, 1996). In this study, we held the first three rounds of cognitive interviews among young people aged 15–16, 17–18, and 19 years. We employed verbal probing techniques with six adolescents in each group. The remaining four rounds were spread over three weeks to follow up questions, probe on meanings of resilience, explore the reasons for varied responses, and gather insight on the clarity of the items to improve the English and Chichewa interview guides (Heather, Lambert, Kinzie, & Gieser, 2012).

To minimise bias in both the pilot and post-pilot studies, the first author trained the same four research assistants on the purpose of the study, objectives, and processes to administer the survey. The research assistants were part of the mentorship program under the UFC team. They underwent three rounds of completing the CYRM form with feedback sessions to ensure standardised administration of the questionnaire (Jia and van de Vijver, 2015). In addition, weekly and monthly meetings were held with the data collection team to ensure consistency in the language used and instructions to complete the survey.

The pilot established a draft of context-specific questions, which incorporated the CYRM-28. This was presented and discussed with the advisory panel to ensure contextual relevance. Slight changes were made to the wording as all questions were translated into the vernacular to ensure that adolescents were able to understand the

questions. A single survey questionnaire with the modified CYRM-28 was then drafted (Appendix 8.2).

The second phase of data collection took place with individuals and in groups in Blantyre from November 2018 to June 2019. The final questionnaire was administered to 406 adolescents from UFC ART and teen club clinics in Blantyre. The questionnaire, as described previously, was structured and included both open- and close-ended and Likert-scale questions (Windle et al., 2011; van Rensburg et al., 2015).

The adolescents completed the paper-based questionnaire in a classroom set-up in the lecture hall at the College of Medicine through 20 group sittings (9–20 adolescents each), with some individuals participating on other days to participate and enable us to reach our required sample size. Each question was read aloud to participants, with questions clarified if needed, by the first author. The respondents were given a minute to write down their responses to each statement. The research assistants helped those adolescents who independently filled in the questionnaire to ensure that they had understood all questions and completed the questionnaire. The four adolescents who had writing and hearing problems, respectively, were helped by the research assistants present at each group sitting. The likelihood of experiencing bias in the results are minimal because the ALHIV were required to tick most of the responses in the questionnaire.

4.8 Statistical Data Analysis

Quantitative data were captured from the completed paper questionnaires into a REDCap electronic data entry form. REDCap is a secure, web-based application designed to support research data capture. It provides space for validated data entry and automated export procedures to STATA version 14.2 in readiness for analyses(Harris et al., 2009). Descriptive analysis was performed on demographic and psychometric measures to summarise characteristics of participants. Minimum, maximum, and ranges were reported for all relevant variables. Medians and interquartile range were reported for skewed continuous variables and means and standard deviations for continuous and normally distributed variables. Frequencies and percentages were used to describe the categorical variables.

Reliability measures like Cronbach's alpha were used to assess the internal consistency of the resilience measurement scale. A Cronbach's alpha ≥ 0.70 indicates satisfactory reliability (Tavakol & Dennick, 2011). Kaiser–Meyer–Olkin (KMO) measure and Bartlett's tests of sphericity were used to assess the adequacy of our sample size and inter-correlations between items to warrant factor analysis (Govender et al., 2017). A KMO closer to 1.0 confirms the feasibility for factor analysis (Acock, 2013; Pritzker and Minter, 2014).

The reasons EFA was used in this study include (1) to ascertain the factor structure of the resilience measurement scale, inclusive of all sub-scales (individual, caregiver, and context) to ensure that all items in the scale measured resilience as an underlying construct (Langham et al., 2018) and (2) because our questionnaire items were not normally distributed but were skewed. Informed by Acock (2013), the CFA using structural equation modeling (SEM) in Stata 14.2 assessed the relationships and inter-relationships between different latent factors of the CYRM-28 of observed and measured behaviours. In addition, the CFA determines how the resilience measurement scale conformed to the original conceptual framework (Goretzko, Pham, & Bühner, 2019). Steps are set out in Figure 4. 5.

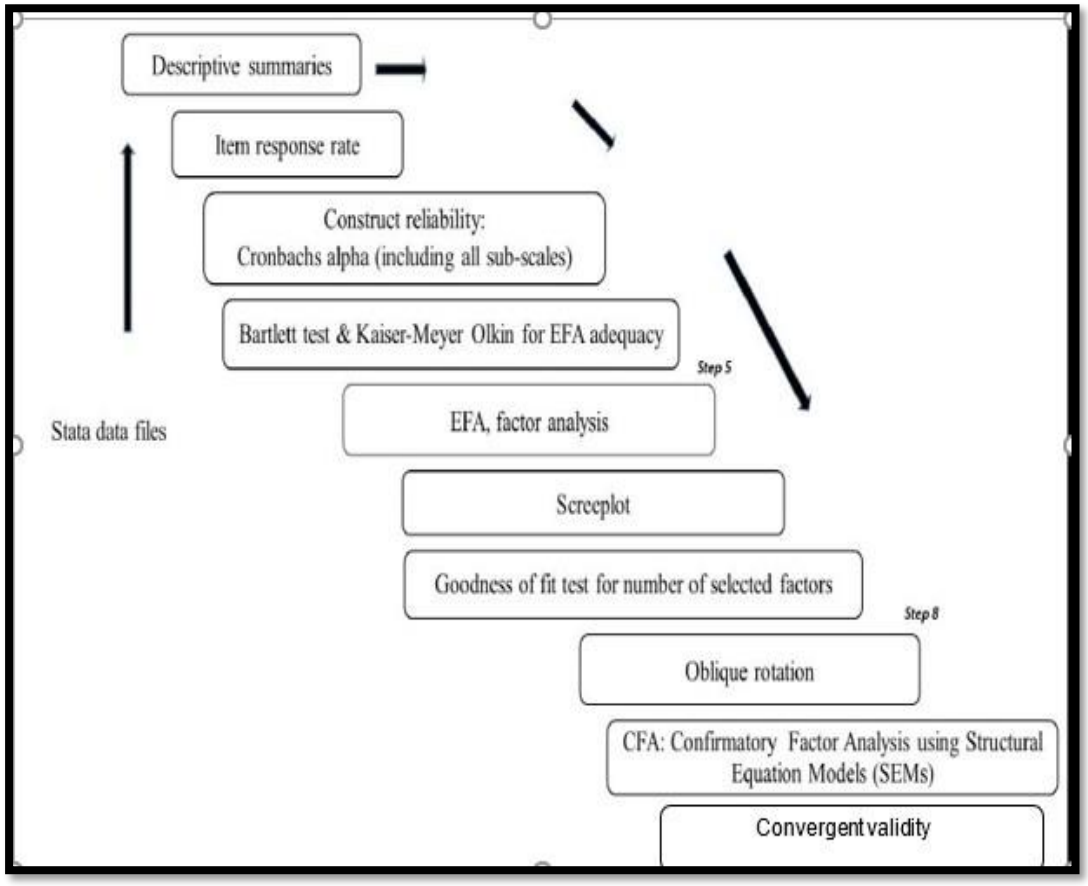


Figure 4. 5: Summary of the data analysis process

The maximum-likelihood estimation method was used to estimate the CFA model. Multiple indices were used to assess the model fit: root mean square error of approximation (RMSEA), Akaike's Information Criterion (AIC), Bayesian Information Criterion (BIC), Tucker–Lewis Index (TLI), Comparative Fit Index (CFI), and Standardised Root Mean Squared Residual (SRMR) (Govender et al., 2017). Values greater than 0.95 indicate excellent fit to the data, whereas values greater than 0.90 indicate acceptable fit to the data (Carvalho & Chima, 2014). In addition, the average variance extracted (AVE) was estimated to evaluate convergent validity with values greater than 0.50 indicating convergent validity as part of exhibiting evidence in full (Sawatzky et al., 2017).

4.9 Results

A total of 406 ALHIV aged 15–19 years participated, with almost equal numbers of males and females. Their mean age was 16.74, SD 1.46. There was heterogeneity between ethnic and religious groups, although the dominant ethnic groups were Lhlomwe, Chewa, and Ngoni (64% of total participants). Only 3.0% of ALHIV did not know their tribe. Religious affiliation, school attendance, access to meals per day, and sleeping spaces varied (See Table 4. 3).

Table 4. 3: Summary of socio-demographic characteristics of participants

Variable	Overall N (%)	Male n (%)	Female n (%)
	406 (100)	204 (50.2)	202 (49.8)
Mean (SD)	1.5(.50)	1.48(.50)	1.55(.40)
Age			
15-16	196 (48.28)	91 (44.61)	105 (51.98)
17-19	210(51.72)	97 (48.02)	113(55.39)
Education			
None	38 (9.45)	19(50)	19(50)
Primary	141(35.07)	82(58.16)	59(41.84)
Secondary	223(55.47)	102(45.74)	121 (54.26)
Ethnic Group			
Chewa	80 (19.70)	42 (52.50)	38(47.50)
Tonga	18 (4.43)	10(55.56)	8 (44.44)
Sena	26 (6.40)	15(42.32)	11(57.68)
Lhlomwe	101 (24.88)	45(44.55)	56(55.45)
Ngoni	79 (19.46)	43(54.43)	36(45.57)
Tumbuka	40(9.85)	20(50)	20(50)
Yao	34 (8.37)	17(50)	17(50)
Mang'anja	12 (2.96)	4(33.33)	8(66.67)
Don't Know	12 (2.96)	6(50)	6(50)
Other	4 (0.99)	2(50)	2(50)
Religion			
Protestants	205 (50.49)	108(52.68)	97(47.32)
Catholics	83 (20.44)	38(45.78)	45(54.22)
Moslems	28 (6.90)	17(60.71)	11(39.29)
Pentecostals	86 (21.18)	39(45.35)	47(54.65)
Other	4 (0.99)	2(50)	2(50)
Ever had a baby			
Yes	12 (2.9)	3(1.5)	9(4.5)
No	394(97)	201(98)	193(95)

Variable	Overall N (%)	Male n (%)	Female n (%)
	406 (100)	204 (50.2)	202 (49.8)
Mean (SD)	1.5(.50)	1.48(.50)	1.55(.40)
Death in the family			
Yes	253(63.3)	129(64.2)	124(62.3)
No	147(36.57)	72(35.8)	75(37.7)
Person who died			
Mother	78(31.2)	35(27.6)	43(34.9)
Father	98(39.2)	52(40.9)	46(37.4)
Brother	24(9.6)	15(11.8)	9(7.3)
Sister	19(7.6)	9(7.0)	10(8.3)
Grandparent	4(2)	3(2.3)	1(1)
Aunt	18(7.2)	11(8.7)	7(5.7)
Ever moved houses			
Yes	207(50.9)	104(50.2)	103(49.8)
No	199(49.0)	100(50.3)	99(49.8)
Frequency of changing homes	63(30.7)	31(49.2)	32(50.7)
Once	53(25.9)	25(47.2)	28(52.8)
Twice	67(32.7)	37(55.2)	30(44.8)
Three or more times	19(9.3)	8(42.1)	11(57.9)
I do not know	3(1.5)	2(66.6)	1(33.3)
Sleeping Spaces			
Alone	167 (41.2)	91(54.5)	76(45.5)
With two or three people	120 (29.6)	61(50.8)	59(49.2)
More than four people	84 (20.7)	36(42.9)	48(57.4)
I do not know	24 (5.9)	12(50)	12(50)
Other	10 (2.5)	4(40)	6(60)
Number of meals per day	11(2.7)	6(54.6)	5(45.5)
One meal	47(11.6)	29(61.7)	18(38.3)
Two meals	322(79.5)	155(48.1)	167(51.2)
Three meals or more	19(4.7)	11(57.8)	8(42.1)
I do not know	6(1.5)	5(50)	3(50)
Other			

Overall, the median score for resilience was 123, with an interquartile range of 110–130. The minimum and maximum scores were 53 and 140, with most scores concentrated on the higher side. Five adolescents attained the maximum score of

140 and only one recorded 53. No adolescent scored the lowest possible score of 28. Bartlett's test of sphericity, 2766.820, $p < 0.001$, showed that our variables had high correlation, which warranted factor analysis. The KMO measure of sampling adequacy was 0.866, confirming that our sample was good enough to continue with EFA (Acock, 2013). The alpha, which is a measure of reliability and showed the internal consistency of the measured dimension, recorded 0.862 for the overall resilience construct whereas the sub-scales showed individual component, $\alpha = 0.733$; relational component, $\alpha = 0.702$; and contextual component, $\alpha = 0.667$. Results in Table 4. 4 show internal reliability for measures of reliability and construct reliability. However, alpha can be high even with items that are minimally related to one another. Therefore, we ran a factor analysis to show correlations between dimensions that represent a shared meaning among the 28-item CYRM measure (Liebenberg, Ungar, & and Vijver, 2012; Mampane, 2014).

Table 4. 4: Alpha reliability

Item	**Sign**	**it-cor**	**is-cor**	**ii-cov**	**Alpha**
1.I have people I look up to in my life	+	0.514	0.454	.29838	0.887
2. I cooperate with people around me	+	0.478	0.417	.30079	0.888
3. Getting an education is important to me	+	0.511	0.467	.30401	0.887
4. I know how to behave in different social situations	+	0.482	0.429	.30285	0.888
5. My parent(s)/caregiver(s) watch me closely	+	0.616	0.581	.30087	0.886
6. My parents/caregivers know a lot about me	+	0.535	0.489	.30164	0.887
7. If I am hungry, there is enough to eat at home	+	0.488	0.429	.30069	0.888
8.I try to finish what I start	+	0.554	0.508	.30004	0.886

9. Spiritual beliefs are a source of strength for me.	+	0.567	0.519	.29868	0.886
10.I am proud of my tribe's background	+	0.550	0.508	.30227	0.888
11. People think I am funny to be with	+	0.520	0.474	.30274	0.887
12. I talk to my family/caregiver(s) about how I feel	+	0.528	0.472	.29878	0.887
13. I can solve problems without harming myself or others by using drugs or violence	+	0.400	0.320	.3025	0.891
14. I feel supported by my friends	+	0.477	0.408	.29854	0.889
15. I know where to go in my community to get help	+	0.446	0.367	.2989	0.890
16. I feel I belong at my school	+	0.535	0.473	.29556	0.887
17. My family stands by me during difficult times.	+	0.519	0.463	.29898	0.887
18. My friends stand by me during difficult times.	+	0.472	0.402	.29886	0.889
19.I am treated fairly in my community	+	0.531	0.466	.2951	0.887
20. I have opportunities to show others that I am becoming an adult and can act responsibly	+	0.539	0.485	.29826	0.887
21. I am aware of my own strengths	+	0.538	0.494	.30225	0.888
22. I participate in organised religious activities	+	0.586	0.539	.29698	0.886
23. I think it is important to serve my community	+	0.530	0.581	.30097	0.887

24. I feel safe when I am with my family/caregivers.	+	0.531	0.487	.30259	0.887
25. I have opportunities to develop skills useful in life, like job skills and skills to care for others).	+	0.499	0.441	.30013	0.888
26. I enjoy my family's/caregiver's cultural and family traditions	+	0.511	0.460	.30142	0.887
27. I enjoy my community's tradition	+	0.514	0.452	.29237	0.888
28. I am proud to be Malawian	+	0.403	0.369	.31258	0.889
Test scale				.30045	0.891* mean

The EFA through factor analysis showed three factors with eigenvalues above 1. The eigenvalues were obtained for each factor to identify a measure of variance. The first component showed an eigenvalue of 5.63, out of 28 items, and explained 63% of the variance. The second and third factors recorded 1.41 and 1.1 eigenvalues explaining 79% variance of the second factor, whereas 92% explained the total variability of the three factors. In addition, we used the scree plot to confirm the three points of inflection for the final analysis (Ledesma, Valero-Mora, & Macbeth, 2015).

Consistent with previous studies on the conceptualisation of resilience as a dynamic process and a multidimensional construct over time (Liebenberg et al., 2012; Govender et al., 2017; van Rensburg et al., 2019), we computed the factor analysis with oblique rotation (direct oblimin) to accentuate and show the rotated correlations on the three components (individual, relational, and contextual) that make up the resilience measure. Two out of 28 items (items 1 and 15) did not load: "I have people I look up to" and "I know where to go in my community to get help." Four items of the CYRM-28 had factor loadings <0.350 (items 11, 13, 17, and 28) showing inconsistencies on the role of individual and contextual components in informing resilience across cultures.

We again performed factor analysis on the three-factor model with eigenvalues greater than 1. Factor loadings in the three-factor solution showed that 15 items loaded on factor 1, whereas 10 items and 3 items loaded on factor 2 and factor 3, respectively. One item – "I feel supported by friends" – loaded on both factors 1 and 3, and one item – "I am treated fairly in my community" – loaded on both factors 2 and 3. 5 shows the three-factor solution under the three sub-scales after rotation. Ten items and seven items loaded on individual and relational components. Nine items out of 10 loaded on the contextual component. Twenty-six items in the three-factor model had good loadings of >0.3, a minimum criterion for threshold loadings (Acock, 2013; Ledesma et al., 2015). Based on theoretical models of resilience, therefore, we adopted a three-factor structure to better explain resilience among ALHIV (Table 4. 5) (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Liebenberg et al., 2012; Pritzker & Minter, 2014).

Table 4. 5: Pattern matrix of the three-factor solution

	Components		
	Individual	Relational	Context
1.I have people I look up to in my life			
15. I know where to go in my community to get help			
2. I cooperate with people around me	.423		
8.I try to finish what I start	.576		
4. I know how to behave in different social situations	.553		
11. People think I am funny to be with	.343		
13. I can solve problems without harming myself or others by using drugs or violence	.341		
14. I feel supported by my friends	.498		
18. My friends stand by me during difficult times.	.440		
20. I have opportunities to show others that I am becoming an adult and can act responsibly	.447		
21. I am aware of my own strength	.485		
24. I feel safe when I am with my family/caregiver	.474		
25. I have opportunities to develop skills useful in life, like job skills and skills to care for others).	.568		
5. My parent(s)/caregiver(s) watch me closely		.581	
6. My parents/caregivers know a lot about me		.499	
7. If I am hungry, there is enough to eat at home		.547	
12. I talk to my family/caregiver(s) about how I feel		.417	
17. My family stands by me during difficult times.		.313	
26. I enjoy my family's/caregiver's cultural and family traditions		.590	
3. Getting an education is important to me			.649
9. Spiritual beliefs are a source of strength for me.			.522
10.I am proud of my tribe's background			.593
16. I feel I belong at my school			.336
19.I am treated fairly in my community			.446
22. I participate in organized religious activities			.637
23. I think it is important to serve my community			.511
27. I enjoy my community's tradition			.580
28. I am proud to be Malawian			.327

The internal reliability of sub-scales was re-assessed using alpha and sample adequacy by KMO, which retained similar results, confirming items for the CFA. This allowed the analysis of the sub-scales to show similar results as in the initial EFA model. Hence, the decision to retain all 28 items for a resilience measure was informed by reliability tests, EFA, and a socio-ecological framework that reflects on individual, relational, and contextual interactions and supports to enable resilience over time (van Rensburg et al., 2015; Ungar, 2016).

Confirmatory Factor Analysis

The confirmatory factor analysis confirmed the three-factor structure (individual, relational, and contextual) of CYRM-28 with clustered items (See Figure 4. 6).

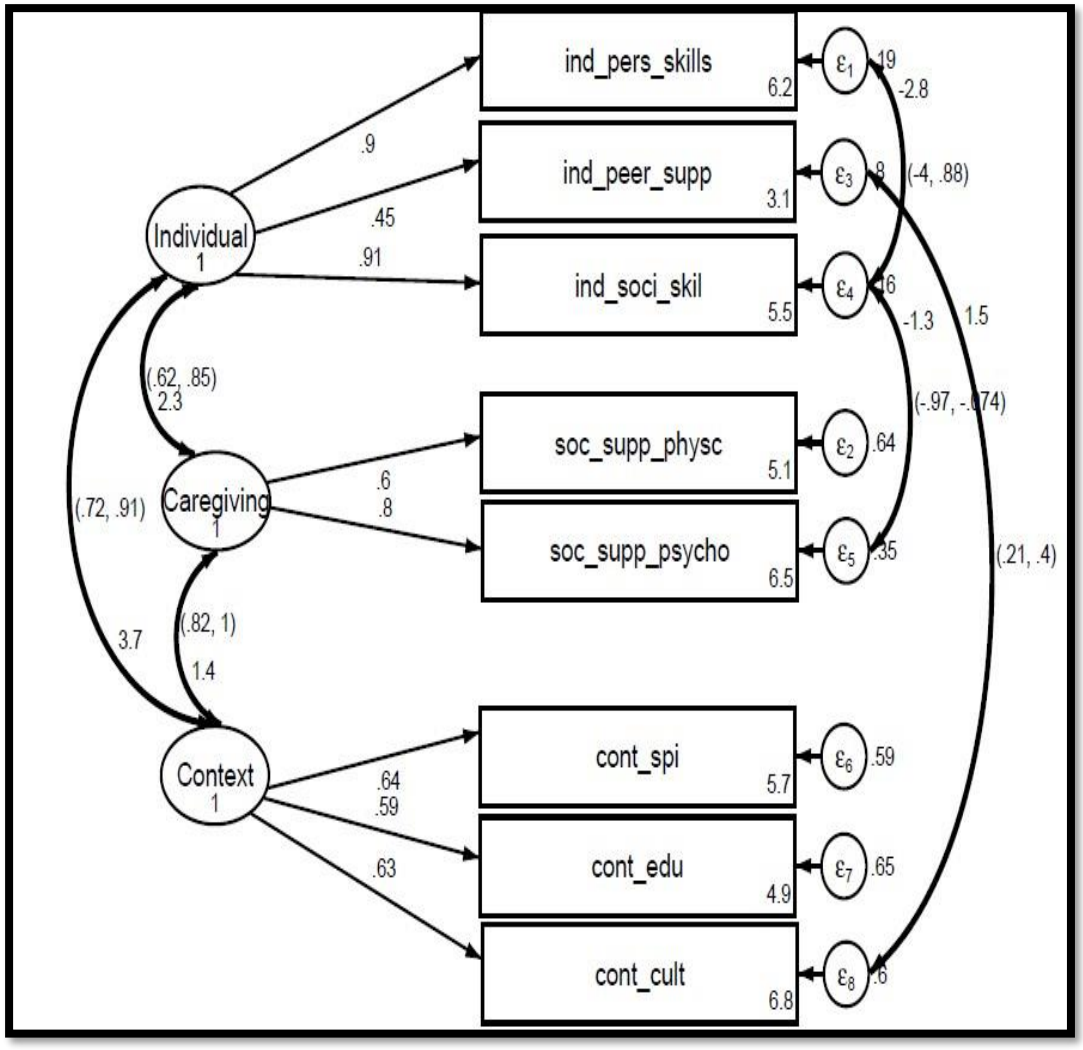


Figure 4. 6: Confirmatory factor analytic model

Statistical methods normally use one statistical test to determine the significance of analysis as well as model fit (Le et al., 2017). Our study employed multiple indices rather than a single index to confirm a model fit to ensure our study results will be comparable at local and international arenas (see Appendix 8.3) for factor-level analysis and comparable results for our model. The overall fit for the source of resilience model after covariance is illustrated as χ^2 ($p < 0.001$), df = 1, RMSEA = 0.06, SRMR = 0.03, TLI = 961, CFI = 982, $p = 0.002$, AIC = 14,287.937, and BIC = 14,412.133. There is a need for flexibility when using multiple indices to apply the goodness-of-fit guidelines to inform decision-making in practice (Govender et al., 2017; van Rensburg et al., 2019). Hence, the *p* value, TLI, CFI, SRMR, and RMSEA showed a relatively adequate fit for our model. The interpretability of the fit indices is significant and provided space to understand correlations across and within the sub-scales, including the overall resilience construct.

The factor loadings in the model were positive, and the standardised loadings were high (>0.60) except for individual: peer support (0.45) and contextual: education (0.59). This suggests that all three latent variables were significant and positively correlated in the sample (Liebenberg et al., 2012; Acock, 2013). The CI for the correlation between the corresponding subscales of context and caregiving shows (0.82) and caregiving and individual components recording (0.62, 0.85) and (0.72, 0.91) for context and individual sub-scales. The strong correlations reflect the presence of resilience as an underlying construct. All items, factors, and sub-scales in this Malawian model were statistically significant ($p \leq 0.001$). Hence, our model confirms that the sub-scales did measure resilience. Composite reliability (CR), and convergent and discriminant validity were performed after fitting the model as part of validating resilience construct in full (Ungar and Liebenberg, 2011). Two dimensions exceeded 0.50 (0.616 individual and 0.50 caregiving), whereas the context recorded 0.38 and had problems with convergent validity. All three constructs had discriminant validity problems (this was expected since all constructs are more related than different (See Table 4. 6).

Table 4. 6: Factor loadings, composite reliability, and average variance extracted.

Construct/sub-scale	Factor loadings	Composite reliability (CR)	Average variance extracted (AVE)
Individual		0.817	0.616
• Personal skills	0.90		
• Peer support	0.45		
• Social skills	0.91		
Caregiving		0.665	0.502
• Physical	0.60		
• Psychological	0.80		
Context		0.655	0.387
• Spiritual	0.64		
• Education	0.59		
• Cultural	0.63		

4.10 Discussion

The purpose of this study was to explore the factor structure of the CYRM-28 in a sub-population of ALHIV aged 15–19 and receiving teen club clinic support in Malawi. This was part of a broader objective to validate the CYRM-28 by assessing the adaptation processes which included slight changes in the wording and translation to vernacular Chichewa. Our study results showed varied perceptions of components and scales contributing to their resilience. In particular, ALHIV perceptions differed on the individual, peer support and education support. This is consistent with previous studies that argue that across sub-populations, there are common resilience elements, but the way they are grouped is different (Langham et al., 2018; Van Breda, 2018). Overall, our study demonstrates construct validity (dependent on measurement scores, (1) content; (2) item responses; and (3) relations to other dimensions, e.g., convergent, discriminant, concurrent (Ungar and Liebenberg, 2011; Pritzker and Minter, 2014), informs gaps in HIV and resilience research (de Araújo et al., 2017; van Rensburg et al., 2015) and highlights the need to be mindful of the role of peers, community, and educational support in the lives of ALHIV. This suggests the value of further qualitative research.

Items 1 and 15, in relation to individual personal and social skills, failed to load in the CYRM-28. This failure of factor loadings is not new; studies using the similar

English-language version of CYRM-28 in Canada and South Africa failed on items 1, 5, and 28 (Liebenberg et al., 2012; Govender et al., 2017). The items that failed to load – "I have people I look up to" and "I know where to go in my community to get help" – may reflect the exceptional nature of HIV/AIDS (Moyer & Hardon, 2014). Fear, social exclusion, self-stigma, and social stigma and discrimination continue to affect the everyday lives of people in Malawi, and this ultimately influences people's interactions with services. However, in line with our theoretical notions on the socio-ecological framework, we retained all statements on CYRM 28-item to measure and understand resilience at multiple levels (Van Breda and Theron, 2018).

In ALHIV research in Malawi, there are mixed outcomes of the role of peers and education in improving well-being and resilience (Amzel et al., 2013; Toska et al., 2016). For instance, Baird et al. (2012) and Toska et al., 2016 have observed that conditional cash transfers linked to school enrolment encourage young people staying in school longer. In association, this lowered teen pregnancies. However, in our study, some adolescents might have underreported their access to educational support as part of the need for incentives for their education. Low factor loadings were also recorded in previous studies in South Africa, Canada, and Australia on items 1 and 28, which provides more evidence on some of the problematic items that make up the CYRM-28 (Ungar, 2016; Govender et al., 2017; Langham et al., 2018). Our study highlights caregiving support and spiritual and cultural supports as key to informing resilience among ALHIV attending ART clinics in Malawi. Focusing on physical and psychological caregiving, adolescents' spiritual and cultural supports through religion and rites of passage have been identified as key protective factors for ALHIV (Van Breda and Theron, 2018; OECD Development Centre, 2018).

The results from modeling and resilience demonstrated problems of convergent validity, evidenced by low to moderate correlations between dimensions. The challenge with convergent and discriminant validity may be a result of the fact that the constructs are composed by a few indicators and were being assessed in the same model (Byrne, 2012). However, using SEM showed that individual, relational,

cultural, and spiritual contexts are closely correlated. The individual personal and social skills work hand in hand with psychological caregiving, whereas cultural and individual peer support factors interact for a better fit. The possible explanation for this is that in some cultures, the status of "being an adolescent" may be connected to less prestige and less respect than that of adults. Previous studies on resilience among ALHIV in South Africa have shown the role of community interdependence as illustrated by ubuntu/batho concepts as key factors underlying resilience (Theron & Theron, 2010; van Breda & Theron, 2018). In our study, ALHIV did not identify as a person in and of the community, but rather, they identified as individuals, with less emphasis on peer connectedness and community membership as sources of resilience owing to the stigma and discrimination of living with HIV. In addition, in relation to discrimination, most societies are adult-centred, meaning that the needs and preferences of adults are given priority compared with those adolescents whose specific interests are not taken into account. Further qualitative research should elaborate on how ALHIV express and interpret their resilience.

4.11 Implications

Current validation studies on resilience note the need to use the CYRM-28 to identify resilience-enabling sources and resources across cultures and sub-population (Sanders et al., 2015; Masten, 2016; van Rensburg et al., 2019). This study was conducted among adolescents accessing ART and psychosocial support at a teen club clinic. This study foreshadows the resilience profiles of ALHIV contextually, and so responds to the need to be sensitive on how ALHIV interact with individual, relational, and socio-cultural resources and dynamics as key sources for resilience.

The provision of services under the model of a one-stop-shop or the differentiated service delivery approach to meet ALHIV complex needs is key to improving resilience-related outcomes (MacKenzie et al., 2017). Adapting and validating the CYRM-28 for ALHIV in Malawi allowed for the description of various factors or resources that they recognise and interact with for better program planning and implementation. Future research might address the usefulness of the CYRM-28 in measuring intervention outcomes.

Strength and Limitations

This study provides preliminary evidence on the use of CYRM-28 in Malawi. By adopting the strength-based approach in this study, we looked at ALHIV interacting in meaning and decision-making processes regarding individual, relational, and resourceful supports in their lives. However, this assessment was a once-off process in a single context, among adolescents attending a teen club clinic. Caution should be applied when extending the results to the general adolescent population. Although we captured resilience among ALHIV with a heterogeneous cultural background, for comprehensive evidence on validation, there is a need to consider adolescents across sub-populations, including those living without HIV, to enrich our findings and to help generalise research and intervention implications.

4.12 Conclusion

Our study contributed to technical and statistical evidence around using CYRM-28 to measure factors and processes underlying resilience among ALHIV in a low-income country. The findings supported the three-factor structure comprising 28 items representing individual, relational, and community/spiritual dimensions. The CYRM is a reliable measure of adolescent resilience, although additional research may be required to validate the instruments among alternative populations and adolescent sub-groups in Malawi.

CHAPTER FIVE

SOCIAL AND INSTITUTIONAL RESOURCES FOR ALHIV

Paper III

5.0 Introduction

Blessings N. Kaunda-Khangamwa, Innocent Maposa, Moffo Phiri, Kennedy Malisita, Alister Munthali, Effie Chipeta, Sam Phiri, Lenore Manderson. Service use and resilience among adolescents living with HIV (ALHIV) in Blantyre, Malawi, *International Journal of Integrated Care* (Under review since 1 July 2020)

Objective 2: Describe and analyse adolescents' resilience-promoting resources among ALHIV.

- To understand available formal and alternative support and resources for service use with ALHIV, caregivers and health workers
- Describe associations between levels of resilience, risk, service utilisation, and satisfaction among ALHIV

An abstract of this manuscript was presented as a virtual poster as part of the 23rd International AIDS Conference:

Blessings N. Kaunda-Khangamwa, Innocent Maposa, Moffo Phiri, Kennedy Malisita, Alister Munthali, Effie Chipeta, Sam Phiri, Lenore Manderson. *Service use and resilience among adolescents living with HIV (ALHIV) in Blantyre, Malawi.* Virtual poster exhibition (PED1127) at the 23rd International AIDS Conference. 6-10 July 2020

I refer to activities auspiced by the Teen Club Clinic (TCC), a three-year-old intervention programme. The programme is informed by differentiated service delivery/patient centred care initiative. The purpose of this paper was not to evaluate the practice. Rather, I refer to the relationships, how promotive resources and risk factors interact, and whether services have direct, indirect and total effects and significance on resilience.

A mixed method approach was used to generate data to account for the differences in service use, frequency and satisfaction, risks and resilience. A survey with 406 ALHIV was conducted using a self-administered questionnaire, 26 in-depth interviews with ALHIV, 12 group discussions with 144 caregivers, and 35 health workers attending a 2-day workshop explored service use and resilience. Multimethods analysis was employed to test and compare correlations, validity and complex interactions that influence resilience among ALHIV.

The quantitative results showed 70% of ALHIV were concurrently clients of three or more services, with the majority mostly satisfied with the teen club clinic. There were variations in internal and external forms of risks, range of services, and frequency of use, satisfaction and support that influence resilience. I refer to their service use history, frequency and satisfaction, in relation to surrounding risks and resources, both available and not. Persons Most Knowledgeable (PMKs) about ALHIV lives, such as caregivers and health workers who were nominated by the participating adolescents, harness outcomes on service use history. Structural equation modelling (SEM) allowed me to test multiple relationships simultaneously within a conceptual model. This was important to understand resilience as a multidimensional construct with several variables that are suspected to have complex inter-correlations.

The qualitative data reflect more complex interactions on access to services, with caregivers and adolescents seeking alternative care from spiritual and traditional healers. I argue that service use is culturally and context-based, and that adolescents are more likely to use services if they are satisfying their life needs. ALHIV are multiple service users and I have added lessons learnt and practice implications.

5.1 Abstract

Introduction: Adolescents living with HIV (ALHIV) experience social and health challenges that warrant the provision of services and relational support to build resilience. Little is known about how social, community and health services help. We examine formal and alternative service use by and resilience of ALHIV participating in a teen club clinic (TCC) programme.

Description: TCC is an adolescent-centred differentiated care model offering a 'one-stop-shop' for HIV/SRH services to ALHIV. A survey was conducted with 406 ALHIV to determine the frequency of use and satisfaction with services. In addition, we conducted 26 in-depth interviews with ALHIV, 12 group discussions with 144 caregivers, and observations of workshops held for 35 health workers.

Discussion: About 70% of ALHIV were concurrent clients of three or more services. The multimethod analysis showed variations on risks, range of services, frequency of use and satisfaction. Interview data reflected complex factors influencing access to services, with caregivers and adolescents seeking alternative care from spiritual and traditional healers.

Conclusion: Adolescent centred-approaches have the potential to enhance resilience, promoting resources and outcomes. However, seeking alternative support from spiritual support and traditional healing may affect patterns of service use over time.

Keywords: Adolescents living with HIV, adolescent-centred approaches, Malawi, resilience, service use, teen club clinic.

* * *

5.2 Introduction

Adolescents experience high levels of risk associated with living with HIV, other chronic conditions, abuse, violence, family dysfunction, and community danger. These indicate the need for accessible services (Adjei & Saewyc, 2017; Mwalabu et al., 2017; Skovdal, Maswera, Kadzura, Wringe, & Gregson, 2020) including social welfare, juvenile justice, education and physical and mental health services (Sanders et al., 2015; van Breda & Theron, 2018). Existing studies by Ungar (2008, 2016) and Ungar & Liebenberg (2011) identify an association between satisfaction with services and resilience and functional outcomes, including better decision making, resisting high-risk behavior, competence, connections to others, empowerment and continued service use. Exploring the interaction between risks, services and resources is key to finding better interventions to support ALHIV.

Differentiated Service Delivery (DSD) is a patient-centred framework, developed through WHO and adapted at country level to meet the needs of specific populations to reduce health systems inefficiencies (UNAIDS (Joint United Nations Programme on HIV/AIDS), 2014; World Health Organization, 2015). For ALHIV, the teen club clinic (TCC) model of DSD has gained momentum since 2016 to ensure adolescent-centred HIV care (Reif et al., 2018). In Malawi and South Africa, studies of TCCs have identified the role of community-based professionals such as mentors, nurses and psychologists (Skovdal & Belton, 2014; Theron, 2013) in fostering resilience, including supporting the retention of ALHIV on ART programmes (Kaunda-Khangamwa, Kapwata et al. 2020) and assisting HIV negative adolescents to access contraception and antenatal care(Callahan et al., 2017). We know little of ALHIV service use and alternative care resources and supports.

Formal services for young people facing adversities, such as child welfare, mental health services, alcohol and drug services and juvenile justice, facilitate positive outcomes (van Rensburg et al., 2017). Informal and alternative services including traditional rituals, do not predict better psychosocial outcomes (Panter-Brick, 2015) although questions remain about cultural context, adolescents' choices and use of opportunities to support resilience.

5.3 Problem Statement

Satisfaction with adolescent-centred services is associated with relationship building, comprehensiveness of interventions, empowerment and respectful engagement with adolescents (Sanders, Munford, & Liebenberg, 2017; Saul et al., 2018). Previous studies in the south and east Africa show mixed evidence of access and provision of services, adolescents experiences, health workers and caregivers involvement on institutional service use among adolescents (Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009; Skovdal et al., 2017; Theron & Malindi, 2010; Zgambo et al., 2018). In Malawi, adolescent girls and young women (AGYW) receive public health and social service support for HIV prevention through the Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe (DREAMS) package (Saul et al., 2018) to ensure well-being. The social ecology and supports surrounding vulnerable adolescents are critical, but there has been little attention to service use satisfaction and resilience. Ensuring that service provision is contextually and culturally responsive is key because ALHIV in poor resource settings are most likely to use services when they are meaningful and respectful of context.

Description of the Care Practice: Teen Club Clinics

The DSD is known locally as the Saturday teen club clinic/TCC (MacKenzie et al. 2017). It appears useful to support ALHIV on ART in terms of retention and adherence (Kim et al. 2014, 2015). The TCC in Malawi is a one-stop-shop offering comprehensive HIV clinical care and SRH and psychosocial services for ALHIV aged 9-24 years. Services include health education and support, individual and group counselling, regular consultations with ART treatment refills, and targeted services at the facility level (MacKenzie et al., 2017). Group size varies according to discussion topics, gender, age (9-14, 15-19 and 20-24 year olds) and setting, with up to 20 to 90 participants in given activities. ALHIV attend the same group meetings with the same health workers (clinicians, nurses, nutritionist and mentors) who follow them up throughout the year.

Most meetings take place once every two months at the Umodzi Family Centre (UFC). At each meeting, ALHIV arrive at the reception, receive their files and proceed to a common area for medical screening (weight, temperature, blood pressure). Health workers and mentors have their own consultation spaces to provide individual support. Group activities include role-playing and health education sessions, with lunch provided and transport costs reimbursed. Health workers and mentors also contribute to a social welfare fund to help ALHIV with transport and school fees.

Ethical Considerations

Ethics approval was provided by The Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M180465) in South Africa and the College of Medicine Research and Ethics Committee (COMREC) (P.04/18/2389) in Malawi. Ethics consideration was recognised at all levels, including study design, data collection, analysis and presentation (Embleton et al., 2015; Folayan et al., 2014).

5.4 Methodology

A dynamic and iterative mixed-methods study [43] included: 1) a self-administered questionnaire survey of 406 ALHIV; 2) in-depth interviews with 26 ALHIV; 3) 12 group discussions with 144 caregivers; 4) workshops with 35 health workers attending a two-day workshop; and 6) analysis of the Electronic Medical Records (EMR) of the 406 ALHIV.

The study took place in the TCC programme of the UFC at Queen Elizabeth Central Hospital (QECH) in Blantyre from 1 November 2018 to 30 June 2019. Stratified sampling was used to identify ALHIV and health workers involved in the UFC ART and TCC programme. The strata were based on TCC attendants (full or partial) and non-attendants. Sample size calculations reflected the number of adolescents attending the clinic, and this strategy was similar to that used in prior TCC studies (MacKenzie et al., 2017).

Each of the 406 ALHIV identified a Person Most Knowledgeable (PMK) about their lives, either a health worker, parent or other caregivers. Health workers (19 female, 16 male) included clinicians, a pharmacist, nurses, members of the HIV testing team, mentors, medical records officers, and monitoring and evaluation team members. Of these, 49% were aged 18-29, with three above 50 years. All adolescents nominated PMKs, but the response rate to invitations sent to PMKs was relatively low, with about 34% turnout, due possibly to stigma and lack of interest. Despite the low turnout, we were able to capture relational perceptions and experiences on service utilisation among ALHIV. Just over half of the health workers were single (53%), 31% were married, and 16% widowed or divorced. Of the 144 parents and caregivers (mean age 34), 62% were reported as working, 28% home-makers, 8% in school and 2% retired. Forty-eight per cent were married, 43% single, 9% widowed.

Measures

Quantitative data were collected using two pretested structured questionnaires (CYMR-28 (Kaunda-Khangamwa, Maphosa et al. 2020) and the Global Early Adolescent Survey [GEAS])(Chandra-Mouli et al., 2017) and medical records from the Electronic Medical Records (EMR) System of the TCC. The EMR provided information on age, gender, age and year at ART initiation, cumulative treatment outcomes and viral load (See Table 4. 1 above).

The CYRM-28 included survey questions on socio-demographics, risks, service use, frequency, and satisfaction to enable a multicomponent approach to explore relationships and patterns between service use and resilience (Li, Liebenberg & Ungar, 2015). The GEAS health instrument was developed by WHO, UNFPA and John Hopkins Bloomberg School of Public Health in urban areas of 15 low-income countries (Blum et al., 2017; Mmari et, 2017), and included four sub-scales (family, peer, school, and community). The ALHIV completed a GEAS-Health Instrument module with sub-scales (Chandra-Mouli et al. 2017) to determine individual risks and relational and context-based influences of health and well-being. Items in instruments and sub-scales were rated on a 5-point Likert scale, ranging from '1= not at all' to '5= a lot'. Cronbach's alpha (α) and construct reliability scores for all

instruments and subscales were calculated to assess the internal consistency of measurements. In general, a good reliability score is above .60 (Acock 2018).

Instruments and Scales

The CYRM-28 captured risks at multiple individuals, relational and contextual levels using sub-scales, with ALHIV responding to statements such as: 'I am able to solve problems without harming myself or others'. The α for the CYRM-28 was 0.863. Access to services and utilisation were measured according to Li et al. (2015) and Panter-Brick, (2014, 2015) to quantify the frequency of services used by ALHIV over time; services that they needed but could not get; and satisfaction and meaning with services.

The service use data collection tool was informed by in-depth interviews and focus group discussions in the pilot study, from advisory panel meetings, and caregiver workshops (Theron 2013, Ungar 2016). Services included educational support, community teen club, family planning clinic, and traditional healers. A 3-item scale (1= always, 2= sometimes and 3=never) measured adolescents', health workers' and caregivers' responses. Reliability for the measure on the number of services utilised by ALHIV, parents and health workers was 0.709, 0.607 and 0.797, respectively.

To capture service use and frequency, we isolated eight services that ALHIV frequently mentioned under service use (see further below). The overall reliability score was 0.917. The quality and satisfaction of services centred on adolescents' experiences of frequently nominated services. The service satisfaction questions included 13 items such as 'I helped choose this service'. The alpha was 0.853.

Fifteen statements measured the influence of peers in adolescents' lives, for example, 'How many of your close friends think that it is important to study hard/smoke cigarettes/drink alcohol/use drugs/get tested for HIV, take ART?' The responses were recorded on a 5-point scale, ranging from '1=All' to '5= I do not know'. The scores were reversed for analysis. The reliability score was 0.816. At the community level, internal and external risks were captured by focusing on varied forms of supports (7 items) and danger (12 items) using the GEAS. The

alpha for internal and external risks sub-scales were 0.824 and 0.859, respectively. The GEAS provided opportunities to assess the role of family and communication, connectedness and monitoring of adolescents**.** The alpha for this sub-scale was 0.770.

Data Collection

An invitation was sent by TCC receptionists to ALHIV, parents and caregivers to attend interviews at the UFC or the Lecture Hall at the College of Medicine. Workshops and guardian sessions were held at intervals and facilitated by the first author to introduce the study and assess their service provision, to ALHIV in the past year. ALHIV, health workers and PMKs were encouraged to reflect on their experiences in the past year, and ALHIV use of and/or access to formal and alternative service provision were explored (Creswell, 2014).

Two workshops with health workers and 12 guardian sessions with parents/caregivers were held to allow them to inquire and contribute to ALHIV service usage. Focus group discussions were held at weekends to suit adolescents and parents attending school, or working or in business, and to coincide the adolescents presenting for medication refills at the ART clinic. Interviews were held on alternative weekends at the UFC and Malaria Alert Centre seminar rooms and facilitated by the first author to maintain consistency, trustworthiness and confidentiality (Kaunda-Khangamwa, Kapwata, et al., 2020). Discussions were based on questions around what it meant to do well ‘despite facing challenges in their lives', with clarification on what services ALHIV used.

CYRM and GEAS forms and nomination of PMK were completed by ALHIV in a classroom set-up in a lecture hall, with 20 groups sitting over different days. Each statement on the 50-item questionnaire was read out loud by the first author, and respondents were given a minute to write down their responses for each item. Special support was given to adolescents with hearing or vision problems to ensure that they understood the questions and were able to respond (Kaunda-Khangamwa, Kapwata, et al., 2020).

Data Analysis

To explore adolescents' risks, formal and alternative services usage and frequency, and satisfaction to assess resilience, we used a four-step process: 1) multiple response analysis (MRA), 2) composite scoring and reliability, 3) effect sizes through regression, and 4) structural equation modelling (SEM). The procedures in the analysis were also informed by the resilience manual (Ungar 2016). MRA computed and summed up the health workers, ALHIV, and PMK data to capture the quantity of service provision and utilisation among ALHIV. Composite and average scores were compared, and the data were summarised using descriptive statistics (mean, SD, ranges and quartiles). Correlation coefficients were recorded to ascertain associations among adolescents and variables ranging from risks, service use, frequency and satisfaction. Correlations of approximately 0.1 indicated a small degree of relation, while 0.3 and 0.5 indicate medium and large degrees of relation respectively (Bosco, Aguinis, Field, & Pierce, 2015). The SEM involved three processes of exploratory factor analysis (EFA) in testing reliability and internal consistency, and in assessing the direct and indirect effects of the multiple factors in the hypothesised model in Stata v14.2 (Craig et al., 2018). Inferential statistics, effect size, regression and SEM followed to show the practical significance and relationship of service use and resilience in practice (Feinn, 2012). Confirmatory factor analysis (CFA) tested the fit and construct validity of the scales. Path analysis confirmed the patterns and relationships between risk factors (personal, family, peer, community internal and external) and service usage, frequency and satisfaction.

For the qualitative data, the authors familiarised themselves with the transcripts and notes made during fieldwork, taking account of both formal and alternative service use. The first author used deductive analysis (Creswell, 2014), using Bronfenbrenner's socio-ecological framework (Bronfenbrenner, 1979) to examine the multilevel links and interactions influencing resilience and functional outcomes (Hall, 2016, Li et al. 2015). To capture ALHIV's capacities, processes, and interactions to service use and resilience, we coded six tiers within their

socioecology using Nvivo software 11: 1) individual; 2) family; 3) school 4) community; 5) structural; and 6) national (policies and intervention programmes).

The first author also presented and held intensive discussions on the results and analysis processes with co-authors and the UFC clinical and M&E staff to triangulate study findings and interpretation (Creswell, 2014; Theron & Theron, 2014). Quotations were identified to best represent the themes on service use and resilience-related outcomes.

5.5 Results

The results presented below are drawn from the initial sample of 406 ALHIV, health workers, and parents and other caregivers. Most ALHIV were multiple service users, characterised by formal or institutional services including ART (338, 83%), TCC (308, 76%), community-based teen clubs (308, 76%), YFHS (276, 68%) and schools (244, 60%). Alternative services included traditional and spiritual supports seen to respond to health-related and social vulnerabilities that young people experience in adolescence. Service use alone had a mixed impact on resilience. Satisfaction with the TCC showed significant influence on functional outcomes such as community-based service use, better decision making, and fair viral load results: 273 (67%) were suppressed, 92 (23%) were not suppressed, and 41 (10%) reported as missing results. Enhanced TCC programmes and support from health workers had an impact on ALHIV resilience-related outcomes. Demographics for ALHIV, including current age, ART initiation year and cumulative treatment outcomes for the study period are set out in Table 5. 1 below.

Mean, Range, Reliability and Inter-Correlations

Factor structures, as observed in response patterns (Kaunda-Khangamwa, Maphosa et al. 2020), showed resilience to be multidimensional and dynamic across sub-populations. For all measures, we confirmed factor structures, reliability, correlations and validity prior to conducting inferential statistics. Cronbach's alpha scores indicate good internal reliability across all dimensions, except for a specific service use domain on cultural services (α= 0.59 due to lower response rate), 0.77

Table 5. 1: Summary of demographic characteristics of PLHIV and ALHIV

Variables			
			Total
Persons living with HIV			33239
Sex			
Male			14476
Female			18763
	Non-Teen club	**Teen Club members**	
Sex (10-24 years)			3945
Male	1447	251	
Female	2000	247	
ART initiation age			
<10	3247	350	3597
11 to 14	719	122	841
15 to 19	883	33	916
Current age			
10 to 14	1059	237	1296
15 to 19	958	244	1202
20 to 24	1430	17	1447
Initiation year (10-24 years)			
1995 to 1999	0	0	0
2000 to 2004	89	1	90
2005 to 2009	1382	62	1444
2010 to 2014	925	50	975
2015 to 2019	1051	54	1105
Cumulative treatment outcomes (15-19)			
Transferred out	13	0	13
Retained	185	221	406
Defaulted	758	28	786
Stopped	2	1	3
Died	0	0	0
Total not retained	773	29	802
Viral load	**Non-Teen Club**	**Teen Club members**	**Total.**
All ALHIV (10-24)	-	-	35%(n=3500)*
All adolescents (10-24)	-	90%(n=498)	
Virologic failure (10-24)	-	24%(n=447)	21%(n=1225)
Virologic failure (15-19)	-	59%(n=106)	35%(n=252)
Viral load suppression (10-24)	-	75%(n=447)	79%(n=1225)
Viral load suppression (15-19)	-	44%(n=335)	31%(n=973)
Missing	-	14%(n=238)	

*Results for viral load for some ALHIV were missing.
Source. UFC Electronic Medical Records (EMR) System. Baseline data as of 1 November 2018- 30 June 2019.

(family risk) to 0.92 (service usage frequency). Health workers and parents/caregivers recorded 0.80 and 0.61 on service use, respectively.

Correlations ranged from -.07 to 0.35, indicating a weak relationship between family and personal risks (0.28), internal community and peer risks (0.31), internal and external risks (0.35), and service frequency and quantity (0.28) (Table 5. 2, below). These results suggest the distinctiveness of the factors under assessment as well as the variance of responses across ALHIV (Azfredrick, 2016; X. Li, Chi, Sherr, Cluver, & Stanton, 2015).

Table 5. 2: Mean, SD, Range and reliability of each factor and inter-correlations.

	Mean	SD	Range	1	2	3	4	5	6	7	8	9	10	11
1.Personal risk (ALHIV)	23.4	9.91	7-45	**.84***										
2.Family risk	23.8	7.85	7-50	.28	**.77***									
3.Peer risk	50.5	8.95	15-75	.12	.15	**.82***								
4.Community risk (Internal)	25.5	8.92	10-50	.12	.12	.31	**.82***							
5.Community risk (External)	25.5	7.64	7-35	.18	.13	.19	.35	**.86***						
6.Service use (quantity)	46.5	5.71	25-54	-.07	.00	.17	.07	.04	**.71***					
7. Service use (frequency)	106.0	28.6	55-255	.03	.04	.12	.05	.11	.28	**.92***				
8. Service use (satisfaction)	19.5	5.99	0-39	.04	.08	.07	.15	.12	.10	-.14	**.85***			
9. Service use (PMK)	46.6	3.68	25-54	-	-	-	-	-	-	-	-	**.61***		
10. Service use (HW)	40.6	9.02	0-54	-	-	-	-	-	-	-	-	-	**.80***	
Resilience (ALHIV)	118.9	14.9	53-140	-.08	.09	-.04	-.07	.00	.04	.02	-.04	-	-	**.86***

*Representing reliabilities for factors (Cronbach's alpha), no correlation coefficients. (-) missing ratings on a different dimension.

Service Use

Multiple group responses on service nominations using MRA found that service use differed slightly among ALHIV, parents/caregivers and health workers. Most parents/caregivers responded that ALHIV were concurrent service users. Three hundred and eighteen (78%) had accessed HIV-related services, including TCC 112 (30%), ART clinic 100 (27%), YFHS and educational support 40 (11%) and the community-based teen club 25 (7%).

Responses on service use and referrals among health workers working with ALHIV were similar to those of caregivers, on the following services: ART clinic and TCC 29 (16%), ART clinic 26 (15%), community-based teen 25 (14%), YFHS 17 (10%) and educational support 14 (8%). Parents/caregivers reported lower utilisation than

health workers for Sexual and Reproductive Health (SRH), Family Planning (FP), Sexual Transmitted Infections (STI), emergency pill, gynaecology care, maternity care, mental health, correctional, traditional healers, and spiritual services. Most common ALHIV service use reports are shown below (See Table 5. 3 below).

Table 5. 3: ALHIV frequency of service use

Nominated Services	Health Services	Frequency of service use				
		Always	*Sometimes*	*Never*	No response	Total
Sexual &Reproductive services	Youth-friendly health services clinic	184	92	130	-	406 (68%)
	Ante-natal Clinic	7	7	385	7	399 (3%)
	Maternity	37	20	349	-	406 (14 %)
	Labour ward	7	6	382	11	395 (3%)
	Gynaecology	4	1	374	27	379 (1%)
	Emergency Pills	5	1	372	28	378 (1%)
	STI Clinic	85	44	276	1	405 (32%)
	Family planning clinic	3	14	363	26	380 (4%)
	Skin specialist	8	2	369	27	379 (2%)
HIV Clinic	Teen club clinic	234	74	98	-	406 (76%)
	ART clinic	302	36	68	-	406 (83%)
Educational services	Education Support	159	85	162	-	406 (60%)
Mental Health	Mental health support	22	24	360	-	406 (11%)
Correctional services	One-stop centre	35	39	331	1	405 (18%)
	Police service	14	22	368	2	404 (9%)
Community services	Youth centre	95	115	196	3	403 (52%)
	Community teen club	242	61	102	1	405 (75%)
	Community Outreach Clinic	86	83	237	2	404 (42%)
	Traditional healers	27	44	335	26	380 (27%)

Qualitative data on service use showed mixed responses, as most participants had limited knowledge of services outside the teen club. Most health workers, caregivers and adolescents mentioned failure to refer adolescents to other health-related departments due to time constraints:

> I fail to refer some adolescents to gynaecology [department] because some of them refuse, while others need me to act as their guardian so that they are helped faster. It becomes a challenge due to time constraint (health worker, female).
>
> It is difficult to refer adolescents because of lack of time to walk through the referral process as well as to follow the standard follow-up visits (health worker, male).

Some caregivers and health workers encouraged ALHIV to remain in school rather than present for ART services because of the importance placed on education. Some caregivers commented on possible ways that they could use rituals and customs such as rite of passage rituals, using religious pastors and other spiritual leaders, could improve the lives of their children. Health workers and caregivers were divided on the role of traditional healers, with the former seeing no advantages: "There is no need to send a child to a traditional healer. Sometimes their work is not scientifically proven to heal diseases" (health worker, male). However, caregivers and older adolescents considered traditional medicine to be significant, and some parents and male adolescents used traditional medicines such as *mchape* to cleanse their bodies since they do not menstruate. One mother, in explaining the importance of traditional medicine, explained: "I need more spiritual support, the prayers and sometimes we also use traditional medicine to cleanse her system. As a family, we also encourage her taking ART, but we cannot forget where we come from" (mother, 33 years to daughter, 17 years). Older boys and girls also showed interest in herbs for sexual function and response.

Service Use, Frequency and Satisfaction

Frequency of service use varied according to the composite and average scores from the eight different service dimensions (See Table 5. 4). The most frequently used were educational and community-based teen club services. Most ALHIV needed but could not get the following services: SRH, YFHS, mental health, child welfare and cultural services (rite-of-passage ceremonies). Most ALHIV reported that they did not need to use correctional services.

Table 5. 4: Service use scores and other descriptive statistics

Service use frequency	Scores	Mean	SD	Min-Max	Cronbach's Alpha
Community services	Composite	18.5	7.11	6-35	
	Average	2.6	1.02	1-5	0.820
HIV/ART care services	Composite	17.7	6.14	4- 40	
	Average	2.2	.77	.5-5	0.731
Educational Services	Composite	12.9	5.23	5-25	
	Average	2.6	1.05	1- 5	0.719
Youth-friendly services	Composite	16.9	7.17	8-15	
	Average	1.9	.79	.88-5	0.814
Mental Health	Composite	11.9	4.87	0-35	
	Average	1.7	.69	0-5	0.695
Child welfare	Composite	10.4	5.2	1-35	
	Average	1.49	.74	.14-5	0.824
Correctional services	Composite	7.23	3.10	5-30	
	Average	1.2	.52	.83-5	0.818
Cultural Services	Composite	10.35	3.98	5-24	
	Average	1.7	.66	.83-4	0.593

On service use satisfaction, ALHIV preferred the TCC with which they had a lot of contact. They were satisfied with the quality of services (395 [97%], mean 32.37, SD, 5.93 min =13 and max= 39). Few adolescents (1%) mentioned the church or community teen club as providing services satisfactorily. Only four ALHIV reported having no access to any services, despite being recruited through the ART clinic. In addition to the TCC providing ART and support, most adolescents mentioned that it provided a conducive environment to make friends or develop an intimate relationship, manage their lives, and access health education and monetary support to pay their school fees.

> The mentors [ALHIV role models] and health workers who provide the service are very friendly and they value sympathy and empathy (Tiwale, female, 19 years).

> I have learnt a lot under the teen club. I appreciate myself more. I interact with others better. I found what I was missing in my life (Timo, female, 15 years).

> I stopped doubting myself. I have more confidence and I take my medication (Kemo, male, 16 years).

Structural Equation Modelling

To understand complex patterns of resilience, we used the transactional model known as SEM or path analysis (Stapleton, 2011) (See Figure 5. 1--Path analysis model of risks, service use, frequency, satisfaction and resilience). The results of the initial model were a poor fit.

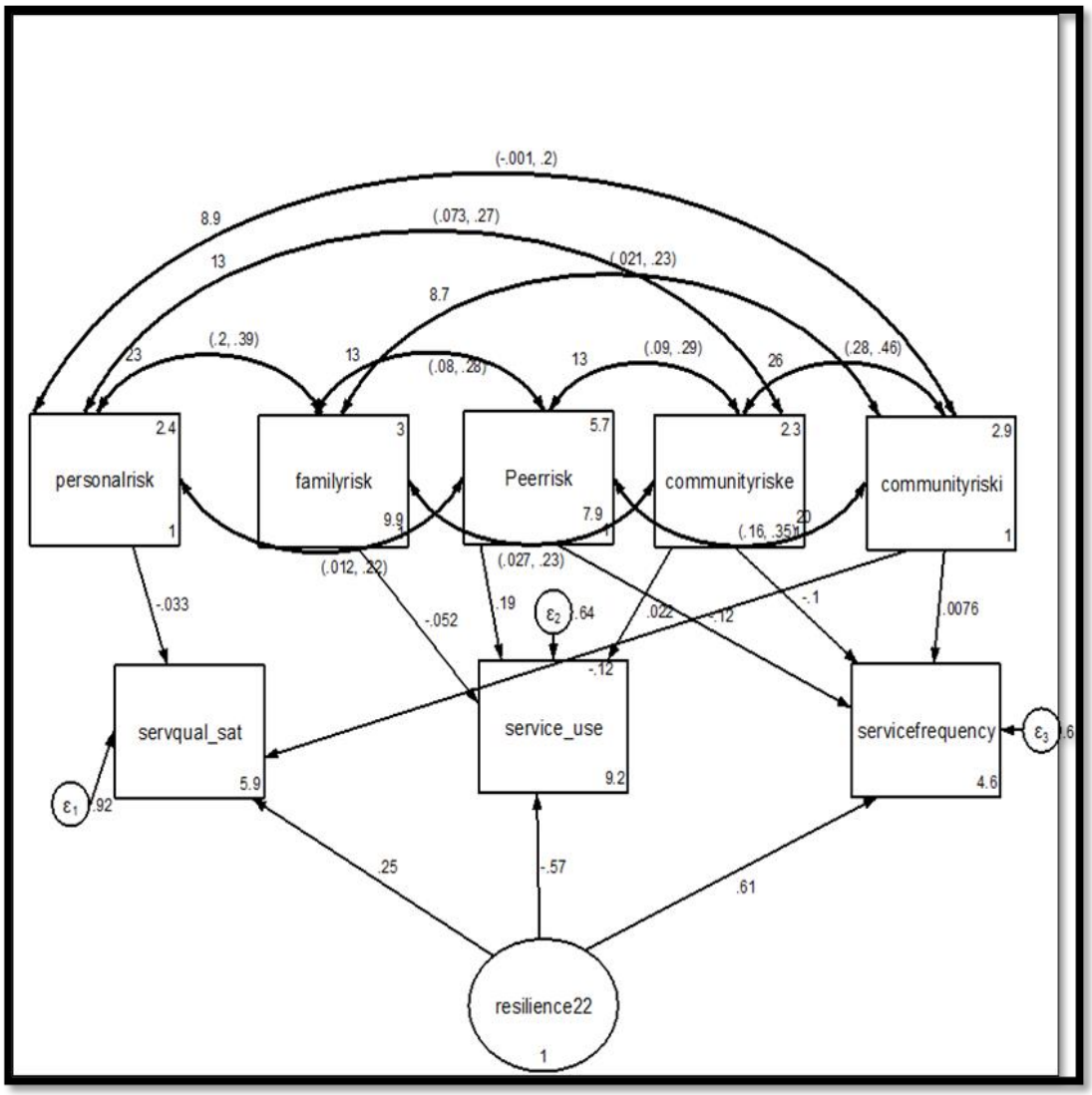


Figure 5. 2: Path analysis model: Risks, service use, frequency and satisfaction [13].

[13] Outcomes with standardised maximum likelihood direct effects. *Reported coefficients differ significantly from (-) 0 ($p<.05$). N= 357/406

We modified this by adding a path on internal community risk and service frequency to service satisfaction; and peer risk and external community risk to service frequency. The results for the modified model showed good fit: p-value= 0.525, Root Mean Square Residual Approximation (RMSEA)= .000, Comparative Fit Index (CFI)= 1.000, Tucker-Lewis index =1.027, Standardised root mean squared residual (SRMR)= 0.021. We combined statistical and methodological approaches in assessing health development in the face of risk, such as examining direct and indirect effects in multiple regression analysis with SEM (Fergus & Zimmerman, 2005).

The paths between risks, service usage, frequency, satisfaction and resilience were further analysed to show the collective strength of relationships of multiple variables (Creswell, 2014). Internal community risks and resilience proved to be statistically significant (p-value <0.001) with direct effects on service satisfaction. ALHIV facing peer risks and external risks were more likely to use services than youth facing personal risks or internal risks. Peer risks and resilience were also statistically significant, with direct effects on service use frequency. Overall, resilience had a positive influence on service use frequency as depicted by the standardised coefficient of .61. The higher the resilience, the more often services were used but the fewer services were used over time. There was no indirect effect of risk dimensions and other variables to overall resilience (See Figure 5. 1 above).

Association Between Risks, Service Use and Resilience

To reflect on the differential functioning of resilience processes and scores across age and gender, correlation and strength of relationships were assessed. The CYRM-28 standard minimum and maximum scores indicate 28 and 140, respectively (Liebenberg et al., 2012). In the current study, the minimum and maximum scores were 53 and 140. The mean score was 118.2. To categorise the high and low resilience scores, we used the 50 percentile as the cut-off, with study participants scoring above 50 defined as having a higher resilience. The distribution of resilience scores for the lowest quartile was between 53 and 110, the second quartile 111-123, third 124-130, and fourth (131-140). At 25%, 108 ALHIV scored 110 or lower; at the upper quartile, 75%, 87 scored above 124. According to the

resilience research centre manual, the higher the resilience score, the more resilience components/supports are present (Ungar 2016).

Associations between service usage and higher scores of resilience were significant. ALHIV with high resilience scores used more services (p-value <0.001), with young men having a higher score of service use than girls. A high score in service use frequency and satisfaction with TCC reduced the use of multiple services. Those with primary school education were three times less likely to access services than those not in school; ALHIV not in school and those aged 17-19 used more services over time. Those with a suppressed viral load had a lower score of service use (See Table 5. 5 below).

Table 5. 5: Associations between resilience, service use & viral load suppression.

Variable	Coeff.	p-value	95% conf. interval	
			Lower	Upper
Resilience level				
High resilience	Ref	-	-	-
Lower resilience score	.92	0.043	.03	1.82
Service use frequency	-.56	0.000	-.72	-.04
Service use satisfaction	-.05	0.170	-.13	.02
Gender				
Female	Ref	-	-	-
male	.61	0.18	-.30	1.50
Education				
No education	Ref	-	-	-
Education (Primary)	-3.12	0.000	-4.81	-1.56
Education (Secondary)	-1.82	0.02	-3.31	-.33
Age category				
(15-16)	Ref	-	-	-
Age groups (17-19)	.12	0.81	-.84	1.07
Viral load				
Suppression	Ref			
Suppressed	-1.03	0.034	-1.98	-.77

5.6 Discussion

The study explored service use, frequency, satisfaction, risk and resilience among ALHIV aged 15-19 attending an ART clinic and TCC. ALHIV used formal and alternative services available to them within their socio-ecology to do well despite adversity. Health workers and PMKs -- adults who knew a lot about ALHIV lives -

- supplemented the data on service use experiences and offered multiple perspectives. All indicated that ALHIV used three or more services, including the ART clinic, teen club clinic, community-based teen clubs, YFHS and schools. PMKs, including biological parents and other caregivers, mentioned traditional and spiritual support to enhance ALHIV well-being. Using health workers and PMKs to negotiate resources supports the notion that both relational and institutional ecologies are key in sustaining ALHIV well-being. Multiple perspectives are crucial to informing integrated service provision and plans.

ALHIV frequently used institutional support, both ART clinics and TCC. TCC especially (369/406, 91%) ensured participant satisfaction through its comprehensive programmes and accommodation of health workers. This is consistent with research on the potential benefits of adolescent-centred approaches for ALHIV (Feyisetan et al., 2014; Mutambo et al., 2019). Service use frequency had statistically significant direct effects on service user satisfaction. Our analysis of qualitative data extended our understanding of this, indicating that satisfactory service experience with TCC was integral to ALHIV well-being. This in turn ensured better clinical results (i.e. reduced viral load) and enhanced support from health workers. Previous studies on how health workers facilitate resilience have been disappointing (Chandra-Mouli, Lane, et al., 2015; Feyisetan et al., 2014). The current study shows that health workers in teen club settings played a double role as provider and mentor and were able to form positive and caring relationships with ALHIV. This shift away from a paternalistic focus on health worker relationships with ALHIV is critical to the formation of autonomy, informed choices and decision making among ALHIV (Kok et al., 2018). Within a positive clinic environment, with comprehensive and 'bundled programmes', ALHIV felt a sense of belonging and felt in control of decision making, so contributing to resilience.

Prioritising the ART clinic and TCC among ALHIV is not unexpected given their health needs and the DSD policy drives to provide patient-centred care (Kok et al., 2018; World Health Organization, 2017). In this context, health workers provided extensive psychosocial support to ensure ALHIV had a say in how services were delivered, that they understood them, and experienced a sense of belonging and

satisfaction over time. Health workers in teen clubs tend to play a double role as providers and relational supports, influencing young people's access to requisite resources to help sustain their well-being. Previous studies in Malawi show that TCC attendance has the potential to reduce attrition and improve viral load suppression, hence showing the salience of health interventions and YFHS among key populations (MacKenzie et al. 2017, MacPherson et al. 2015). Our study indicates that ALHIV with suppressed viral load had a lower score of service use as they were satisfied with services to provide by the TCC. ALHIV appreciated the respect accorded to them in the clinic and role-play activities, and the support and interactions which strengthened relationship building. These factors appeared to support not only access and treatment adherence but encouraged self-care, effective communication and participation (Betancourt et al., 2013; Zapata et al., 2017).

Sociodemographic variables, service use and resilience were associated in our study. Previous studies show that older youths, young women, and adolescents in general report higher levels of service use and moderate resilience scores (Sanders et al. 2017, Ungar 2016) compared with younger adolescents and males. Our study shows that adolescents aged 17-19 and most ALHIV were seeking services elsewhere and recorded moderate resilience scores. The mean resilience score for ALHIV in Malawi at 118.2 is consistent with other key populations (Oliveira, Machado, & Aranha, 2017). In addition, young men and all out-of-school youth reported greater service utilisation, suggesting their capacity for positive adaptation regardless of life circumstances. This is consistent with a report on YFHS in Malawi, which observed that older and male adolescents strived for autonomy and greater independence, creating space for better decision making for better service use (Feyisetan et al., 2014).

The unique aspects of our study focused on promotive factors, direct, indirect and total effects, and their significance on resilience. The interaction between service use frequency, satisfaction, peer risks, internal and external community risks are key in influencing resilience. However, we view resilience not as a final accomplished outcome, but as a dynamic and complex process. In the current study, individual dimensions were connected with social and contextual influences as part

of the multiple variables previously found to be associated with resilience (Govender et al., 2017; Liu et al., 2017). The interaction of resources within and externally, and continued engagement with services, enhance resilience for ALHIV. These findings inform our understanding of the interaction of complex factors to ensure resilience in different situations and over time (Theron & Theron, 2010; van Breda & Theron, 2018).

Feyisetan and colleagues (2014) and Ungar (2016) argue that increased service use does not necessarily mean better health or social outcomes, female ALHIV used limited services, reinforcing the understanding that service availability does not translate into utilisation (Ungar et al. 2013, Wright & Masten 2015). The comprehensiveness of activities and improved quality of services enhanced service use satisfaction (Zapata et al., 2017). SEM and regression analysis demonstrated positive and direct effects between risks, service usage, frequency, satisfaction and resilience, but there was no association between resilience and viral load suppression. Given the increased vulnerability of ALHIV, particularly females, future studies are needed to examine resilience-promoting spaces and places within the adolescent-centred, TCC models to enable equitable access and provision to services and supports.

5.7 Lessons Learned

Policy

- The TCC model facilitates differentiated care in relation to gender, age and clinical outcomes.
- The adolescent-centred approach offers autonomy and allows ALHIV to voice their needs.
- The TCC model paves the way for active interactions and equal partnerships between ALHIV, health workers and parents/caregivers.
- The one-stop-shop caters for the provision of services by different health workers in different rooms, facilitating internal and external support.

Practice

- Reflecting on resilience supports adolescents being seen as 'agentic beings' with the potential to enhance their access to services.
- ALHIV are engaged in informed and shared decision-making not only for HIV care but other social and health matters.
- Tailor-made HIV programming is needed to meet multiple ALHIV needs, including counselling, psychosocial services, and transport and education allowances.
- ALHIV service use and care pathways are complex and require teamwork and integration of different supports and care settings.

Limitations

Our study was cross-sectional, within a single facility in Malawi, which makes it difficult to determine the causal processes and external validity. We depended on ALHIV self-reports on service use histories and support within the past year; hence their experiences of and access to formal and alternatives services may be unreliable because of recall bias (Creswell, 2014). Working with ALHIV and attending UFC ART clinic and TCC may also have caused selection bias. The low turnout by parents and caregivers as PMKs made it difficult to link their data with ALHIV. Lack of completion on entries in the registers and EMR database also provided challenges in defining relationships, viral load, clinic registration, and attendance sheet outcomes. However, multiple sources of data and perspectives using qualitative and quantitative methods provided complementary information and allowed a deeper understanding of service use and resilience-related outcomes.

5.8 Conclusion

A mixture of health-related services (ART, teen club clinic, YFHS), school and community-based teen clubs form an integral part of ALHIV formal service provision; satisfaction with these services is associated with resilience. In addition to formal service use, most PMKs regarded traditional and spiritual care as alternative supports to ensure a holistic provision of care for ALHIV. There were significant associations between sociodemographic variables and resilience, and

positive and indirect effects on the same, supporting the idea of services nurturing ALHIV well-being. The adolescent-centred approach made it possible to promote service use which helped ALHIV beyond the clinical care.

Resilience is a complex construct and its supportive value is dependent on multiple support systems and processes that include individual autonomy and independence, typical and atypical relational maintenance, institutional and policy support. The qualitative findings strengthened our understanding of the relationship between service use satisfaction, including enhancing access to care, participation, and empowering ALHIV and caregivers within the TCC. The multiple roles of health workers in partnership with parents/caregivers encouraged adherence to medication, provided psychosocial support and monitored viral load, all of which fostered resilience and reduced adversity. The TCC setting offers comprehensive activities and ultimately promotes resilience and well-being among ALHIV. Thus, TCC is an example of a core package of interventions that combine evidence-based approaches that go beyond the health sector.

CHAPTER SIX

FORMAL AND ALTERNATIVE PATHWAYS ADOLESCENTS USE FOR THEIR RESILIENCE

Paper IV

6.0 Introduction

Kaunda-Khangamwa, B.N., Kapwata, P., Malisita, K., Munthali A., Chipeta, E., Phiri, S., Manderson L. (2020) Adolescents living with HIV, complex needs and resilience in Blantyre, Malawi. *AIDS Research Therapy* 17, 35. https://doi.org/10.1186/s12981-020-00292-1

This multicase study approach addressed Objective 3 of the study, to describe and analyse formal and alternative pathways of adolescent service use that promote positive outcomes, and to determine how ALHIV negotiate and navigate within their family, teen club clinic supports, relational and contextual resources for their well-being.

Four case studies are presented as part of understanding the multiple and ongoing nature adversities presented by ALHIV. These adversities influence the diverse pathways through adolescence and complex interplay between individual, relational and institutional support around them. I define pathways as the sequence of contacts with individuals or organisations prompted by the ALHIV own effort, and/or person most knowledgeable about adolescent lives to seek help or not (Siu, Kennedy, & Bakeera-Kitaka, 2016). Inspired by ARV clinic ethnographies *Will to Live. AIDS therapies and the politics of survival* by Joao Biehl (2009) and *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS* by Vinh-Kim Nguyen (2007; 2010), I realised that the pathways adolescents negotiate cannot be explained in a single interview or self-reports. I had to attend to the complexity of ALHIV experiences within different contexts. I struggled to understand the pathways to resilience, with consistent observations coupled with the interviews with individual and group discussions illustrated the variations of experiences among ALHIV.

Using mixed methods, I employed a multiple case study approach, to allow triangulation of evidence on each case as well as providing a holistic understanding of resilience among adolescents with complex needs. The multiple methods included: 1) CYRM survey to identify cases with complex needs, 2) followed up through qualitative interviews and field notes to gain a deeper understanding of these complex needs, 3) referred to patient files/health passport to situate clinical challenges, 4) used ecomapping exercises to personalise cases and to strengthen the diagrammatic representation of resilience enabling resources and supports.

During the post-survey interviews, I requested 26 ALHIV to draw ecomaps as part of a visual drawing exercise to collect and organize data about families and institutional supports, thus complementing and triangulating information about available resources and supports in the past year. The drawings took place in groups and were followed by in-depth interviews to discuss the strength of relationships and meanings ascribed to resources and persons as depicted in the eco-maps. Participants were asked to help me understand their ecomap by describing the nature of the relationships between family members and family and resources outside of the family. The ecomap was a graphic representation of a family's resources, services and relationship to the world (Harold, Mercier, & Colariossi, 2016; Hartman, 1978). We document four composite cases into four single stories, so providing a 'thick description and nuances' of the eco-maps and interviews to show how adolescents' resilience evolves.

In particular, we focused on the following key themes: complex needs, accessing the service as coordinated or not, the effect of these services on easing exposure to risks, and capacity to improve knowledge and promote decision making processes and empowerment among ALHIV. The cases catered for meaning and decision-making processes surrounding ALHIV in the face of adversities as well as the resources they had included in their drawings. The concept of 'strategic silence' is coined as part of deepening our understanding and interpretation of the pathways that ALHIV negotiate for their wellbeing.

The cases, including eco-maps as diagrammatic representations of supports and resources, challenge the role of social and relational supports in enabling resilience among ALHIV. They bring to the fore relational and institutional networks, gender and power dynamics among ALHIV, especially emphasising that both female and male adolescents' lives matter in relation to complex needs and resilience-related outcomes. The complexities at the individual level and relational interactions within the family and institutional support inform the pathways which ALHIV take for their wellbeing. The argument in this study is that the pathways that ALHIV take are not unidimensional but dynamic and variable trajectories involving multiple courses of action with back-and-forth movements (Siu et al., 2016). The ultimate aim was to learn the essential factors and negotiations that promote ALHIV resilience-related strengths and encourage positive outcomes.

6.1 Abstract

Background

Adolescents living with HIV (ALHIV) in Malawi experience multiple challenges associated with their illness and various social, environmental, economic, and cultural factors. In exploring their various medical concerns and social vulnerabilities, we consider the role of multiple services in creating a pathway for resilience.

Methods

Multiple methods and case studies allowed for triangulation of evidence and provided a holistic understanding of resilience among adolescents with complex needs. The research methods included: (1) a survey to identify examples of young people with complex needs, (2) qualitative interviews and field notes to further explore these needs, (3) patient files and health passports to identify clinical challenges, and (4) ecomapping exercises to personalise cases and identify resilience-enabling resources and supports. We present four case studies to highlight the complex experiences and access to services of ALHIV and to illustrate their growing power and decision-making capacity over time.

Results

Adversity experienced by ALHIV varied by gender, family situation, years of schooling, and use of teen clubs for support. The two female adolescents emphasised their need to be accepted and how this impacted sexuality and reproduction. The two males illustrated how ideas of masculinity influenced their sexual practice and involvement with health services and the correctional justice system. Multiple risks (alcohol use, sexual activities) and complex needs (belonging, having a purpose in life/productive activities, autonomy, desire for offspring) influence pathways to resilience. ALHIV were able to strengthen their wellbeing by resisting negative behaviours and peer pressure and caregiver interactions through ‘strategic silence’.

Conclusion

ALHIV experienced self-transformation as a result of taking ART, with fewer severe episodes of illness and distressing skin conditions. Continuous engagement at the teen club clinic transformed both productive activities and social relationships among ALHIV as they set life goals, gained a sense of empowerment, requested SRH services, and formed intimate relationships. These transformative opportunities allowed them to learn ways of minimising the risk of reinfection and violence, and of navigating health worker–the caregiver–adolescent interactions.

* * *

6.2 Introduction

Many adolescents, globally, experience poverty, abuse, learning difficulties, family breakdown, stigma and discrimination (Kim et al., 2017; MacKenzie et al., 2017; Reif et al., 2018). Infection with HIV compounds these disadvantages. Compared with peers of the same age without a chronic illness, ALHIV have difficulties economically, socially and psychologically. This leads to low aspirations, poor goals and a sense of failure (Betancourt et al., 2013; Donenberg Geri & Pao, 2003; Laughton et al., 2013). A culture of silence around HIV and sexual reproductive health (SRH) issues is still dominant and is at times strategic to avoid exclusion (Betancourt et al., 2013; Limaye et al., 2012; Manderson, 2012; Skovdal & Belton, 2014). In this article, we used a case study approach to identify the complex characteristics of ALHIV in Malawi to explain how young people manage their lives in the face of adversity.

Poor access to contraception exposes adolescents to unintended pregnancies and sexually transmitted infections (STIs), including HIV. Fifty percent of births in sub-Saharan Africa are among women aged 15-19 years, and early pregnancies and births reflect early sexual debut and low contraception use (Callahan et al., 2017; Toska et al., 2015; Toska, Pantelic, Meinck, & Keck, 2017). Unintended early pregnancy affects the physical maturation of young women and can result in forced marriage, disruptions to education, and mother-to-child HIV transmission (Bain et al., 2018; Callahan et al., 2017). Continuing social stigmatisation may influence young women to seek an unsafe abortion and risk death to avoid community

ostracism (Eshun-Wilson et al., 2019; Polis et al., 2017), while stigma also impacts directly on adolescents – male and female – with HIV (Bain et al., 2018). HIV/AIDS is the second leading cause of death among adolescents aged 10-19 globally and in sub-Saharan Africa (Bain et al., 2018; WHO, 2018). However, early death from HIV is no longer inevitable.

To understand how adolescents', navigate and negotiate the 'complex mix' of social, biological, physical and cultural experiences for their wellbeing, we adopt a complex needs perspective. Most studies on complex needs focus on people with mental illness, who have experienced substance or sexual abuse, learning difficulties, physical challenges, poverty or social exclusion (OECD Development Centre, 2018; Rankin & Regan, 2004). 'Complex needs' are tied to disadvantaged circumstances of clients and the difficulties service providers face in working with them (Ungar, Libenberg and Ikeda, 2014). These issues are significant for ALHIV as they negotiate the complexities of their personal and social lives, as Rankin and Regan (Rankin & Regan, 2004) suggest:

Understanding complex needs is important in several senses. It allows practitioners to explore the breadth and depth of people's needs and the interaction between different needs. It also highlights a severely excluded group: people who require a more carefully targeted approach from universal services (Rankin & Regan, 2004).

Ungar and colleagues use the terms 'complex needs' and 'multiple service using youths' interchangeably to capture the challenges of adolescents in accessing education, and interacting with child welfare, correctional and mental health services (Ungar, Libenberg and Ikeda, 2014). They argue that because the provision of psychosocial services is delivered in departmental silos, there is a lack of information flow, poor intrapersonal relationships, and structural boundaries. This results in poor services and care for young people (Harrison, Newell, Imrie, & Hoddinott, 2010), and has led to the increasing trend for 'bundled' health care programmes, e.g., 'family support, psychosocial support and SRH services' (Reif et al., 2018), or 'minimum health package for STIs, HIV and AIDS, family planning information and services, nutrition, sexual abuse, adolescent pregnancy, and psychosocial support' (Fleischman & Peck, 2017; Saul et al., 2018). A combination

of acceptable and clinically scalable health-care packages that address social and behavioural factors, complemented with structural support, are considered to have a maximum impact (Reif et al., 2018; Saul et al., 2018; Toska et al., 2016). This is true in low and middle-income countries as well as high-income settings.

In Malawi, young people use medical and social services with mixed outcomes (Feyisetan et al., 2014; P. MacPherson et al., 2015; Makwemba et al., 2019; Mwalabu et al., 2017; OECD Development Centre, 2018; Zgambo et al., 2018). Medical, biological and social factors influence the complexity of diseases and wellbeing over time, with interactions across these factors influencing health-seeking and outcomes (Manderson & Warren, 2016; Mendenhall, 2016; Willen, Knipper, Abadía-barrero, & Davidovitch, 2017). The complex mix of social and biological factors is conceptualised as a syndemic, in which there is often stress both as a cause and as the result of physical health problems (Singer et al., 2006; Willen et al., 2017). Structural disadvantage and vulnerability, family fragmentation, extreme poverty, food insecurity, lack of shelter and interpersonal violence further shape risk and outcome. Our interest in this article is in how to intervene. We turn to a teen club clinic model in Malawi as presented by Kim and colleagues (2014, 2015) and MacKenzie and colleagues (2017). Drawing on case studies, we consider how disease (including TB, STIs, HIV), structural factors (gender, class, poverty, education) and social forces (child-headed homes or correctional/juvenile centres, unintended pregnancy) complicate the wellbeing of ALHIV (Bain et al., 2018; Ross et al., 2020; Toska et al., 2016; Zgambo et al., 2018).

6.3 Methodology

Resilience, Socio-Ecological Framework and ALHIV

Resilience is defined as the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being, and their capacity individually and collectively to negotiate for these resources to be provided in culturally meaningful ways (Ungar 2008). The concept of resilience highlights the interactions between protective and constraining factors and processes that need to be considered for adolescents to do well despite adversity

(Bain et al., 2018; van Breda & Theron, 2018). Ungar's definition is grounded in a socio-ecological understanding of resilience. Both resilience and ecological approaches centre on the complexity of processes and, interactions, with a shift of focus from individual traits, relational, community to institutional support (Bronfenbrenner 1979, Ungar 2008). We use resilience as a strength-based perspective to enable insights into positive outcomes among ALHIV and to counter the dominant negative narratives of ALHIV. In describing this, we illustrate how attention to resilience establishes space to identify unique perspectives and to give voice to ALHIV in Malawi (Panter-Brick, 2014).

Study Design

In this study, we used a multiple methods approach with case studies to examine the experiences of ALHIV as influenced by age, gender and the utilisation (or not) of health services (Creswell, 2014; Yin, 2009). We created narratives of these adolescents accessing services to gain an understanding of their lives. Data collection included the administration of the Child Youth Resilience Measure-28 (CYRM-28) to identify adolescents' complex needs and service usage, recorded qualitative in-depth interviews, and field notes. These data were supplemented by a review of patient files and health passports to situate clinical challenges, and an ecomapping exercise to personalise experiences and to strengthen diagrammatic representations of social and health services utilisation over time (Morgan et al., 2017; Yin, 1994).

Setting

The study from which the cases were drawn was conducted at an ART and teen club clinic in Blantyre (National Statistical Office, 2019). This city has a population of about 800,000 people and is described as a hotspot for HIV, with a prevalence of 18% among persons aged 15-49 (Ministry of Health, 2017; National Statistical Office, 2019). The teen club was set up in 2010 and is currently run by Lighthouse Trust at the Umodzi Family Care (UFC) clinic at the Queen Elizabeth Central Hospital (QECH) in Blantyre. The teen club provides adolescent-centred psychosocial support to ALHIV, with its program adapted from the Baylor College of Medicine (USA) International Paediatric AIDS Initiative Centre of Excellence

Curriculum (MacKenzie et al., 2017). The club had a membership of 3,500 young people aged 10-24 as of June 2019 and serves as a one-stop-shop offering comprehensive HIV care and supports including SRH, nutrition, education and entrepreneurship services for ALHIV. Other services are prevention, care and treatment for other STIs (such as gonorrhoea, syphilis and genital warts), targeted family planning, teachings on sexuality, and basic computer skills. The 10-19 year olds meet monthly, while the transitioned teens (usually 20 years and above) meet once every quarter of a year.

Sampling and Participation

Purposive sampling with maximum variation was used to select adolescents who self-identified as having experienced multiple or complex health and social problems. We explained to them that we wished to learn about their lives and experiences as individuals, their relationships and interactions with others in their communities, and access to services. Individual written and verbal consent at the start of the interview process was used for adolescents aged 18 and 19. Younger adolescents, aged 15-17, assented and was supplemented by signed parental/guardian consent and verbal approval given during parent/guardian sessions. To maintain confidentiality, we attribute quotations with pseudonyms and some of the details of those whose cases are included in this article have been changed.

Data Collection

From 2015, the first author volunteered part-time at the teen club, and from November 2018 to June 2019, collected data over eight months. A closed-ended survey was conducted with 406 ALHIV using the CYRM-28 survey to gather socio-demographic details and information on their access and utilisation of health and social services. Twenty-six (26) in-depth interviews (IDIs) were then conducted, spread out across the months of fieldwork. Five of the 26 IDIs were scheduled by phone call within the week, and the investigator invited the adolescents to suggest a place of their choice, with the time chosen to build rapport and maintain confidentiality. Sometimes we sat in or outside of an adolescent's home, at the netball or soccer grounds at their school, or in my makeshift office that I had

decorated to provide an accessible and comfortable space in which young people could relax and talk freely. The next two rounds of the interviews with ten adolescents were held in my makeshift office, where we reflected on the narratives and responses from the IDIs while focusing on their own experiences at the teen club and with other service providers.

We accessed the participants' clinic files and health passports (personal health cards) to capture their history of illness, including infections co-occurrent with HIV. In present each case study, we include viral load results and examples of illnesses as indications of the severity of HIV-related issues, adherence to medical treatment, service-seeking histories and provision of health care and support. Finally, 20 of the 26 adolescents participated in an ecomapping exercise, drawing their families and the resources they had used in the past year. (Appendix 10, 10.1 and 18). Using a pen or pencil and paper to graphically represent people or services in their lives, such as friends, school relationships, relatives, doctors, neighbours and church members, these data helped us to triangulate our findings on service usage and relational supports and strengthened our findings on how structural factors (gender, social and health services) affected young people's narratives. To maintain consistency and trustworthiness, all interviews were conducted by the same person (first author), were digitally recorded, and lasted 45-60 minutes. Bottled water, soft drinks and buns were provided during breaks in interviews. Study participants were reimbursed transport costs at the end of each interview.

Data Analysis

Data analysis was phased. In the first phase, we summarised ALHIV socio-demographics, the quantity of service use and clinical outcomes using descriptive statistics, (See Tables 4. 3 and 5. 1 above and 6. 1 below) summarises their socio-demographic data and backgrounds. The discursive analysis of the drawings (ecomaps) with participants identified key experiences and themes (Hodes et al., 2018; Rempel, Neufeld, & Kushner, 2007). These ecomaps and themes were linked to data from IDIs to strengthen each case (Kuhn, Ford, & Dawalt, 2018). Framework analysis was used to make sense of the IDIs, notes from the adolescents' clinic files, health passports, and field notes. All data were typed into Word and

imported into NVIVO 11 to allow us to code all paragraphs and categories that showed multiple vulnerabilities and services.

Data were indexed along in three tiers – individual, relational and contextual – to highlight the complexity of young peoples' lives. We noted all details related to lifetime or life history and teen club clinic experiences, including knowledge of HIV status, disclosure processes, taking ART, friendships, family, love and sexual relationships, pregnancy, service usage, STI treatment processes, education services, labour ward experiences, and if relevant, interactions with correctional services. Charting allowed for themes within and between cases to be summarised. (See Table 6. 1) presents the main themes that emerged from the data according to tier. In this article, we have selected the life experiences of four participants to represent the main findings.

Table 6. 1: Main themes for ALHIV life experiences

Individual	Relational	Contextual factors
Age	Parental/Guardian interactions	Institutional support
HIV status	Death of single or both parents	Educational services
Gender	Fear of disclosure	HIV clinical and psychosocial services
School status	Lack of affective relationships	Clinic teen club
Premarital status	Peer pressure	Spiritual and herbal support
Strategic silence	Strategic relationships	Safe spaces where adolescents learn

6.4 Results

6.4.1 Case Studies

The four young people were aged 15-19, two young men who we call Timveni and Widze, and two young women, Chiletso and Chifuno. The experiences of Timveni

and Widze indicate the influence of ideas of masculinity on service usage and relational experiences. Chiletso and Chifuno were both out of school, and their accounts emphasise their need to be accepted and how this influences their reproductive lives. (See Table 6. 2**,** below) summarises their backgrounds.

Table 6. 2: ALHIV case study participants

Pseudonym	Age	Gender	Level of education	Present Occupation	Background notes
Timveni	17	Male	College	Student	Both parents passed away; alcohol misuse; multiple sexual partners; mouth ulcers; STIs
Chiletso	18	Female	Primary school	Small-scale business	Both parents passed away; ran away from home; pregnant at 14; living alone with a four year old child; transactional sex; STIs
Chifuno	16	Female	Primary school	Primary school drop out	Out of school; learning difficulties; unprotected sex; non-disclosure to partner; living at home with a single parent.
Widze	15	Male	Primary School	Student	Questioned by police twice; juvenile detention services twice; poor adherence to ART; tuberculosis

These four young people illustrate and explore the totality and complexity of adolescents struggles in different spaces. These four ALHIV all attended at least some teen club clinic meetings, utilised alternative health facility services, and reported that they were doing well (Ungar 2015, van Breda & Theron 2018). But their divergent experiences heightened the complexity of information that emerged from the reviewed clinical files, health passports, and ecomap drawings of ALHIV,

the latter identifying various medical and social resources. The in-depth interviews relayed the complexity of their medical histories, friendships, and relationships, and factors that resulted in social inclusion or exclusion. Their experiences provide the basis for our comprehensive analytical conclusion (Mendenhall, 2016; Morgan et al., 2017).

Timveni 17-Year Old Male

Timveni, or Timve as he preferred to be called, lives in what people locally refer to as a 'ghetto' (slum) in Blantyre, the commercial city in Malawi. We used to meet in the ART clinic corridors and exchange pleasantries, and sometimes he would walk me to my office, 2 km away. When completing our initial survey, Timve had requested psychological support, and I was mindful of his circumstances. We first met for an interview at his school. The second time we met at his home, and the third time at my office. As we began to talk for longer periods, Timve spoke of the value he placed on having me listen to the 'pain' in his life:

> Each house I have lived in has different morals and beliefs, and it becomes difficult to change my behaviour every time I change houses. I have changed households more than four times. Sometimes I am forced to do work for other people. At the age of 8, I was sickly. My dad took my brother and me to a herbalist to get medicine to strengthen our immune system. Six months later, my health had deteriorated. A close friend of my dad drove my brother and me 400 km away from Blantyre to get tested and start antiretroviral treatment. In the same year, I lost my dad. My mom died a year later.

With both of his parents deceased, Timve's brother is the only close family member that he has. He remains deeply unhappy about his mother's untimely death. He remembers her telling him that life was not easy, especially when you take ARVs because it is a lifelong task. He reported that he sometimes feels angry and depressed: "I need therapy. Sometimes I feel mentally insane and feel like nobody listens to me." Timve has stayed at intervals with different aunts and uncles, but his relationship with them is complicated and has led to resentment. The aunt and uncle with whom he was living when we spoke provide him with food and shelter, but he

believes they do not understand him and do not love him, and he yearns for compassion and touch. Timve feels excluded from the interactions of others in the only home he has known for the past five years, especially after his aunt disclosed his status to neighbours. He also feels rejection by and alienated from others in the community.

Timve's grief and loneliness have led to his use of alcohol and sex, and he yearns for romantic relationships. His sexual debut occurred when he was 11 years old. He had joined a gang in his neighborhood who taught him how to pay for sex at guesthouses. He is embarrassed when he reflects on this in the interviews and claims that he has no control over his sexual feelings. The girls replace his mother, who he misses deeply. When he is with a girl, he feels cared for and safe. "All I need is a hug. Some warmth… you know what I mean." His girlfriend of the moment, of his age, provides him with affection, and he has stopped having multiple relationships because the teen club discourages this.

Timve explains that he does not look for sexual intimacy, but that most of the girls he dates encourage him to sleep with them: he consummates the relationship as a sign of trust and love for the girl. For Timve as for other adolescents in this study, there was little transparency among young people about the nature of any romantic relationships and poor communication about protection. Timve does not remember the number of times he has been involved in unprotected sex, and although he fears girls becoming pregnant, he uses condoms inconsistently. He has disclosed his HIV status to a few, but not all, girls, but he also emphasises that those to whom he has disclosed did not request that he use a condom. Timve gets condoms from the toilets or the reception area at the teen club, but he does not like these as they are thick and not perfumed. From the age of 15, Timve has had various part-time jobs, providing him with money to buy expensive condoms that are soft, perfumed, and relatively easy to use.

Timve attends the teen club clinic to please his aunt. Even so, he has attended all scheduled teen club meetings for the past two years, and it is, he says, one of the few places where he feels alive; he laughs a lot. His health passport shows that his viral load was below the detection limit as determined in dry blood spot samples

(commonly reported as< 839 copies/ml by the local laboratory) in December 2018, suggesting good adherence to ART; according to contemporary WHO guidelines, a viral load below 1000 copies/ml was considered "virologically suppressed." He has had other health problems, however, including mouth ulcers and skin lesions. The sores in his mouth affect his smile since he fears being stigmatised, and he has visited Lepra (the hospital's Dermatology Department), a five-minute walk from the teen club, for treatment. He also attends a private clinic for SRH-related services when he gets STIs; he is embarrassed to talk about this. His ecomap (Figure 6. 1 below, adapted from Hartman (1978) depicts the relational and service support he has used in the past year.

Timve also spends time at church to please his aunt, and he refers to his endless search for connection and love at the teen club at the church. He pays attention to his dress and personal presentation at church and teen meetings to demonstrate respect for the family and membership. He also seems confident; he argues that he has the potential to become someone in his life. People surrounding him acknowledge that he is intelligent. He is studying for a bachelor's degree in mathematics and he is optimistic about this. He promises to work hard in his life, at school and in part-time jobs, so his brother (for whom he feels responsible) can move with him into a rented house.

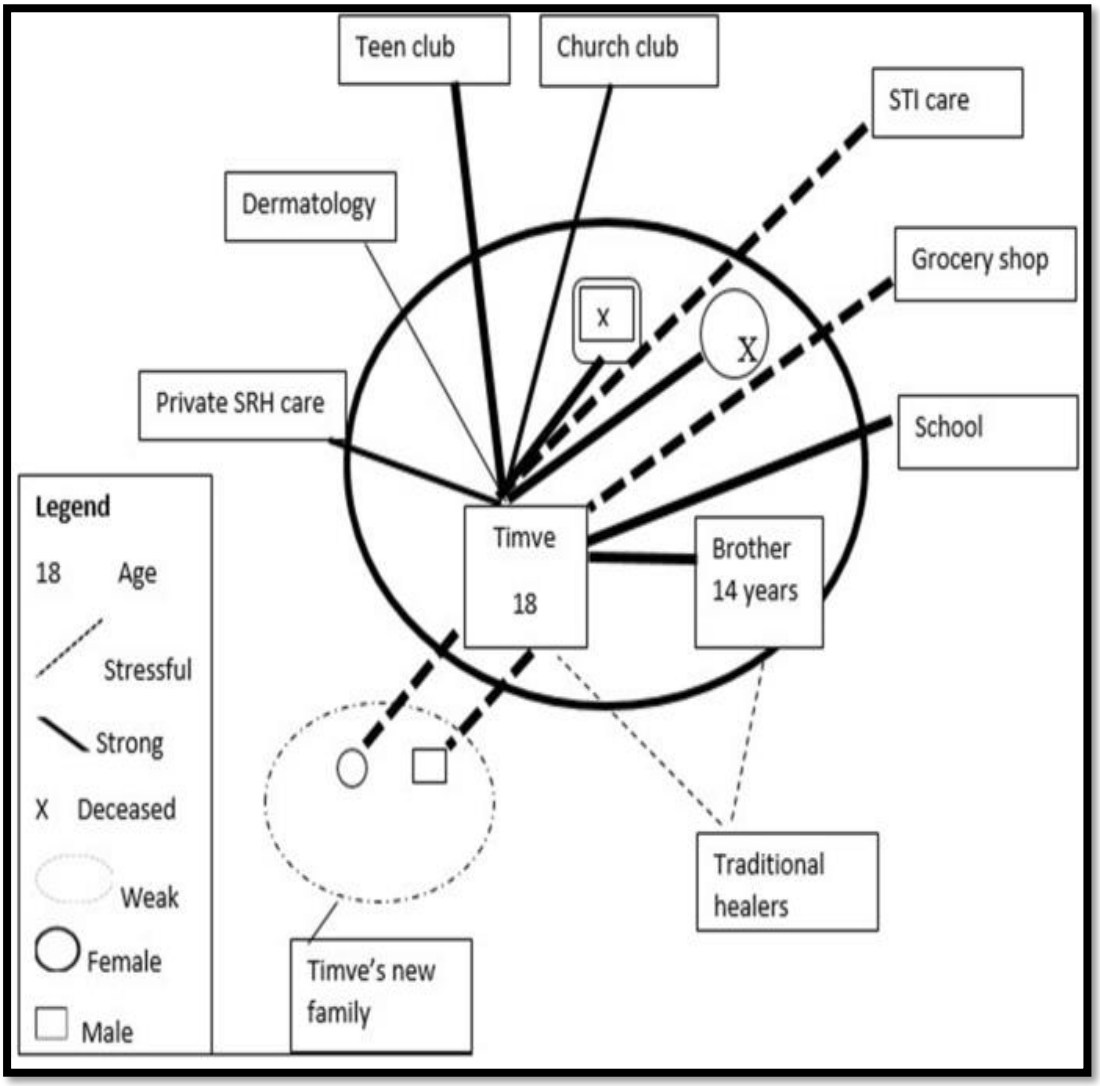


Figure 6. 1: Timve's ecomap. December 2018.

Chiletso 18-Year Old Female

We always met at Chiletso's home, which was a bedsitter in a high-density area of Blantyre. Our meetings took place on Sunday afternoons after church. Chiletso is devout; she maintains her church calendar with weekly prayer meetings, including those that she hosts intermittently at her home. She believes in God as all-powerful, and that God has made provisions for her in the form of food, shelter, and protection in her solitary life. We shared roasted maize and sweet potato for tea whenever we met. Chiletso is grateful because the teen club clinic provides space for her to talk about her life and needs. The club offers counselling sessions and an opportunity to have social relationships with others. Chiletso and her grandmother were referred

to the club in 2010 when Chiletso was 8 years old and had been discharged from the central hospital. Chiletso was born with HIV "like mother-to-child transmission," and she gets her medication from the teen club. She is happy, despite complaining that she is poor and blaming herself for dropping out of school; she refused to tell me her last grade. She dreams of becoming self-reliant. Her dreams for a better future led her to start a cross-border business, bulk buying juices from Zambia to sell in Malawi to meet her everyday needs.

Chiletso's mother had died, although sometimes she claims that she is a "double orphan" since she does not know her father. She has strong family support. She loves her grandmother, aunts, and uncles, and is very proud that they help her when she is in need. However, she prefers to live alone and has done so since she ran away from home at 16 because her grandmother kept telling her to get help from her dead mother at the graveyard. Tears swell up in Chiletso's eyes when she talks about her mother. She wishes she were alive. Chiletso attends counselling with club mentors as part of the therapeutic sessions organised by teen club facilitators (See Figure 6. 2 below, adapted from Hartman (1978).

It took four meetings with Chiletso before she was willing to discuss the main reason she had run away from home. That Sunday afternoon in February 2019, she began to discuss how she became pregnant. She emphasised that she did not have a choice; she argued that no 14-year old chooses to become a mother. She said she did not know much about contraception but claimed that she became pregnant so that she could get help. She did not consider abortion because she regarded her pregnancy as fate. Her mother had not aborted her. She kept the pregnancy secret until she was in labour. Chiletso reminded me that one of the reasons she frequents the teen club is to find space to talk freely and get easy access to "this," pointing to where Norplant had been inserted by one of the nurses at the teen club. I acknowledged the advantages of the 'bundled' services or a 'one-stop-shop' at the teen club that gave young people access to both ART care and contraception.

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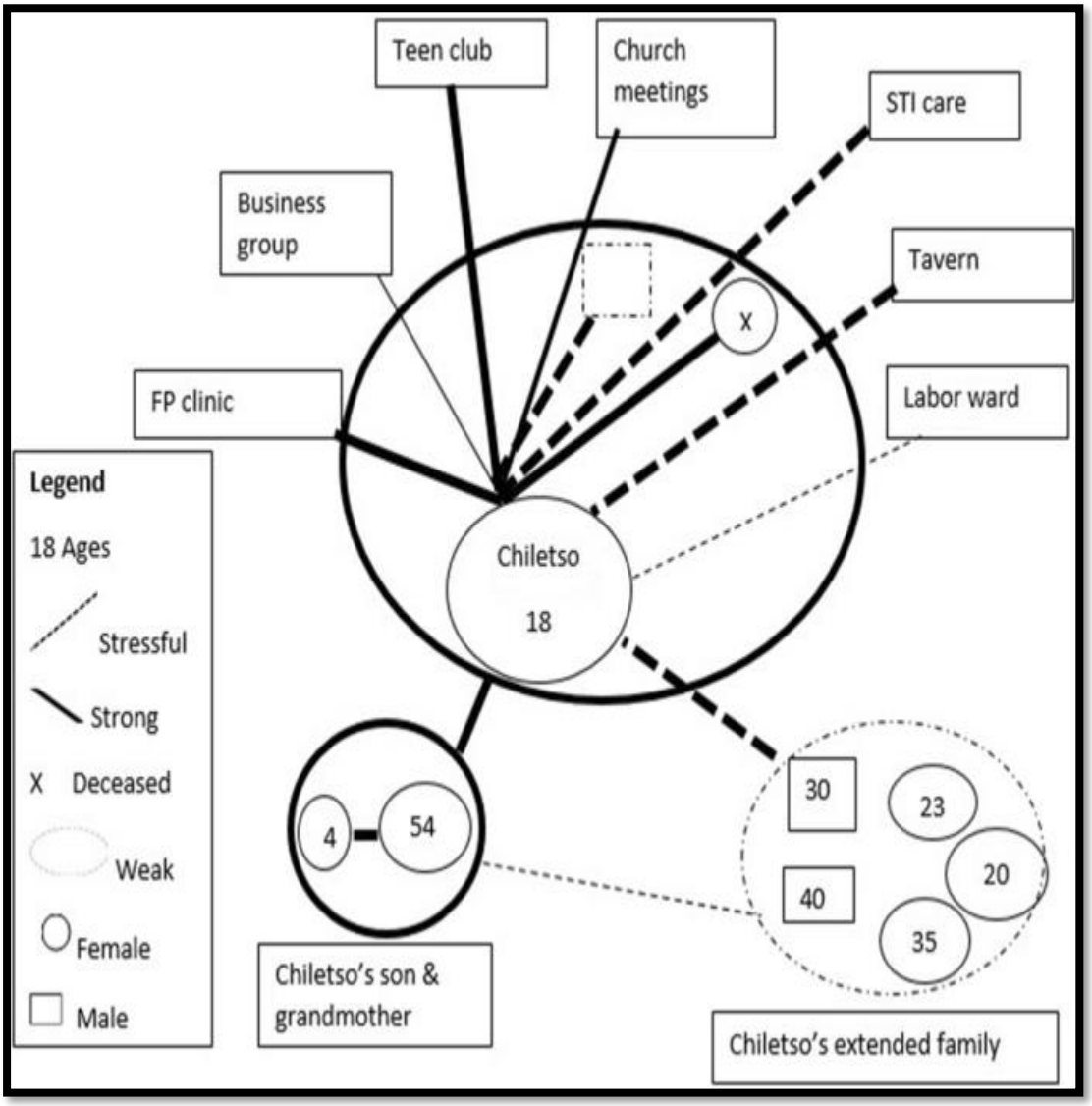


Figure 6. 2: Chiletso's ecomap. December 2018

Chiletso did not breastfeed her son because she had sores everywhere. Her medical records show that she had reacted badly to ART medication and that had caused the skin reaction. While her skin reaction was disfiguring, she insists that she will always adhere to ART medication because now it helps her to keep her skin beautiful. Her viral load continues to be below the detection limit in dry blood spot samples. Her grandmother, who lives in a village, came to Blantyre, and took away her child. Chiletso maintains she would not have survived this long if she had been left alone to take care of her son. Extended family members buffer the impact of adolescents' pregnancies.

Chiletso becomes sad when she talks about becoming what she calls a 'child prostitute' to survive and pay her rent. Sometimes she fails to make the US $10 to pay rent for a month, and she is evicted by her landlord. She tries to stay with friends when she has no cash but some, at least, are reluctant to accommodate her because they are afraid, she might infect them; the stigma and discrimination associated with her HIV status is the main reason she lives alone and strives to do well. She hopes to get a partner and start a family soon, but she will wait patiently to marry someone who will fully accept her. She is willing to delay disclosing her status until she is sure she can trust her partner.

Chifuno 16-Year Old Female

Chifuno likes to call herself my sister. Whenever we met at my make-shift office, she remarked that we looked alike. Chifuno maintains that she excelled at school, but after being in and out of the hospital a couple of times, her performance weakened. She began repeating classes and experiencing learning difficulties. She is frustrated because most friends with whom she was in primary school are now in high school; she has now repeated grade 5 three times. Even worse, some teachers have suggested that she is too old to be in primary school, and this annoys her because opportunistic infections due to HIV have delayed her progress. She decided to drop out of school as she prepared to start grade six. She mentions that she does not like reading anymore and she is functionally illiterate in both English and Chichewa. She wants to start a business, either opening a salon or making and selling duvets with the help of her mother, a single parent. However, 2 years after leaving school, she is currently at home and is not working.

Chifuno found out that she was HIV positive two years before the interview. From 2015 to May 2017, she had poor viral load results (74,000 copies/ml), frequent periods of hospitalisation, and ART failure. The ART clinic switched her medication, and her viral load is now suppressed below the detection limit in dry blood spot samples.

> I thought going to the hospital when one is ill, is normal. However, I was surprised by how often I had to be taken to the hospital and the fact that I was the only child in the house who was frequently taken to the

> hospital. By the time I was able to read and see all those posters at the hospital, I realised I was HIV positive.

Chifuno's grandmother continually monitors and counsels her about her health. She also periodically attends the teen club, although she is now 18 and feels she is too old to do so; the teen club clinic is open to young people who have disclosed their HIV status and are aged 8–24. Chifuno cannot relate to younger members. Separate group meetings are held depending on age and sub-group, defined by colour [grey, green, yellow, blue, orange], to which they belong. The older teens (20–24 years) meet once every quarter of a year, and Chifuno identifies with this older group.

Chifuno lives with her biological mother but she has not disclosed her status to her. She does not talk much with her mother, who she says is "difficult." Her mother has been married twice. Chifuno has no contact with her father, and her family do not talk openly about him. Some say he is in South Africa; her aunt says he died. Secrecy and conflict affect disclosure in the family. However, Chifuno mentions that being in love "keeps her alive." She spends most of the time with her older boyfriend at her grandmother's house. Although they were not formally introduced, both families know about the relationship and have accepted it. Chifuno enjoys sexual intimacy; while they used contraception initially, now they have unprotected sex, and she looks forward to now becoming pregnant. She is letting nature take its course in her life and love life.

ALHIV strive to manage their lives through "strategic silence," consciously and purposefully avoiding disclosure of their status to avoid the anxiety and emotional distress they experienced when first advised of their status. Chifuno has not disclosed her status to her boyfriend. She neither thinks about infecting her partner or being re-infected, nor does she think about STIs. She says she is playing the role of a fiancée and speaks of being "promised to marry," the local idiom adolescents use to refer to a serious relationship. Hence, she defers to her boyfriend to make all decisions. He is very argumentative, and as a result, she does not ask him to use protection as she fears he might get offended or accuse her of infidelity. She has tried to encourage him to go for HIV testing services, without seeming pushy, as she does not want to raise suspicions about her status. She explains that she is

waiting patiently for him to suggest that they visit the health centre and get tested and counselled together. Good and accessible health services are close to her home; but to avoid exposure and maintain her privacy, she goes to the teen club clinic get her medication.

Widze 15-Year Old Male

I met Widze, who was 15 years old, in the adolescents' "back to care" office. The back-to-care team is a mentoring team that follows up adolescents who miss ART or teen club sessions; one of the team had contacted Widze because he had defaulted from care. His clinical records also showed that he had had tuberculosis in 2018. I gave him an invitation letter and an assent form to give to his guardian and asked him if we could meet the following week at my office. Widze is the last born in a family of four. He refuses to talk about his parents, who died six years ago. Widze believes that his brothers and sister do not love him, and they do not want him to live with them. He feels like a 'nobody' in their home. Widze blames his brothers and sister for not disclosing his HIV status to him; they had never explained why he had to take medication every day for life. However, he acknowledges that his older brother introduced him to the teen club; he had attended it once.

Widze's brother, who is his guardian, reported him to the police twice, and Widze has been questioned and retained by juvenile correction services twice. The first time the police detained him was because he beat up the man who was undertaking domestic work for his brother. He argued that he was not in the wrong because the man had disrespected him. He refused to talk about why he was sent to juvenile services the second time. He is angry and hurt that his brother reported him to the police and that, as a result, he had to spend time in the correctional service without his medication. This was evidence that his family wished him to end his life prematurely.

Widze has few friends and he says little about them; he describes himself as a loner. Yet despite this, his unhappiness at home, and his brushes with the law, he is a confident young man. He loves school, is hardworking, and speaks eloquently. He prefers to spend time with his teachers, who he believes wants the best for him. He attends special part-time classes without charge and receives special attention,

books, and support because the teachers know he is an orphan who needs extra support. When he disappears from school and presents to juvenile services, he mentions that he wishes he could go back and stay at the day school and not in his brother's home because his teachers do not question his absenteeism:

> Sometimes, I am away for two weeks. My teacher will not ask me too many questions. He encourages me not to miss school and helps me to catch up during part-time lessons. I do not pay for those lessons. That teacher cares for me.

Widze was reported as defaulting by the teen club tracing team and was followed up. His viral load results were initially poor above 1000 copies/ml, in January 2019. The day he came to the back-to-care room, he explained his absence as due to his busy schedule at school and that he lacked time to attend ART clinic. He promised to become a regular attendee at the teen club, but I have yet to meet him in the corridors of the teen club and we never had the chance to talk again. His medical records show that he finished his TB dosages, and the most recent viral load results were suppressed below the detection limit in dry blood spot samples by June 2019.

6.5 Discussion

HIV acts as an entry point to services and improved knowledge on adherence, treatment-seeking, and relational support for adolescents and young adults during various life transitions. The four case studies presented above illustrate the complexity of the social lives and health needs of ALHIV in their homes, at school, within the community and at the ART and teen club clinic settings. The main themes of their stories reflected interaction within these four ecologies. They showed conflicts, affective peer and mentor support, individual risks, the breakdown of affective relationships, institutional support, and adolescents striving to do well despite their adversity.

Widze, Chifuno, Timve and Chiletso all have complex needs. However, partial attendance at the teen club supported their adherence to ART medication resulting in undetectable viral loads. While an undetectable viral load does not mean that a person's HIV is cured, it does offer tremendous promise for their overall health, wellbeing, and reduced risk of viral transmission to others. Findings in our study

establish a counter-narrative for ALHIV of positive decision-making and meaning-making, including where and how they seek help as they strive for wellbeing. It is imperative to look at the context and culture-specific aspects of ALHIV 'doing well' by negotiating intimacy, peer and institutional support, love, safety and connectedness (Feyisetan et al., 2014; Makwemba et al., 2019; Shapiro & Ray, 2007; Toska et al., 2015).

Individual factors such as age, gender, level of schooling and pre-marital relationships have been thoroughly discussed in the literature as key determinants that affect adolescents' health and social outcomes (Baird et al., 2012; Craig et al., 2018; MacPherson, Richards, Namakhoma, & Theobald, 2014; OECD Development Centre, 2018; Toska et al., 2016; Underwood & Schwandt, 2016). While social determinants may reify the familiar dominant narrative of the risk discourse, ALHIV having increased mental health problems and lag in adherence, contraception use, disclosure, and viral load (Cluver et al., 2018; Feyisetan et al., 2014; Kim et al., 2016; Lusinje et al., 2015; Mandalazi, Bandawe, & Umar, 2014; O'Shea, Gerard, & Kazer, 2015; Skovdal et al., 2017; Toska et al., 2015; Zgambo et al., 2018). In this article, the adolescents had been involved in sexual relationships at a young age. An increasing number of young men are involved in casual sex with older women and girls within their age groups in Blantyre. In adolescent health, both girls' and boys' perspectives matter.

In our study, adolescent defaulters who had a poor viral load and were not attending the ART clinic were followed up and brought back to care. Providing one-to-one sessions with Widze offered him space within the adolescent back-to-care room to discuss his life experiences with his mentors. Widze was able to talk about the challenges he was facing at home, which affected his attendance at the ART and teen club clinic. The presence of trusted back-to-care tracers, coupled with a conducive environment, encouraged him to openly express his feelings. The youth wellbeing policy review for Malawi mentions that support from friends and family encourages adolescents' participation and empowerment (Mwalabu et al., 2017; OECD Development Centre, 2018; Zgambo et al., 2018). Van Breda and Theron (van Breda & Theron, 2018) also note that affective support from various groups of

people a ‘supportive social ecology’ is key to successful social and health outcomes. Hence the relational factors in the home and at institutions are crucial for ALHIV’s social and health-related outcomes.

However, we found mixed responses from participants about the role of friends and family to encourage wellbeing and handle health-related shocks, in particular, disclosure and discrimination. For instance, Timveni and Chiletso experienced difficulties interacting with their uncles and aunts because their family members had told others of their HIV status. Denial, secrecy, child-parent conflicts, stigma and discrimination all affected young people’s understanding of living with HIV (Mandalazi et al., 2014; Moyer & Hardon, 2014; Muula, 2009). Through the two ecomaps and case study narratives, we learn that extended family members and friends could be father/mother figureheads and best friends to adolescents, but they were not entirely trusted.

ALHIV feared that because their adoptive guardians/caregivers were not responsible for their infection, they felt no constraint in telling others of their [the adolescents’] HIV status. Mandalazi and colleagues, who studied adolescents who were perinatally infected in Lilongwe, also found that adoptive guardians felt relatively free to disclose the adolescent’s status because they were not responsible for or answerable as the source of an adolescent’s HIV infection (Mandalazi et al., 2014). This contrasts with van Breda and colleagues, who have argued that among a general population of adolescents, the most prominent supportive relationships were friends, parents and caregivers, and teachers (van Breda & Theron, 2018). Betancourt and colleagues, in a review of mental health, resilience and HIV, stated that disclosure and openness were related to resilience and self-efficacy. At the same time, silence, secrecy, and stigma contributed to feelings of self-hate, anxiety, hopelessness, and confusion among HIV/AIDS-affected children (Betancourt et al., 2013). However, ALHIV in our study did not feel well supported, and hence they were reluctant to disclose their status. They resorted to ‘strategic silence’ as opposed to disclosure as an opportunity cost for personal and family wellbeing (Manderson, 2012) and to support their resilience.

Religion played an influential role for two people presented above. Timveni went to church as a means of maintaining connectedness with family and church. Religion encouraged Chiletso to lead a stable life, knowing she was protected at all times. Ashaba and colleagues likewise found that religion offered ALHIV hope for the future in rural Uganda (Ashaba et al., 2019). Attending church or a mosque provides religious support that can strengthen individual and group networks (Ungar et al. 2015, van Breda & Theron 2018).

Despite health facilities and governments trying to 'normalise' HIV by the routinisation of testing, diagnosis and treatment, through the 'test and treat policy' of patient-centred care, for ALHIV, the disease remains exceptional (Chihana et al., 2018; Prust et al., 2017). Chiletso's, Timve's and Chifuno's accounts illustrate SRH-related challenges including negative emotional outcomes such as regret and physical health outcomes – STIs and pregnancy (Meyer et al., 2017; Toska, Pantelic, Meinck, & Keck, 2017; WHO, 2017b). We see the responsibility of institutions to meet adolescents' needs. ALHIV become involved in casual sex to gain a sense of affection and belonging, and for some, as a means of survival. To avoid unwanted disclosure, they do not request or insist on protection during sex. This is in line with findings from a systematic review of being on ART in Africa, which indicated that competition for relationships, material and marital responsibilities lead adolescents to difficulties to access support (Eshun-Wilson et al., 2019). There is need to balance adolescents' sexual interests and the rules defining sexual relationships to enable a negotiation space that allows for choices (delayed sex, less unsafe sex, contraception use, sexual knowledge) and informed consent.

For Chiletso, having a child 'normalises' sexual activities and pregnancy outcomes (Lusinje et al., 2015; Mwalabu et al., 2017; Undie et al., 2007). In addition, having a child in some African societies is seen as enhancing both male and female identities as fathers or mothers (Mfecane, 2011; Mwalabu et al., 2017). However, Chiletso gave birth at a very young age. She now uses contraception and plans to do so until she considers that she is ready for another pregnancy. Unintended and/or early pregnancy reinforces the need to continue sexual education and learning

among ALHIV. The teen club model as a 'one-stop-shop' tries to cater to medical, social, relational, SRH and psychosocial support (Editorial, 2016; Lusinje et al., 2015; Mensch, Hewett, Gregory, & Helleringer, 2008; Zgambo et al., 2018). This contrasts with most studies that view provider-adolescent relationships as hindering communication about sensitive issues (mental issues, sex, pregnancy, STIs), leading to poor health outcomes (Mensch et al., 2008; Mwalabu et al., 2017). Reflecting on how ALHIV talk and experience sex suggests changes in the experience of sex among young people, and both young men and women openly talked about love, intimacy, safer sex, contraception and marriage in the teen club in Blantyre.

Chiletso and Timve refer to their need for a psychologist to listen to their pain and help them to deal with rejection. Widze sought TB care and adhered to treatment until he was cured. Chifuno intermittently attends the teen club despite her concern that she might be too old to do so. The teen club provides a space for adolescents to walk in at any time to access counselling and empowers them to let their needs to be known. The participatory approach that ALHIV take to maintain their health and wellbeing confirms that both young men and young women have risk profiles that need continuous support over time (Editorial, 2016). The success of the teen club shows the importance of a one-stop-shop with the availability of mentors and health providers to monitor and protect young people. A key recommendation is to improve the integration of service provision and care of ALHIV (Grimsrud et al., 2017; Prust et al., 2018, 2017). As Grimrud and colleagues quote Cynthia Silvia Parker, Interaction Institute for Social Change, "(i)t is not about everybody getting the same thing. It is about everybody getting what they need to improve the quality of their[adolescent] situation" (Grimsrud et al., 2017).

Despite the lack of coordinated care, the four adolescents discussed in this article strived to do well despite adversity. A characteristic feature of all four is that they recognised their challenges and were motivated to do better. Both young men aspired to improve their socioeconomic status through education: Widze continued to go to school despite being in and out of the juvenile centers; Timve worked hard to get a degree. Both young women continued to dream of becoming

businesswomen despite their learning difficulties. They also both, sought knowledge of contraception. Chifuno cherishes her love relations and considers using services closer to her home to avoid transport costs. Liborio and Ungar (2009) argue that involving adolescents in work can be burdensome. Still, it also encourages a sense of hope, agency and respect from others for contributing to their wellbeing (Libório & Ungar, 2009). The four adolescents discussed above continue to reflect on their lives and hardships and reframe positive goals related to their education, sexual and reproductive health, maturation and entrepreneurship to enhance their lives (Adegoke & Steyn, 2017, Masten 2014b).

Limitations

The study was conducted with ALHIV attending ART and teen club clinics in urban Blantyre. The findings may be unique to the four ALHIV and cannot be generalised, although the four were selected because they illustrated themes identified by all study participants. By including two young men and two young women, we hoped to reduce gender bias and provide in-depth insights on complex needs for both genders. Despite the possibility of interviewer bias, the first author had volunteered in the teen club since 2015, and this may have encouraged the ALHIV to give 'honest' responses and talk freely with her.

6.6 Conclusion and Recommendations

ALHIV are a diverse group with needs in multiple areas. In this article, we illustrate the value of attending to their diverse narratives as they strive for a better life, sense of autonomy, aspirations and improving health-seeking behaviors and health outcomes. Adolescents, we note, act strategically. In order not to undermine their resilience and maintain the support system around them, they opt for silence concerning their HIV status.

The complex needs for young people can affect their service usage but can also motivate them to do well despite adversities (Willen et al., 2017). While in Malawi, adolescent care at a country level is fragmented due to service specialisation, the teen club clinic (as a one-stop-shop) is a key resource that ALHIV recognise as providing them with space to learn and enrich their lives. The support from the teen

club clinic is not only clinical and motivational, encouraging adherence to ART and helping to suppress ALHIV's viral load; health workers and mentors also address young people's evolving needs and decision/meaning-making processes. Coordinated and integrated services prove to be valuable to meet the complex needs of ALHIV over time.

Social and relational resources are not just found; they are in part created by adolescents themselves. Ecomaps and case study narratives revealed that adoptive parents or guardians and friends were not fully part of a 'social-ecological support' network. The maps illustrated the role of the family structure in HIV care and support (Mandalazi et al., 2014; Moyer & Hardon, 2014), but how ALHIV interact, relate and discuss their health among themselves and with others is nuanced and strategic. Future studies among ALHIV should explore strategic silence and secrecy within the relational, community and institutional supports, using longitudinal studies to understand how adolescents build and sustain relationships in various sociocultural contexts (Cluver et al., 2018; Macdonald et al., 2017; Mandalazi et al., 2014). This approach is key to creating wellbeing or resilience frameworks to support ALHIV across sub-Saharan Africa.

CHAPTER SEVEN

SOCIAL SPACES AND PLACES THAT MATTER FOR ASRH

Paper V

7.0 Introduction

Blessings N. Kaunda-Khangamwa, Alister Munthali, Sam Phiri, Effie Chipeta, Lenore Manderson. *Spaces and places: Sexual and Reproductive Health and HIV care for adolescents in Blantyre, Malawi* is under review in AIDS Care Psychological and Socio-medical Aspects of AIDS/HIV. Submitted 11 November 2020).

This paper addresses Objective 4 and aims to explore SRH ecologies that influence resilience among ALHIV. In it, I demonstrate how ALHIV experience SRH matters in different spaces and places. I focus on how ALHIV accounts on sexuality, reproductive lives and service use among ALHIV continue to evolve. A strength-based perspective such as resilience on SRH related matters provides young people with the possibilities for in-depth discussions on sexual function, pleasure, contraception or condom use. Such strength-based approaches provide adolescents' spaces to engage with challenges associated with their ages and gender at home, community, school and teen club clinic (see Figure 7.1 below), and illustrate group learning through open communication and presentations that ALHIV attending teen club clinic experience as part of their collaborative learning.

I operationalise the multidimensional aspects of SRH experiences among ALHIV, as occurring within their homes, school, teen club clinic and communities, in both physical and social spaces. This drew attention to variations in boundaries of space and ASRH experiences. The framing allowed me to explore the multilayered influences (individual, relational, social, cultural and structural) for ALHIV to account for myriad and complex discourses of ALHIV intimacy and sexual matters as part of prioritising SRH in ALHIV.

The potential implications of the findings for SRH is the diversity in access to support provided by and experiences in public (school, clinics) and private (homes,

church, parks, hotels) spaces. These spaces exist amidst young people's knowledge base, and their concerns for privacy and safety, allowing them to share facts and reflect on past and present sexual experiences. This in turn enable me to identify current and anticipated needs of young people aged 15-19. The semi-formal sessions in schools, the teen club clinic, workshops and church played critical roles in providing health education which informed sexual interest, desires, intimacy, service use and contraception.

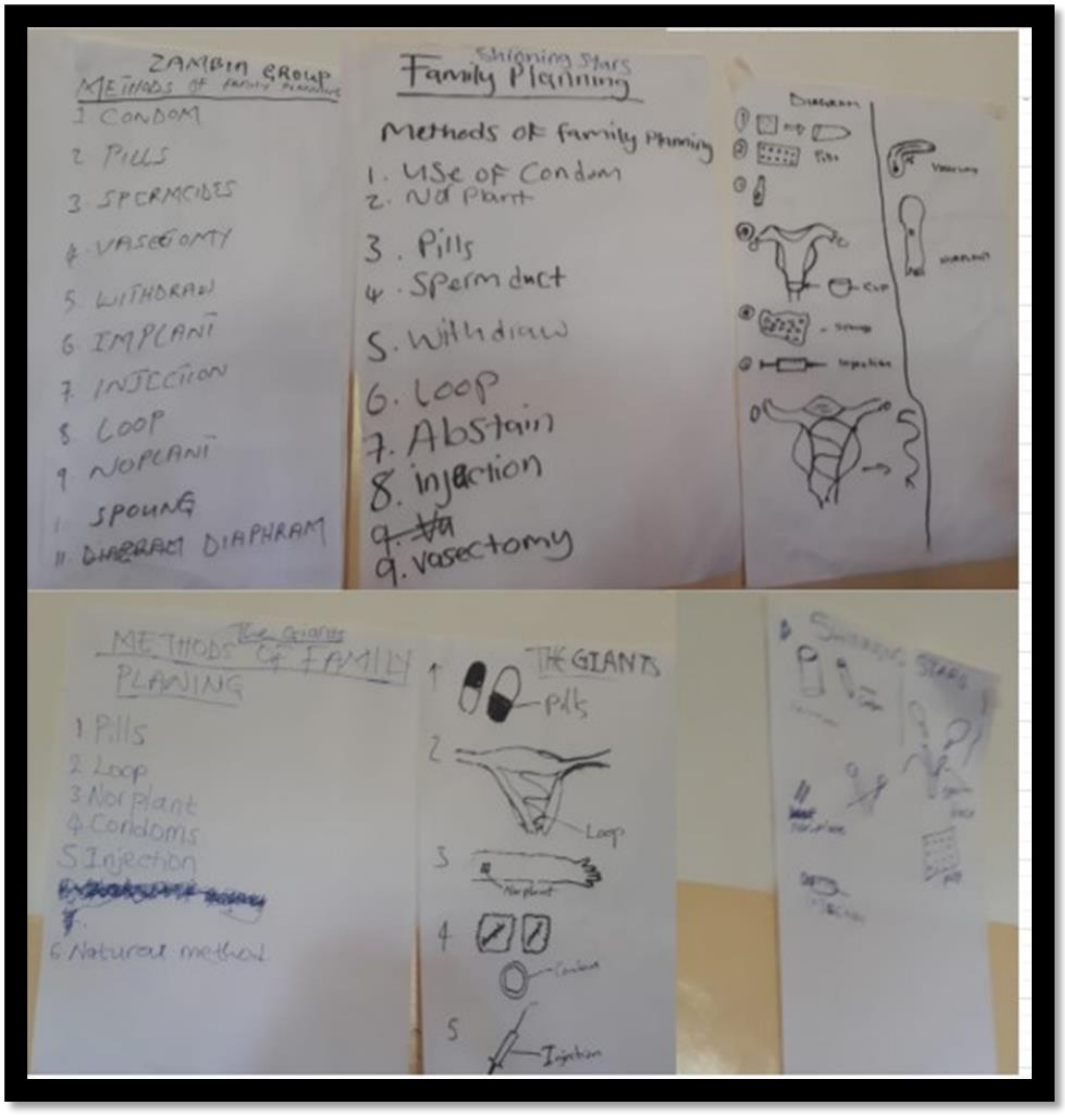


Figure 7. 2: Family planning methods drawn by adolescents aged 17-19[14]

[14] Drawings presented during an SRH workshop in Mulanje (December 2018)

The rites of passages retreat provided platforms not only for the development of life skills, sense of pride, and positive social image but also paved the way for sexual preparedness. Communication in homes and rite of passage ceremonies also challenged and strengthened ALHIV experiences, as parents, mentors and caregivers tried to engage with them dialogically and positively.

This paper provided me with an opportunity to counter the widely traditional notions of ALHIV sexuality, reproductive lives and contraception use as risky, with little or no communication and characterised by barriers to service use. The paper addresses the gap in the growth of discussion of 'healthy sexual behaviors' that have been largely absent in Malawi.

HIGHLIGHTS

- Adolescents living with HIV have sexual function, pleasure and contraception needs, including strong reproductive and future aspirations.
- Homes, schools, teen club clinics and community activities are enabling spaces that support SRH positive outcomes and well-being.
- Spaces and places ensure a nuanced framing of ALHIV sexuality.
- Rites of passage are reframed as supporting informed choices around SRH, particularly abstinence and contraception use.

7.1 Abstract

The provision of care and support for young people living with HIV aims to build safer sex negotiation skills, 'sexual readiness,' 'reproductive preparedness,' and a decrease in unintended pregnancies and STIs. However, little is known about the potential roles of different spaces and places for young people in this regard. We draw on data from a study conducted in Malawi, using an ethnographic approach, including observations at enhanced antiretroviral and teen club clinic sessions, in-depth interviews, and workshop sessions with health care workers and caregivers. Using a socio-ecological framework, we describe multilayered physical and social spaces that positively impact adolescents' SRH and wellbeing. We argue that homes, schools, teen club clinics and community settings all function as

interactional, relational and transformational spaces to allow ALHIV to talk about and receive information on SRH, sex, sexual function, pleasure, intimacy and relationships. ALHIV perceived that comprehensive SRH support enhanced their knowledge, sexual readiness and reproductive preparedness. Even so, their desire to reproduce at an early age complicated their adoption of safer sex negotiation skills, intimacy and SRH care. Engaging and talking about SRH and related issues continue to evolve in different physical and social spaces, emphasising the value of the diversity of location for support and resources for ALHIV.

Keywords: Malawi, clinics, reproductive preparedness, service use, sexual readiness, Sexual and Reproductive Health

*** * ***

7.2 Introduction

"Sacred, profane, protected, open, exposed; private, public spaces, urban and rural places" all affect the everyday lives of people (Foucault, 1984; Foucault & Miskowiec, 1986, p. 22), including adolescents, influencing their health and wellbeing. Place and space may either constrain or facilitate access to the resources individuals need to experience resilience in the context of HIV infection (Izugbara & Undie, 2008; Pols, 2016). Abbott-Chapman and Robertson (2015) describe predominant spaces for adolescents (home, work and school) in which they engage, including private and public spaces (bedrooms and recreational settings) and 'third places' (parks, community, virtual) which enable different kinds of dialogue, creativity, participation and empowerment. Evidence in Malawi and Zambia indicates the value of single-sex settings providing safe spaces for young women to ensure a conducive physical space for mentorship, friendships and easily accessible networks to meet their complex needs (Austrian, 2017; Svanemyr, Amin, Robles, & Greene, 2015). Spaces for adolescents, for any purpose, are not neutral, but in any given society are influenced by lived experiences, power structures, social and institutional relationships, and cultural attitudes. In the context of this article, attitudes towards sexuality and reproduction evolve over time and influence what might be discussed, by and with whom, and where.

We focus on the importance of ‘where’, and debates on the definition, application and conceptualisation of space (Weszkalnys 2004). Some researchers have conceptualised spaces as static and restrictive, leading to the framing of a ‘crisis in the settings’ serving vulnerable populations such as adolescents, women, the elderly, and the queer community (Foucault, 1984; Meer & Müller, 2017). Others have defined space in terms of the physical structure and symbolic representation, both of which constrain service use, delivery including protecting the integrity of those living with HIV (Fielden et al., 2011; WHO, 2018). Accounting for individual and collective participation across settings has the potential for creating multidimensional meanings of place.

We see space as “permeated with social relations” (Lefebvre & Nicholson-Smith, 1991, p. 286), meanings and experiences that are (re) produced by and supported through social relations. At the same time, we use the definition of a place “as space with a purpose, includ(ing) physical spaces, people, programmes and representations” which can be “interpreted, narrated, perceived, felt, understood and imagined” (Abbott-Chapman & Robertson, 2009, p. 421). Places also provide space for experiential learning that is sensitive, stimulating and informative to adolescents living with HIV (ALHIV) (Skovdal & Belton, 2014; Svanemyr et al., 2015). In this article, we focus on ‘spaces and place’ as contested environments in which heterogeneous, multiple and fluid interrelationships are explored (Massey 2005; Abbott-Chapman and Robertson 2015). There is a short description of the specific mechanisms and processes through which spaces shape positive outcomes for vulnerable adolescents, particularly ALHIV (Callahan et al., 2017; Kaunda-Khangamwa, Kapwata, et al., 2020). We discuss how insights into ALHIV experiences of sexual and reproductive health (SRH) matters in different spaces and places can uncover and illuminate broader issues on health and wellbeing.

The provision of ‘safe spaces’ at home can play an important role in addressing inequity and social exclusion, and countering inequalities, stigma and SRH misinformation. (Adegoke & Steyn, 2017; Jones, Pincock, Baird, Yadete, & Hamory Hicks, 2020). However, discussions on sex, reproduction and contraception in people’s homes is not the norm in most African communities,

including in Malawi, and this tends to silence ALHIV due to their fear of censure or increased tension (Adegoke & Steyn 2015, National Statistical et al. 2019). In sub-Saharan Africa, different ethnic groups and settings are strongly influenced by religion, local norms, and values which emphasise that sex belongs within marriage and domestic spaces, subject to rituals and social control to secure reproduction (Boislard et al., 2016; Jones et al., 2020). An exploration of the provision, designation and maintenance of separate or safe spaces within homes support dialogic processes which may be used to inform positive SRH-related matters often overlooked (Feyisetan et al., 2014; Marie, Robles, & Canoy, 2019). We provide an extensive discussion on supports and resources that involve family or home and communities, that enable open and transparent communication about SRH.

Community-based initiatives (community clubs and meetings) afford space for information and support, enabling adolescents to develop accessible communication on reproductive needs, share SRH knowledge, and information on readiness for sex (or its delay) and contraceptive use (Fleischman & Peck, 2015; WHO, 2018). For some adolescents, becoming sexually active is better explained by the notion of readiness than the age of legality or age at first sex (Biney & Dodoo, 2016; Salam et al., 2016). This is pertinent in Malawi because sexual preparedness and parenthood are encouraged at a very early age in some cultures through rites of passage held pre-puberty and around menarche (Makwemba et al., 2019; Munthali & Zulu, 2008). This tends to create ambiguities in relation to ASRH outcomes. Adolescents feel bound by adult expectations and social traditions to place a high value on sexual preparedness by participating in different forms of initiation, having a partner and early motherhood. These values generate barriers to contraceptive use while also conflicting with values promoted by religion and, in contradiction, contemporary public health education. Below, we explore how ALHIV engage in community activities and within community spaces, and how support systems enable adolescents to make 'healthy' choices on sex, reproduction and contraception.

Teen club clinic support under Differentiated Service Delivery (DSD), introduced in 2016 in low and middle-income countries including Malawi, saw policy-level

programmes with dedicated physical spaces visit days and multimonth ART dispensing (Global AIDS Update, 2020; Prust et al., 2018). In Malawi, the clinics are also referred to as Saturday teen club clinics, or as youth or child-friendly spaces or safe spaces (MacKenzie et al., 2017). The spaces provide clinical, psychosocial, and SRH support (Mutambo et al., 2020, MacPherson et al. 2015). The teen club clinic appears useful to support the retention and adherence of ALHIV on ART, but in this article, we move beyond this to consider the capacity of adolescent-caregiver-health worker spaces, retreats and workshops as transformational, enabling ALHIV to do well in relation to various SRH matters (Obrist et al., 2010).

Conceptual Framework

We draw on Bronfenbrenner's socio-ecological model and the multilayered significance of place, settings, relationships and contexts (Bronfenbrenner, 1979, 1986; Kearns & Milligan, 2020). A given place combines physical, social and symbolic spaces, affording "therapeutic or transformative" health outcomes for different people at different times and in different situations (Kearns & Milligan, 2020; Skovdal & Daniel, 2012). Some scholars refer to personal spaces, community-based interventions and institutional support, cultural settings and activities, including rites of passage, as all providing focused physical and social spaces enabling adolescents to access resources to support learning and well-being (Munthali & Zulu, 2008; Thamuku & Daniel, 2012). Most of these spaces are gendered and/closed (male or female only), which leverage individual and group experiences, passive and active, and challenge the power relations in which ALHIV are involved (Jones et al., 2020). We explore these multiple areas -- homes, schools, community activities and teen club clinic -- as enabling spaces that support SRH positive social and health-related outcomes for ALHIV.

7.3 Methods and Data

Study Design

Ethnographic research was conducted from November 2018 to June 2019. We collected data through participant observations of enhanced teen club clinic settings (preparatory and monthly meetings, guardian sessions, workshops and retreats). In-

depth interviews were held with young people and health workers; and focus group discussions (FGDs) with caregivers on exploring with whom, what and how young people discussed sex, intimacy, sexual interests, intimate relationships and service use. The purpose was to understand the dialogic interactive dimensions, consultations and available spaces for adolescents to request and talk about SRH needs and service utilisation. This research conforms to ethics and human research guidelines and was approved by the Human Research Ethics Committee (HREC Medicine) of University of the Witwatersrand (M180465) and the College of Medicine Research and Ethics Committee (COMREC)- (P.04/18/2389) in Malawi. All participants provided written informed consent.

Study Sites

We examined ALHIV aged 15-19 years attending a Umodzi Family Centre (UFC) antiretroviral and teen club clinic at Queen Elizabeth Central Hospital (QECH) in Blantyre, Malawi. The teen club model is an adolescent-centred differentiated care model that appears useful to retain ALHIV and ensure their adherence to ART (Kim et al., 2017; MacKenzie et al., 2017). It brings together male and female adolescents, of any number from 20 to 90, on a Saturday, once every two months. Consultations are provided in an environment that aims to be equitable, accessible, acceptable, appropriate, and effective (Simon, Benevides, Hainsworth, Morgan, & Chau, 2015), and the clinic provides refills, assesses and supports adherence, and provides clinical and laboratory (viral load tests, CD4 count) support. The teen club also provides psychosocial support through workshops and one-to-one counselling on a need's basis, in relation to HIV, adherence, disclosure, stigma and discrimination, puberty, communication, depression, substance abuse, gender-based violence and entrepreneurship. SRH-related topics are delivered in different forms -- lectures, peer discussions, role-plays and group discussions -- to age specific-groups (10-14, 15-17 and 18-24 years), and include discussions of sex, friendship, romantic and sexual relationships, contraception and pregnancy. In addition, semi-formal spaces at workshops, retreats, homes and cultural activities ensure connections among ALHIV, helping them to gain a deeper understanding of the enhanced SRH support for ALHIV.

Study Participants

A total of 54 study participants were interviewed. They included 26 ALHIV aged 15-19 who joined when they were around 8-10 years old; 21 caregivers/guardians identified by adolescents as Persons Most Knowledgeable (PMKs) about their lives and seven health workers involved in delivering teen club clinic programmes. The PMKs were encouraged to share some of the ways that they broached SRH topics and sexual relationships in their homes and at teen club meetings.

Data Collection

Participant Observation

The first author frequented the teen club clinic and observed preparatory meetings on Wednesdays and Saturday meetings, guardian sessions, workshops and retreats. Observation varied from one to eight hours, depending on the sessions, allowing time to form friendships and have deeper conversations, while maintaining extensive field notes on SRH needs and aspirations. During the meetings or sessions, she spent most of her time observing the participants and engaging in conversations related to friendship, romantic matters, partnered behaviors, sexual needs, knowledge, choice and pleasure. Sometimes, she watched male and female adolescents facilitating, presenting on different health and social topics (adherence, career pathways) and particularly on sexual functioning, pleasure and contraception. She served the ALHIV during meal-times and sat with them in the clinic corridors or lawns till the end of the break time, talking about life issues in general. She participated and at times facilitated role plays, where she learnt about sex and pregnancy representations, contraceptive use and future aspirations. As part of ensuring data saturation, in-depth and group interviews were embedded in participant observation.

In-depth Interviews

The first author had been a volunteer at the UFC ART and teen club clinics for four years before commencing her PhD studies (Author 2020). Her role paved the way to identify office space in the grounds of the Centre for Reproductive Health, where she could sit with and interview adolescents without being disturbed. For

interviews, ALHIV identified safe spaces to share their life experiences: these included make-shift office, other offices and seminar/lecture rooms at the clinic, school grounds and their homes. In addition to these interviews, 26 ALHIV booked appointments with and sometimes invited the first author to their homes to further discuss their lives. Seven in-depth interviews were conducted to capture health care workers' perspectives on adolescents' SRH practices and resource supports. Eight parents requested face-to-face sessions, held in secluded spaces at the clinic or during guardian sessions, to discuss SRH matters bothering them and ALHIV. Seminar rooms and lecture halls were used for quantitative data collection and workshops with health workers and parents or guardians. All of them were interviewed during the weekends, particularly on Sundays, a conducive time for working participants.

Focus Group Discussion.

FGDs were conducted with caregivers and health workers on ALHIV experiences about coming of age, sex, protection, and relationships, initiation ceremonies, at church and the clinic. The first author participated in eight SRH group sessions facilitated by health workers and mentors, including fourteen club clinics, three workshops supported by nationally based mentors, and a week-long retreat for the graduation class from pediatric to adult care of ALHIV aged 18-24 at a resort area in the southern region. All sessions began with a preparatory meeting with health workers (a doctor, nurses, clinicians, a pharmacist) and mentors (ALHIV role models). At each hour-long session, ALHIV were given a chance to formulate a scenario related to SRH, lead and coordinate a role play on the importance of staying in school or STIs, or simply ask questions during a health education class.

Nurses and mentors facilitated discussions on family planning methods. ALHIV were organised into groups of about 10, given flip charts and markers, and asked to draw and discuss the types of family planning methods with which they were familiar. Each group was given 15 minutes to discuss and raise questions about this and other SRH issues. The in-depth and group interviews enabled triangulation and afforded a nuanced and richer exploration of SRH related experiences.

Data Analysis

Preliminary analysis to create a codebook occurred concurrently with data collection. Detailed observation notes were taken, and in-depth interviews, focus groups and workshops were recorded, transcribed verbatim and imported into NVivo 11 software for coding. The first author undertook initial thematic coding and the development of sub-themes based on framework analysis (Srivastava & Thomson, 2009); the results were shared with co-authors, health workers and mentors. The broad themes and sub-themes were divided into nine categories covering socio-demographics, SRH talks, knowledge, needs, desires, preparedness, readiness, sexual function and social spaces where ALHIV communicated or experienced SRH related issues. Codes related to the themes were then used to identify recurring themes, linkages and similarities. Workshops with health workers, mentors and caregivers were conducted to assist with iteration and interpretation, which allowed for constant comparison of themes to understand ALHIV experiences.

7.4 Results

Sexual Information Learning and Sharing

ALHIV responses on SRH, knowledge, choices, pleasure, desires and function, and partnered behavior, varied and were affected by age. SRH-related information derived from clinics, school, family and friends. Younger adolescents (aged 15-17) were open to talk about friendships, abstinence and condoms, asking direct questions such as “When is the best time to have sex?”. Older ALHIV (18-19 years) talked freely about health education on sex, partnered sexual behaviors and service use at teen club clinics, and about relatively anonymous spaces (make-shift office, parks); as discussed below, discussion of these issues supported them in making informed decisions about their sexuality and managing relationships. Older ALHIV also discussed issues in private spaces related to sexual desires, sexual function, and marital and reproductive responsibilities.

SRH and Sexual Innocence in the Home

Almost all parents saw their home as a protective place for care and relational support for ALHIV. Physical spaces such as bedrooms, spare rooms, and backyards in their homes provided them with privacy to discuss sensitive topics. Talking about sex and SRH were sensitive topics within homes, and evoked mixed emotions during the interviews. Most caregivers were young people's biological parents, who found it difficult to disclose that they were the source of infection. Yet despite this, parents and health workers claimed that they adopted an 'open door and open communication' rule to talk about sex and prepare adolescents for issues related to SRH.

> When my child comes back from school, he stays at home. I don't see a lot of girls coming to visit him. He is usually with his mother, so the girls do not come to visit him or the other boys. So, I feel like maybe when girls want to come, they think twice to do so, because of me. My son is protected in our home space (FGD, a mixed group of parents).

Caregivers saw their children as sexually innocent and were reluctant to talk to them about sex and condoms. Despite their children attending initiation ceremonies that assumed sexual activity, caregivers considered it desirable for their children to remain sexually innocent, and they encouraged 'virginity' until marriage and 'sexual abstinence'. Parents who were HIV positive felt guilty for infecting their children; this motivated them to talk to their children about the risks associated with early sex. Regular attendance and participation in guardian sessions at the teen club clinic allowed parents and other caregivers to reconcile their guilt and come to terms with what they referred to as 'moral labels' and enabled discussions about sex, contraceptive use, decision making and action. Home was a convenient space for parents to talk with their children, although because of continued stigma and misinformation, not all found it easy to do so:

At the teen club, both male and female adolescents are taught together, and adolescents learn about those things as a group. Still, when we go home, there is not anybody else who is aware of his status, there isn't anyone who might come from somewhere to enlighten the child. It is difficult…to tell my child that I am the

one who infected him. I need him to be careful out there. For me being a parent as well as a guardian, I am supposed to enlighten the child (Mother, 43 years old).

Relational Spaces and SRH

Different settings not only allowed or inhibited SRH related talks. During in-depth interviews (Author, date) in the make-shift office, a relatively neutral and anonymous space, ALHIV aged 15-17 talked freely about visiting each other in their homes, walking in school grounds and spending time alone with the opposite sex, often as friends rather than as intimate partners. Young people tended to refer to 'self-love' and ‘sexual preparedness’ to speak about reaching certain goals in life before engaging in intimate relationships. In FGDs, most participants referred to abstinence and condom use when asked about sex and childbearing. They repeated the same morally laden discourse at home, church and school, with an emphasis on staying safe and ‘remaining sexually pure’ to protect themselves from the negative consequences of early sex and early motherhood. A few reported not being in a relationship or love, and were reluctant to join the discussion; others discussed the value of having a choice to be sexually active or not:

I have personal goals. Others say that they must get educated first. On the other hand, you have five friends and all of them are asking you, why are you still a virgin, this and that? However, with personal goals, you would like to complete your education. I am aware that once you have sex with someone, there is a high risk that you might get pregnant. One might get diseases. In all that, one needs to keep on going, knowing that they have goals. I keep on pushing. I want to achieve. It is just a choice (Simbe, male, 16 years).

Participants aged 18-19 years provided rich accounts in both FGDs and IDIs on sex, desire, protective sexual behaviors, and condom use. Both male and female ALHIV discussed the establishment of intimate relationships from the ages of around 15-17, which evolved from friendship to romantic relationships. Asked to define a ‘romantic’ relationship, most ALHIV referred to intimate behavior that included hugging, kissing, talking and spending time together on the phone, in public and private spaces such as parents’ and friends' homes, boys’ quarters (servants or housemaid quarters), hostels, ‘themed’ parties, hotels, guesthouses and city parks.

Most adolescents did not see much difference between romantic and sexual relationships in private spaces:

P7: Romance involves sex… sometimes … romancing each other like kissing…hugging…sex...

P8: With romance, you might meet at home, or you may go somewhere else… he [boyfriend] might be able to tell you that you must come at home and you may have sex right there… which means that is also romance... (FGD, mixed gender, 18-19. years).

Spaces for negotiation between ALHIV and caregiver, and ALHIV and health worker, were critical components to SRH learning, allowing adolescents to explore whether or not to embark on an intimate relationship, with whom, where to meet, and how to spend time. At home, ALHIV were able to open up and discuss the challenges of beginning intimate relationships because they had learnt the skills to broach the subject during guardian sessions and teen club meetings; they could discuss their expectations with their parents and caregivers, with the latter providing a supportive role. Negotiations for intimate relationships occurred at home, in the botanic gardens, at hotels, friends' houses, and parks, with the support of friends, partners and caregivers.

R3: Maybe the boy might have a friend and that friend of his has a house, and you might be able to go and meet at his friend's house if he stays by himself…

R8: And sometimes for an adolescent to be involved in sex, it is also dependent on peer pressure, for instance, I stay at the hostel… at the hostel, we discuss many things, and we also open up as boys, it might happen when we are interacting in the sitting room (FGD, males, 19 years).

Female and male respondents reacted differently to homes, the teen club clinic, parties, parks, and hotels as sites for intimacy. Young men saw the local parks as cheap, affording them privacy to relax away from the public gaze. Young women, however, were anxious about being in public and spoke of the discomfort of relaxing in bushy spots. For both genders, meeting and having fun in secluded areas of the park (close to trees or bushes), and sitting and talking with one's friends or

partners, allowed them to form intimate relationships. The length of the relationship determined expressions of affection, needs and moments of intimacy, and motivated young couples to discuss the possibility of having sex, to seek HIV testing and use contraception, and to consider childbearing or ending a relationship. On different occasions during interviews, ALHIV demonstrated how intimacy and SRH issues were discussed:

> In my relationships, maybe hugs were allowed… and the kissing part was just by mistake and just because I said that we do have goals… (speaking with confidence) just because I had some goals, that is the reason I excluded sex… I know…firstly because I knew myself and other things like my goals… my likes and dislikes**…** (Sindi, female 17 years).

Talks on sexual health and relationships were highly gendered, with female ALHIV lacking the confidence to discuss condom use, negotiation tactics, and correct and consistent condom use, particularly when they were invited to hotels or guest houses. Male adolescents did not always remember to carry condoms when meeting their girlfriends at private places and expected the young women to be responsible for contraception. ALHIV had comprehensive knowledge about SRH as a result of attending teen club meetings. Although some young women assumed that their partners would make decisions on contraceptive use, others chose not to use contraception so that they can conceive later:

> P4: At first, he might be able to say that you must use a condom, and it's possible…, and the girl might also be able to say that let's use protection and it is also possible for a girl to tell a boy that, "let's have sex". And it is also possible for a boy to say to the girl, let us use protection…
>
> P4: Some boys think it is a bit delaying.
>
> P5: But family planning, maybe for a girl who does not have children it is not good (participants agree)
>
> P6: For one to get pregnant, it becomes very challenging since they started practicing family planning while very young… most of the people adopt family planning methods after having a child… (FGD, mixed gender, 18-19 years)**.**

SRH Matters and Communication in Schools.

ALHIV, parents/caregivers and health workers were ambivalent about the role of schools to provide comprehensive knowledge and skills on SRH related matters. Some ALHIV mentioned the school as the first place at which they learnt about sex, condom use and how to access emergency pills. Others emphasised that school was a 'safe space' that encouraged girls to stay longer in school; that allowed friendship of both genders; promoted peer learning; and nurtured life skills, to ask questions about SRH, and to discuss and negotiate sex, abstinence and contraception:

> P1: I started to learn about sex at a primary school.
>
> P2: Me too also at school…
>
> P3: For me, here at the teen club [clinic]…
>
> P4: Well, if I cannot abstain, I use condoms
>
> P5: I got the information from different books, even those from primary school, it's all there… even social media too (FGD, males, 15-17 years)

Most participants were alluding to the physical spaces and the comprehensive life skills syllabus in primary and secondary schools, which allowed both genders to learn about adolescence, sexuality and enhanced life goals. The challenges they faced around SRH and relationships were highly gendered. Some reported that young pregnant women were expelled from school and isolated at home, leading some to run away and stay alone or with peers who they trusted. Some parents mentioned boys' bad behaviors that led to substance abuse, non-adherence to ART medication, and being expelled from school. Parents and health workers were unanimous that both genders still struggled with being HIV positive, stigma and discrimination in school, and making informed sexual choices.

> P3: I know that it is inevitable that these children will one-day start sleeping around whether I like it or not. The schools are doing their part. That is why I encourage them to collect condoms from the hospital and learn how to use them when that time comes.

> P1: These kids have been sent to boarding school while on treatment for HIV, it becomes challenging for them to continue with their medication because adolescents fear being exposed to their friends. This is one of the challenges children living with HIV are facing in boarding schools.
>
> P6: In my case, my child has been mocked and bullied because of her physical condition in school. This has been a great discouragement in her life and it always demoralises her hardworking spirit (FGD, caregivers, 25-48 years) .

The ease of talks in the SRH sessions with health workers at teen club meetings and guardian sessions contrasted sharply with presentations in schools, as described in some one-to-one in-depth interviews. Some ALHIV could not describe experiences in school because they had left school due to poverty, but they were unhappy that people living with HIV/AIDS were depicted as sickly, thin and sad. Those familiar with school-based sessions, both health workers and ALHIV, bemoaned the 'negative' representations and stigma around HIV:

With the current life skills syllabus in school, primary or secondary. So, what happens is that the adolescents come and ask us questions about what happened, how do the drugs work, and what they should do. So, you find that they have gone to school and they hear contradictory things… 'What do HIV people look like? They develop sores on the skin, they lose weight'. Such statements disturb ALHIV (Semi, mentor, 19 years).

Rites of Passage at Community and Church Meetings

Caregivers and ALHIV mentioned SRH related topics that were included in group discussions and community-based sessions at church and community meetings. These were held in quiet and conducive places for conferences and in retreats in resort areas. Week-long and weekend programmes and retreats were held within communities and at churches during school holidays, with separate spaces for adolescent boys and girls. The sessions and content delivered varied by geographical area and age, as emphasised by adolescents from different regions and denomination (Christian and Muslim). Some of the sessions included mentors selected by community members to lead and facilitate

topics on cultural, social and economic development, sexuality, and parenting roles, potentially providing young people with a space for empowerment.

A few mothers sent their daughters and sons to attend week-long or weekend-based church or community rite-of-passage programmes to learn about "good habits" and receive spiritual guidance. In both community and church-based activities, caregivers appreciated the opportunity for young people to learn and discuss romantic and sexual partners, contraception and spiritual support. Some caregivers did not trust the mentors, however, and considered them to be ill-informed and inexperienced, unable to offer appropriate support and reinforcing stigma, misinformation, and misperceptions of those living positively. Such caregivers counselled their sons and daughters at home on sexual functions and reproductive responsibilities.

Irrespective of age, gender and ethnic background, the sessions revolved around social roles and responsibilities, 'sexual readiness and satisfaction' and 'reproductive preparedness and contraception'. Most female caregivers in Blantyre described traditional initiation ceremonies. These were held in initiation camps outside their home villages in temporary shelters of grass and sticks, set up just for this purpose and then burnt to the ground once the young participants were sent home. ALHIV echoed in group sessions how to enhance sexual function and satisfaction using herbs and other cultural informed practices such as labia elongation and penetrative sex after circumcision. These spaces marked the transition from adolescence to adulthood, while they also enhanced sexual and reproductive preparedness and sexual restraint as a matter of morality.

> P1: Eh… (Sigh) Preparing ourselves is like…, for instance nowadays they say that … our generation, it is meaningless to go to the initiation huts. If someone likes you…they like you. And sometimes you may also hear that, ah…, that [young woman] has been chased in marriage because they did not have this and that [elongated labia] …, and the marriage ended. So, we are under pressure and we start asking parents this and that [preparing ourselves] …, and on the other hand while you are asking your friends to help and they will advise you to attend the initiation ceremony…I think along those lines…(FGD, 18-19 girls)

Most female adolescents and female caregivers in FGDs and IDIs beamed with pride as they talked about initiation ceremonies as occasions to prepare their bodies, and to learn about sexual function and sexual pleasure. Adolescent boys talked of circumcision, seeking the service from a private or mobile clinic, and expected their fathers to support them to learn how to become 'men'. Both female caregivers and ALHIV reiterated that initiation ceremonies were evolving, from strengthening household skills (cooking, cleaning) and good manners, and they included sexual instruction, information about how to please a partner, and labia stretching. However, health workers and male caregivers were vague about the value of these rites to ALHIV or their relevance in negotiating SRH.

> And when they have come of age [from 11 years onwards], they would like to follow traditions and culture, like taking care of themselves so that in the future they are proud beautiful girls and men would be able to desire them. Especially with girls… they say that they would like to meet with older women who might teach them, morals as well as vaginal lubrication and labia stretching **(**FGD, mothers, 35-48 years**).**

We do not prohibit them from circumcision…, because it is their personal choice, we tell them that they might go for circumcision and might go through the process of circumcision. Still, we enlighten them properly that it does not mean that, if they might have sex with a person they might not transmit HIV, and we emphasise on that…**(**FGD, fathers, 38-45 year-olds).

SRH Adolescent-Centred Talks at Teen Club Sessions

During teen club clinic sessions, it became clear that most ALHIV desired to be in relationship with HIV positive peers. The talks centred on the right time to have sex and to discuss the possibility of having a child who was HIV negative when both partners were HIV positive. All ALHIV were open about their status and the challenge this presented to intimate relationships.

> I do not think about relationships, even marriage. I am already sick. I do not believe any man would love to marry dirt [i.e. having HIV] (Gala, female, 17 years).

> I know myself, I am living with HIV, and when I visit my girlfriend, I do not wish her to get pregnant. I love her. I do not wish to have a child now (Viwe, male, 18 years old).

The family planning methods they identified included pills, Norplant, condoms, the loop (IUD), injections, emergency pills and withdrawal. Following the presentations, discussions included the feasibility of withdrawing, misconceptions about family planning, and the use of *gondolosi* (aphrodisiacs). Young men discussed the challenges of spontaneous erections and questions of masturbation after circumcision; young women sought more information on emergency pills, side effects of family planning, and whether Norplant was less effective if one was on a particular antiretroviral regimen. Almost all older ALHIV agreed that not using contraception was the main strategy to become pregnant. Concerns that contraception would lead to infertility indicated an information gap related to family planning methods, questions about this and other SRH issues as presented in flip charts drawn during a workshop. (Figure 7.1 above).

In feedback sessions, almost all ALHIV expressed their concern about pregnancy and STIs as conspicuous outcomes of having sex. Some young people were especially uncomfortable in sessions on STIs and circumcision and expressed disgust at clinical pictures of genital warts, gonorrhoea and syphilis. Only 20/1134 (2%) adolescents had accessed STI care at the teen club clinic. A few boys took advantage of the free condoms available in the male washrooms, but there were stock-outs and some complained that the condoms were not user-friendly – they were "rough, irritating and made them feel uncomfortable." Girls complained about rebuke from some nurses when they raised questions about Norplant or when pregnancy was confirmed.

7.5 Discussion

ALHIV accounts of sexuality, reproduction and service use indicate that not all adolescents were sexually experienced, although some wished to become and others were romantically involved and/or sexually active. Using a socio-ecological and strength-based perspective, such as building resilience on ASRH-related issues, the teen club clinic and other settings combined to provide ALHIV with dedicated

spaces to discuss their health and wellbeing. A fluid understanding of spaces and place guided our analysis to focus on the transformative potential and negotiation of power that impacted on sexual, reproduction and contraception experiences for ALHIV.

ALHIV experiences in their homes, community and institutional spaces help us understand how they dialogically engage with sexual (function, pleasure, protection) and reproductive aspirations and needs. The involvement of health workers, caregivers and parents addressed not only their protective roles but also broader social and health matters that are rarely incorporated in ASRH. Our data provides novel insights of spaces and places affecting discussions of healthy sexual behaviors among ALHIV in Malawi (Kaunda-Khangamwa, Kapwata, et al., 2020). ALHIV reflections on SRH at an individual level highlight their struggles in and outside of relationships including future goals.

Most ALHIV in a romantic or sexual relationship with a partner were appreciative of the comfort, familiarity and support of having a potential partner attending the teen club clinic. This was so because there was no need to explain their status and whether or not to broach topics on HIV testing, viral load testing, or the need to have safe sex. The teen club clinic spaces, in particular, were confirmed as convenient, protective and supportive of equitable relationships, but there was also evidence of continued stigma and discrimination disadvantaging ALHIV in many spheres of their lives (Moyer, 2015; Moyer & Hardon, 2014; Toska, Pantelic, Meinck, & Keck, 2017).

Young people raised questions about having children born without HIV and the specifics and procedures to follow for babies to be born negative; they were eager to learn about and were prepared to address issues associated with sex, contraception and pregnancy. Harden and colleagues argue that romantic connections encourage open sexual communication, leading to contraception use and minimising anxieties about pregnancy (Harden, 2014; Hensel & Fortenberry, 2013). ALHIV had the confidence to link individual, social and medical conversations to make responsible sexual and reproductive decisions. Hence breaching the culture of silence enhanced resilience (Skovdal et al. 2012).

There are disparities in ALHIV disclosures on meeting to have sex, the responsibility to access contraception, their ability to refuse to have sex, and sexual pleasure; these have been noted elsewhere in sub-Saharan Africa and the northern hemisphere (Hensel et al., 2016; Izugbara & Undie, 2008; Saliares, Wilkerson, Sieving, & Brady, 2017; Toska, Pantelic, Meinck, & Keck, 2017). As noted, ALHIV in our study utilised secluded public and private spaces for 'romantic moments' and to have sex away from the adult gaze. This contrasts with most studies, in which adolescent girls are characterised as visiting hotels, inns and motels for prostitution or transactional sex for family survival(Jimmy-Gama, 2009; Krisch, Averdijk, Valdebenito, & Eisner, 2019; Munthali et al., 2004; Nash et al., 2019), and to a lesser extent, the sexual vulnerability also of boys. Izugbara and Undie(2008) , for instance, centred on boys' use of various spaces (home, the bush, classroom, roadside, and hotel room) for sex. In our study, ALHIV associated these spaces with sexual subjectivity (defined as feelings of sexual self-efficacy, pleasure, body esteem and sexual self-reflection) (Boislard et al., 2016, p. 2), including negotiated contraception and condom use. Teen clubs sharpened their skills in self-regulation and communication to handle their relationships (Hensel et al., 2016).

Also inconsistent with most studies, Kok and colleagues (2018) and Russell an colleagues (2018) on the role of relationships in SRH, in our study social relations with peers, partners, caregivers and health workers were productive with regard to ALHIV capacity to handle relationships and make informed choices. The relational support of ALHIV with caregivers, health workers, teachers and mentors created an 'embodied space of care' (Narushima et al., 2020; Woodgate, Zurba, Edwards, Ripat, & Rempel, 2017). Caregivers participated in guardian sessions and accessed alternative sources of support to health care workers, such as teachers, community and religious elders and mentors for comprehensive SRH support. Caregivers supported adolescents to build self-esteem by showing 'self-love', being assertive, introducing their partners to mentors, and sharing their academic and entrepreneurial aspirations.

Parents, caregivers and community members wanted to maintain an active role in supporting ALHIV sexuality. As parents are nominated in the surveillance and

support of adolescents' sexuality, most of them are not happy with early pregnancies. Most parents viewed ALHIV as simultaneously sexual (an adult function) and innocent, ignorant, (i.e., child-like) which caused ambiguity in SRH related dialogues across homes, schools, and clinics. For instance, health workers, parents or caregivers and mentors could speak of 'importance of sex' and simultaneously refer to the morals and dangers of early sex. Others encouraged romantic ideas but were quick to talk about STI's and early pregnancy. Hence, not all parents, guardians or peers enabled positive ALHIV discourses on sex and sexuality (Fielden et al., 2011; Kaunda-Khangamwa, Kapwata, et al., 2020; Mwalabu et al., 2017).

Some caregivers showed mixed reactions to open communication about and access to contraceptive use, sexual function and pleasure, often related to guilt and embarrassment because they were the source of HIV infection. Caregivers were often encouraging their adolescent to delay in initiating sex or the use of condoms to promote safer sexual decision making. Parents feared re-infection, and their children's readiness for and complications of parenthood, consistent with the literature that uses rights-based and utilitarian approaches to SRH matters(Limaye et al., 2012; Villa-Torres & Svanemyr, 2015). Other parents emphasised the need for ALHIV to finish school, take up a professional career or business initiative as a foundation for 'doing well,' before early sex or pregnancy. Previous studies show the potential of multilayered, complex and sometimes contested spaces in ASRH matters (Birungi, Obare, et al., 2009; Svanemyr et al., 2015); we echo the value of support to ALHIV for comprehensive SRH and future aspirations from multiple settings.

The dialogic spaces not only engaged ALHIV, caregivers and health workers but nurtured, strengthened and supported open communication for both genders. Guardian sessions and workshops were platforms to enhance knowledge sharing and gave participants the confidence to discuss sexual matters with adolescents in their homes. SRH topics were included in the school syllabus. However, as we have shown, these focused on puberty, pregnancy, birth control and STIs and stereotyped people with HIV as "sickly, unhappy, having lost weight or continuously

coughing." In contrast with other studies on relational support (Callahan et al., 2017; Zgambo et al., 2018), most parents, caregivers and ALHIV spoke of living positively, accounting for 'sexual readiness' – the ability to express needs, desires, knowledge on sexuality and reproductive preparedness, the need have a child or not, choices available, and preparations made.

Community-based activities at churches and in traditional ceremonies suggest the value of including culturally meaningful ways for ALHIV to engage with different persons in different spaces for sexual and reproduction education. Most parents talked to their adolescents first and then referred them to community-based initiation ceremonies and churches to learn about gender norms, SRH education, spiritual and emotional support. Role models and mentors are chosen by the community or church councils facilitated the activities. While some studies in Malawi have reported ambivalence regarding the role of rites of passages in promoting sex rather than abstinence for both boys and girls (Feyisetan et al., 2014; Munthali & Zulu, 2008). In the current research, initiation ceremonies nurtured ALHIV cultural pride, strengthened their preparedness for sex and parenthood, and contributed to their self-esteem and ultimately, resilience. Others mentioned alternative rites of passage facilitated through churches for health promotion to ensure multiple enabling spaces for ALHIV to affirm their connectedness, normalcy and sexuality as they transitioned from adolescence to adulthood (Makwemba et al., 2019; Panter-Brick, 2014; WHO, 2018).

Institutions with which ALHIV were involved have transformed the way families, communities and health workers talk and engage with comprehensive SRH support programmes. Policy-supported services using the DSD through specialised clinics facilitate adolescents' functional outcome such as improved self-esteem and agency, allowing ALHIV to reflect on their lives, access to contraception, conceiving or not, and refusing sex if they wish. This is consistent with most DREAMS studies that emphasise the provision of 'safe spaces and services supports' for adolescents' holistic wellbeing (Fleischman & Peck, WHO 2018). Participatory spaces were created where ALHIV were able to express themselves on an individual basis and in groups. Retreats, workshops and clinic programmes

function to empower these adolescents who are vulnerable because of their ALHIV status (Kaunda-Khangamwa, Kapwata, et al., 2020; Thamuku & Daniel, 2013).

Feedback sessions demonstrate that the teen club clinic space was important as a source of SRH related information, raising awareness of positive concepts of sexual health, empowerment and satisfaction. The teen club clinic addressed inequality (by continuing to give free access to SRH, HIV care and treatment services) and social exclusion (by providing food and transport reimbursement) through policy-led programmes. It is protective for adolescents' health and developmental outcomes such as safer sex behaviours delayed sexual debut, and the use of contraception.

7.6 Strengths and Limitations

In addition to working with ALHIV, health workers and caregivers/parents, we ensured an ethnically diverse target population to enrich study findings. SRH issues among ALHIV are sensitive, and respondents may have felt obliged to adjust their views, but we tried to encourage ALHIV to be comfortable and speak freely. Confidentiality would not be possible during group discussions (since participants would see each other), but pseudonyms were used in the write-ups.

Our study involved a purposively selected sample of ALHIV aged 15-19, attending ART and teen club clinic, possibly ensuring that they were comfortable to talk about SRH matters. Age of participants might have influenced recall of behaviours, understanding of what was being asked (e.g., how do you understand romantic love?), and influenced responses when reminded of abusive moments (being raped). The first author allowed ALHIV to express themselves and account for their experiences in comfortable spaces. Most accounts on abusive relationships were referred to nurses for support. We did not include quantitative levels of sexual and reproductive service use outcomes (e.g., number those who ever had sex, adolescents using STI care, FP, ever been pregnant) because they are presented elsewhere.

7.7 Conclusion

Support from varied spaces is additive, with each space adding to opportunities provided elsewhere to support ALHIV to make informed choices regarding SRH.

ALHIV in this study had access to multiple enabling learning spaces and persons to support their health and wellbeing. ALHIV, caregivers and health workers-initiated conversations on sex, sexual pleasure, function, friendship and contraception, and spoke candidly and asked questions that enhanced their overall dialogical engagement.

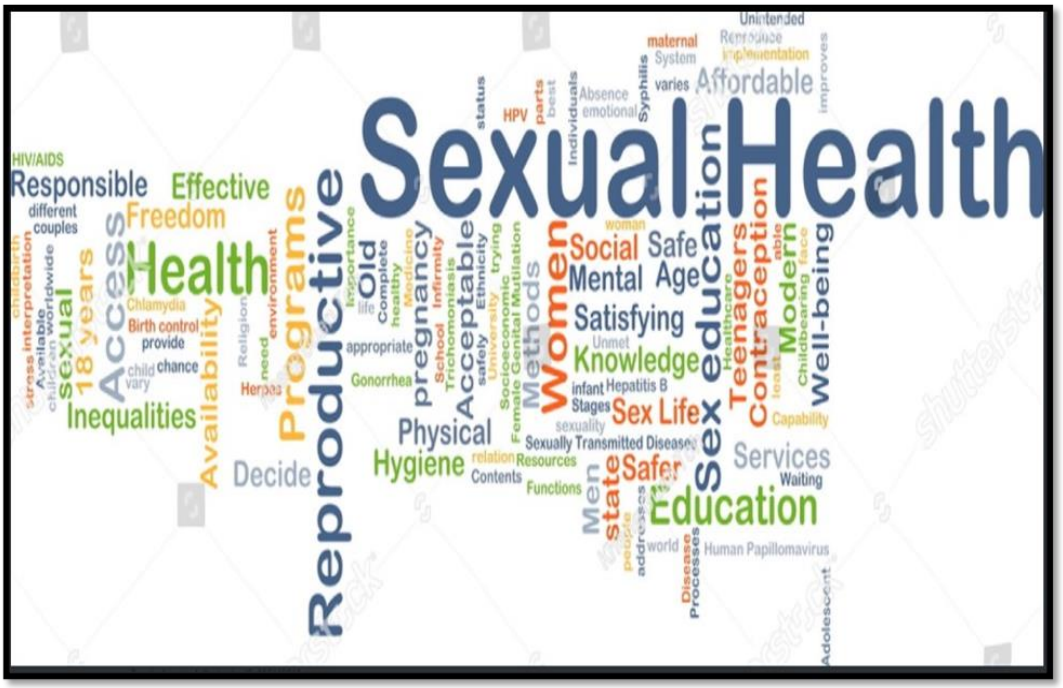
Reflecting on a holistic definition of sexual health and multidimensional framework shows how SRH can include positive or functional outcomes such as increased confidence. As ALHIV mature, they are able to talk not only about friendship but ask questions about sexual pleasure and function. The teen club clinic supported open communication on SRH matters. Harnessing the strengths and competencies of ALHIV advances our understanding of SRH processes as multidimensional, age-dependent, interconnected and continuous. How young people use distinct spaces will potentially have quite different effects on specific outcomes across stages of adolescence.

SECTION C

CHAPTER EIGHT

A SYNTHESIS OF EVIDENCE

8.0 Introduction



In this chapter, I present a synthesis of my research, drawing on previous scholarship and conceptual and theoretical frameworks to illuminate the implications, limitations and conclusions of the study. I draw on the findings of articles I-V conducted as part of this doctorate to contribute to the scope of ASRH, resilience and HIV research.

As a volunteer for almost six years at the teen club clinic, I wondered how ALHIV strived to do well despite living with a chronic condition and taking medication daily. Most of the ALHIV were introduced at the club when they were about eight years, and they continued to attend the club in all seasons and complained when there was no funding as it curbed their meetings and support from friends, mentors and health workers. Having questions towards ALHIV wellbeing provided me with

an opportunity to engage with ALHIV and attend a teen club clinic, in order to explore their resilience and service use guided by the following objectives:

- Determine factors associated with resilience among ALHIV
- Describe and analyse adolescents' resilience-promoting resources among ALHIV
- Describe and analyse formal and informal pathways of adolescent service use that promote positive outcomes
- Explore SRH ecologies that influence resilience among ALHIV

The overall aim was to describe and analyse 'protective factors' and 'resources' that influence SRH service utilisation among ALHIV in Malawi. Chapter one gave the background to and located the study in an institutional context, in relation to adolescents' development and in a policy arena. The second chapter, situated SRH, policy challenges, and research gaps within the broader context of resilience studies, service use and sexuality. The socio-ecological conceptual and three theoretical frameworks (resilience, constructive and interpretive and system theories) were employed to further research understanding and exploration. Chapter three emphasised the potential of working with adolescents to validate research tools and use mixed methods to provide a broad scope of tools and participatory techniques. Data and theoretical triangulation emerged as a strength of the study. My own multiple roles and reflexivity on the research process are made more transparent in Paper I in the same chapter. Chapter four contains the first mixed-method study measuring resilience for ALHIV in Malawi. The validation of CYRM-28 shows a factorial model that challenges individual and ecological perspectives of resilience as dimensions on peer support and education show low loadings (Paper II).

In Chapter five, I employ structural equation modelling (SEM) (Paper III, under review) and offer unique insights on the complex networks of correlates and factors that influence resilience, service use frequency and satisfaction. The findings underscore the potential of institutional factors and processes and policy-enabling environments in ensuring positive developments among ALHIV. Prioritising the ART and teen-club clinic is not unexpected, given the direct relevance for ALHIV centred care and belongingness. Teen-club clinic, parental and guardian support has evolved through patient-centred care, giving multiple and unique contributions to

ALHIV. The case study and ethnographic approaches (Chapters six and seven) respectively widen and deepen our analysis on positive SRH related experiences. These include increased knowledge, better interpersonal communication and presentation skills, reproductive preparedness, sexual negotiation skills, function, pleasure, readiness and self-worth) among ALHIV. In addition, paper IV on complex needs and resilience demonstrated that silence or solitude and secretiveness, as part of daily life, play a constructive role in adolescents' lives. Paying closer attention to ALHIV accounts also captured unique insights on how they employ strategic relationships and silence (Kaunda-Khangamwa, Kapwata, et al., 2020) as protective factors. It enabled young people to embrace complexities related to SRH, including the ability to influence events and maintain some control over their lives. In Chapter seven, Paper V, I illustrate the transformative role of varied spaces and places that support ALHIV to have a voice and make informed decisions over time. I show the fluidity of care and support through institutional alternatives and care networks beyond the families enhance resilience and service use. Rites of passage were reframed as supporting informed choices about abstinence and contraception use. This final paper focused on spaces involved in reframing of sexuality and responsibilities that arise in ALHIV sexual and reproductive lives as they try to improve their well-being.

I turn now to a summary of the literature to elaborate on how deficit-based research and strength-based approaches are read. I reference the manuscript findings and build upon them with the broader literature on resilience, SRH and HIV, and the adapted ecological framework. The focus is on how they speak to complex issues of ALHIV as aligned with research objectives to provide a more critical, nuanced and in-depth presentation of findings.

In this discussion, chapters eight and nine, I acknowledge the dominant discourses around SRH and HIV, and address the ability of adolescents to protect themselves. ALHIV can be categorised as at risk, experiencing pain, suffering, and stigma. These characterisations inform the strength-based approaches that are critical for understanding underlying foundations of resilience for ALHIV (Ford et al., 2019; Gittings et al., 2016). The predominance of ‘medicalised or moralised’ framings

affect the social, mental, health and well-being of most ALHIV. However, a reductionist approach alone heightens constraining discourses and inhibits strategies for empowerment and strategies for action. Despite the acknowledged limitations, the interplay between risk-reductionist approaches and protective elements is useful to account for the strength-based perspectives for ALHIV (ALHIV (Bhana, 2015, 2018; Panter-brick, 2015). The strength-based approach is equally important, and central to this thesis, and ensures resilience and SRH are understood as complex, multidimensional, meaningful with differential functional outcomes for ALHIV. The emphasis is on how ALHIV strive to do well despite adversity as individuals, in relationship or accessing institutional care or not. These are deemed essential to address young people's realities (Bhana et al., 2016; Hensel, Nance, & Fortenberry, 2016; WHO, 2017).

Malawian researchers, like their international counterparts on ALHIV's sexual and reproductive health and lives, have focused on adherence and retention in care at teen club clinics (MacKenzie et al. 2017, Kim et al., 2015, 2017, Self et al. 2018), and the negative consequences of sexuality and childbearing as influenced by HIV. This approach is problematic (Toska et al. 2017, Elshun-Wilson 2019, Callahan et al. 2017), despite that policy-led programmes and 'safe spaces' at home, schools, and teen club clinics have proved to be protective for ALHIV and to address inequality and social exclusion (Kaunda-Khangamwa, 2020; Mutambo et al., 2019; Self et al., 2018). ALHIV experience overlapping and contradictory SRH-related expectations in Malawi; boys are characterised as "invulnerable, with hegemonic masculinity" (Jewkes et al., 2015; Undie et al., 2007) or vulnerable, delicate and fragile, in need of constant protection (Izugbara & Undie, 2008; Mwalabu et al., 2017), or troubled and violent. Girls are vulnerable (Toska et al. 2017; Saul et al. 2018) and expected to be chaste and pure (Bhana 2015). Different spaces or places may be viewed either as physical dimensions, or structured as homes (Mwalabu et al., 2017; Sattler & Font, 2016), clinics (Kim et al., 2017; MacKenzie et al., 2017), schools (Toska et al., 2019; Toska, Pantelic, Meinck, & Keck, 2017; Uhuru et al., 2017) and communities (Henley, 2010; Macdonald et al., 2017). However. their characterisation as unchanging has been problematised to show ALHIV negotiating

and navigating multilevel, changing and contradictory experiences for their health and wellbeing.

8.1 Methodological Innovation

The adoption of mixed-methods in this dissertation research, as reported in the papers, has illustrated the potential to use many different, especially participatory methods, as part of data triangulation This is a particular strength. Involving an advisory panel and adolescents in research and positioning them to inform the adaptation and validation of the instruments recognised their views and ensured their voices were heard (Kaunda-Khangamwa, Maposa, et al., 2020). The multi-methods approach reflected mixed outcomes on ALHIV utilisation of SRH service, across gender and school levels. Adding visual methods such as ecomaps generated service use data and showcased ALHIV as an expert in accessing resources and support over time. I draw on spaces and places, highlighting the 'visible' and 'invisible' in public and private spaces through presentations and activities (group work, role plays, counselling sessions, in-depth interviews) which are key for ASRH experiential learning and experience. Meaningfully engaging active, informed ALHIV peer research allows insight into potential pathways to do well despite adversity (UNAIDS 2016, WHO 2017, 2018) which might not be apparent through other methods. Overall, the multi-methods approach helped to strengthen my contribution to ethnographies on ARV/ART clinics and AIDS treatment centres in sub-Saharan Africa and elsewhere (Nguyen 2010, Biehl 2009, Moyer & Hardon 2014, Hardon & Moyer 2014).

Given the social and ethical positioning of ALHIV, the call is to employ a bottom-up approach to allow peers to engage in data collection for a better representation of adolescents' experiences and perspectives (UNAIDS 2016). The emphasis on employing peer researchers, while appearing to represent ALHIV voices, is not necessarily advantageous. ALHIV might not wish to talk about sensitive issues or chronic illness to peers, and this makes the involvement of older researchers inevitable for study implementation. The hope is that older researchers are able to establish an atmosphere of confidence, play close attention to rapport building for

adolescents to open up, are accommodative, and committed to upholding ethical care (Folayan et al., 2014; Hodes et al., 2018).

8.2 Resilience, Measures and ALHIV

This is the first study to measure resilience among ALHIV attending ART and teen-club clinics in Malawi. The study affirms their unique components (personal and social skills, parent/caregivers support, spiritual and cultural resources) and three-factor structure of the CYRM-28 in resource-constrained countries. The median resilience score for ALHIV was 123, with an interquartile range of 110-130. Minimum and maximum scores were 53 and 140 (Kaunda-Khangamwa, Maposa et al. (2020). It is also evident from my quantitative findings that personal and social skills, caregivers' psychological support and contextual issues such as culture and spiritual support were protective factors, accounting for resilience for ALHIV. Dimensions on peer support and education showed low loadings. The validation of CYRM-28 confirms a factorial model that challenges the individual and ecological perspective of resilience.

The quantitative findings were supported by qualitative data (case studies and ethnographic approaches) in factors promoting resilience. Young people referred to multiple factors ranging from having the autonomy to decide on the time to take medication, attend the clinic or not, clinical outcomes such as having a suppressed viral load, positive self-perceptions, i.e., 'self-love' or self-worth, 'being in school' or running a business, as well as having a partner and childbearing aspirations (Chapters six, seven, eight and nine). Reflecting on the socio-ecological six-level tiers (Figure 2. 1 and 2. 2) for the support of ALHIV, and their interaction with each other, health workers, and parents/caregivers, provide ways to understand variations in individual and group perceptions of resilience. ALHIV mentioned that they felt a strong sense of belonging within the teen-club clinic groups through peer support activities and valued the opportunities to share similar needs and experiences (mentorship, affective/sexual relationships and aspirations for children born without HIV) which contributed to feelings of social inclusion.

Paradoxically, in contrast with most local and international studies, the contribution of peers and school support on resilience were challenged throughout this research study (Bernays et al., 2017; Fleischman & Peck, 2017; Mwale & Muula, 2017, 2018; US President's Emergency Plan for AIDS Relief (PEPFAR), 2017). Most ALHIV refused to be open about their lives to peers outside the teen-club clinic, at home, and in the community for fear of stigma and discrimination. Others bemoaned the negative representation in school curricular. Strategic focus through structural interventions under school support or educational scholarships to cater for skills and competency, address gender disparities and reduce HIV incidence and outcomes. However, these interventions among adolescent girls and young women (AGYW) aged 15-24 do not necessarily result in positive promotion for health for ALHIV. There may be limitations of resources and protective factors, but this is not uncommon. This warrants an exploration of the role of the educational system in enhancing resilience for ALHIV.

A growing body of evidence suggests a blend of factors, multiple and fluid in nature, to have a positive impact for ALHIV (Skovdal et al. 2014, van Breda et al. 2018). In Chapter four, six, seven and eight, I have argued that the interactions of 'protective' factors or dimensions are fluid, and this illustrates the uniqueness of the interplay between individual and contextual elements that inform resilience over time (Kaunda-Khangamwa, Maphosa et al. 2020, Kaunda-Khangamwa, Kapwata et. al. 2020, Kaunda-Khangamwa, 2020a, Skovdal et al. 2014, Eshun-Wilson et al. 2019). I acknowledge other scholars' observations(Dulin et al., 2019; Liebenberg et al., 2017; Panter-Brick, 2015; van Breda, 2018), that not only link resilience with 'good health or social functioning,' but also relate individual/personal dimensions, policy-led teen club clinic programmes and cultural-salient processes and experiences to account for resilience among ALHIV.

8.3 Service Usage

The role of social and institutional resources for ALHIV was emphasised in my findings, reflected by their satisfaction (97%) with the service support provided through the teen-club clinic (Paper III). As alluded to earlier, in chapter five, about 70% of ALHIV were multiple service users of clinics, community teen-clubs,

schools and YFHS. This paved the way for me to understand transitional periods and processes that might have promoted ALHIV 'to do well' or impede positive outcomes (Kaunda-Khangamwa et al. 2020, under review, Chapter Five). ALHIV had low utilisation of STI, family planning and contraceptive use and failed to confirm SRH service use and associations among 15-19-year-olds (see Figure 4. 1, 4. 2 and 4. 3; and Table 4. 2). This implies that although the Teen Club Clinic provided a one-stop shop for ALHIV to access SRH services, the conducive environment alone is insufficient to promote FP and STI care and gynaecology support. However, by virtue of accessing multiple services, ALHIV might be receiving SRH support through community clubs or YFHS. This is well depicted in Timve's and Chiletso's ecomaps (Figures 6. 1 and 6. 2), which illustrate that they access SRH from private health providers (Kaunda-Khangamwa, Kapwata et al. 2020).

Most of the significant associations in this study were not anticipated and are important to repeat here. Young men and all out-of-school youth reported greater service utilisation than young women and young people still in school (see Table 5. 5) or (Kaunda-Khangamwa, Maphosa et al. (2020). ALHIV who were out of school were most likely to use services, and this reflected their autonomy. It also meant that they had increased contact with health services (see Table 5. 3), contrasting with most research with adolescents living in poor resource settings, with limited access to integrated to services and community support (Archary, Pettifor, & Toska, 2020; Chandra-Mouli, Svanemyr, et al., 2015; Kanyangarara et al., 2019; Saul et al., 2018). My study also showed moderate correlations on risk and service use and significant effects for resilience on service use, service satisfaction and service frequency. Although it is difficult to establish that ALHIV using health services have high resilience, the median resilience score for ALHIV was 123, with an interquartile range of 110-130. Minimum and maximum scores were 53 and 140, reported to ensure that the findings were not disproportionately represented.

ALHIV, health workers and parents/caregivers unanimously agreed that health services, particularly the Teen Club Clinic, are central to adolescents' lives and foster resilience. Multiple response analysis from ALHIV, health workers and

parents/caregivers affirmed that the ART clinic, teen club clinics, community teen-clubs, school and youth-friendly services were common services frequently accessed by ALHIV. Specifically, the adolescent-centredness approach, which entails age-appropriate care, participation, inclusion, youth-friendly and collaborative practice, satisfied not only ALHIV but PMKs.

8.4 Enhanced Teen Club Clinic

The outer tiers of the ecological framework represented the institutional (school, teen-club clinic, churches) and policy resource supports (adolescent centred care and interventions) which facilitated ALHIV to question or 'reflect and choose' those spaces that satisfied them and enabled them to transform their lives by giving them a chance to voice their SRH needs and care (Papers III and V). Within the varied institutional resources, knowledge of HIV status, linkage to care, information about sexual function and support to make choices were shared with peers, partners, parents and health care workers (Papers III and V). This allowed service providers to acknowledge ALHIV aspirations, active engagement and participation holistically.

The adolescent-centredness transformed care and support for ALHIV by ensuring that they had consistent information and were able to share decision-making in consultation with a dedicated team of health workers and mentors. The club engaged with ALHIV, parents and caregivers unique needs to facilitate tailor-made discussion of social and health-related topics as well as treatment and psychosocial support as part of ensuring universal health access (WHO 2017, Kok et al. 2018, Grimsrud et al. 2017, 2020, Kaunda-Khangamwa, 2020a, Kaunda-Khangamwa, Maphosa et al. 2020). The teen club also provided psychosocial care, educational support, and basic technology and basic entrepreneurship skills (planning, finance and business management sessions, basic computer skills) as programmes for enhanced skills and service provision.

As illustrated in Papers I, IV and V, ALHIV monthly meetings, workshops, and retreats improved their self-reported knowledge, self-worth, openness, sense of belonging and inclusion of age-appropriate SRH services and support. For instance,

health workers and mentors were open to work with adolescents and talk with them about sensitive topics; in turn, ALHIV were given chances to facilitate or make group presentations on HIV care, adherence, role modelling, dreams and aspirations, or career paths, which contributed to their satisfaction and the popularity of the teen club clinic activities. From a constructionist interpretive perspective, the clinic provided space to support ALHIV to have a voice, and enabled discursive equality (in participatory meetings, workshops) and unrestricted options, not only for resources or service provision but also to support their choice of non-coital or coital relationships, and to achieve an improved livelihood by adhering to medication.

Despite the clinic making allowances for ALHIV to actively take part and influence their healthcare and decisions related to SRH, even when 'youth-friendly' services were adjusted to meet all the preferences of a heterogeneous group of adolescents, still, few ALHIV make use of the SRH services (Chapter four). The descriptive analysis showed a variation on SRH-related services use under the teen-club clinic: (family planning 4%, STI 32%, emergency pills and specialist gynaecological care 1%, and maternity care 14% (Chapter four and five). As alluded to earlier ALHIV service use records under the clinic show ambivalent regard for SRH methods. Hence, no statistical correlation was established between SRH service use and resilience. As discussed above in Papers II and III, ALHIV as multiple service users might be accessing SRH from other service providers. Another possible explanation of low use of family planning, STI care and contraception might be poor documentation at clinic level as some boys reported collecting condoms from public toilets at the clinic and this was not documented (Paper III). Similarly, the monitoring and evaluation team confirmed poor documentation of family planning data due to challenges in using the EMR over the years (Paper II). On the other hand, ALHIV might be seeking sex that is ‘natural or uninterrupted’ because conception and sexual pleasure are prioritised over both contraceptive and infection risk reduction (Ford et al., 2019; Macleod, 2003). Hence, a broader approach to investigate SRH service use within the private and public health facilities is needed.

The notion of resilience illuminated ALHIV as young people negotiating SRH matters. In in-depth and group interviews, ALHIV explained that they found SRH related talks challenging but were able to present them and discuss in-depth at teen club workshops and retreats (Paper V, Chapter Seven). These included 1) requesting and attending sessions to understand how ALHIV can give birth to children without HIV, 2) voicing fears of using Norplant, 3) issues related to sexual responsibility and functioning while being on ART, and 4) health workers refusing to prescribe contraception. Positive accounts of males accessing condoms at the clinic and females having the Norplant inserted or requesting injectable contraception shows there is space for more SRH services provision. Monthly meetings, workshops and the social networks meetings are safe discursive arenas for continuous friendship and monthly consultations for ALHIV, health workers and caregivers. However, the service delivery system under the patient-centred model of care has the potential to become a risk factor which can increase negative outcomes to ALHIV, mainly when the frequency of accessing clinical care or ART refills is allocated only once every four or six months. Taken together, the teen club clinic as a 'one-stop-shop' has the capability to revolutionise SRH discourses, sex-positive dialogues, improved attitude towards and access to contraception, and to crystallise childbearing aspirations.

In comparison to the broader literature on health service use or the teen club clinic, there is a great contrast as patterns of service have focused on barriers to accessing and utilising services for both ALHIV and without HIV such as age restrictions and lack of privacy (Chandra-Mouli, 2015; Eshun-Wilson et al. 2019, Self et al. 2020). In addition, substance abuse, inconsistent condom use, lack of confidentiality, and fear of providers' attitudes (Callahan et al., 2017; Das, Salam, Arshad, Finkelstein, & Bhutta, 2016; Zgambo et al., 2018), foreground the risks experienced by adolescents. In addition, Ungar and colleagues(Ungar et al., 2013) noted that it was not merely the presence of services that enabled adolescents to manage social, physical or mental related adversities; it was the satisfaction with services, the quality of interactions, forms of support system, and the meanings they attached to these services that attract adolescents to utilise them.

Incorporating SRH related dialogues in clinic meetings and workshops encouraged ALHIV to open up and contribute their fears related to sexuality such as sexual function and pleasure, hence contributing to adolescent sexual repertoires (Papers III and V). Most ALHIV valued the idea of having a child as part of confirming their femininity or maleness within the community; however, few respondents actively intended to conceive or stringently avoided pregnancy which might explain the low use of contraception over time (Chapter Four). The affinity for having children for ALHIV is common in Malawi and sub-Saharan Africa as part of a potential pathway for doing well or attaining adulthood or motherhood (Birungi, Mugisha, et al., 2009; Callahan et al., 2017; Hodes et al., 2018; Kaunda-Khangamwa, Kapwata, et al., 2020; Macleod, 2003; Mkhwanazi, 2006). The teen club clinic is a good example that shows the fluidity of care and support through institutional alternatives and care networks beyond the families to enhance resilience and service use (Feyisetan et al., 2014; Macdonald et al., 2017; Manderson, Block, & Mkhwanazi, 2016; Reif et al., 2018). With the adoption of adolescent-centred care, a more holistic view of resource supports in the context of ASRH has emerged in the teen club clinic.

8.5 Resources and Supports: Socio-ecological supports

8.5.1 The Individual ALHIV

Asking about living with HIV elicited mixed reactions among ALHIV, who continued to mention access to protective factors and resources across the socio-ecological tiers/layers. At the individual level, ALHIV mentioned taking medication on time, eating well to maintain good health, a good viral load, and strategic silence as part of self-care/self-worth and autonomy (taking care of one's needs without others, living alone, running a business and having goals). The second and third tiers of the ecological model focus on the relational level, and in this context ALHIV mentioned having strategic relationships with parents/caregiver and health workers. The church, business ventures and institutional support were commonly mentioned at the community level, and these continue to evolve as gatekeepers for enhancing informed choices and decision making and ensuring adequate material and care resources for ALHIV (Kaunda-Khangamwa,2020a,

Kaunda-Khangamwa, Kapwata et al. 2020). Employing businesses or income-generating activities, which for ALHIV involved in cross-border trading, opening a hair salon, using trade skills like fixing electrical appliances/ carpentry at home, or participating in household productive activities, were protective factors for the ALHIV (Chapter six and eight) as this enhanced their autonomy, identities and improved their income and well-being (Liborio and Ungar 2009, Skovidal et al. 2009). The outer tiers represent structural interventions and policy resource supports, including adolescent-centred care and interventions which facilitate ALHIV to question or 'reflect and choose' those spaces that bring them satisfaction and enable them to transform their lives by giving them a chance to voice their SRH needs and care. Within the varied institutional resources, knowledge of HIV status, linkage to care, information about sexual function and support to make choices were shared with peers, partners, parents and health care workers (Papers III and V) acknowledging ALHIV aspirations, active engagement and participation holistically.

8.5.2 Strategic Silence and Relationships

I have defined strategic silence as consciously and purposefully avoiding disclosure of HIV status to avoid anxiety and emotional distress, and I see this as a protective factor for ALHIV (Kaunda-Khangamwa, Kapwata et al. 2020). Most ALHIV intentionally adopted strategic silence to limit stigma and discrimination and to maintain relationships, respect for their parents or caregivers, and to avoid relational loss. Even so, all ALHIV were able to openly talk, discuss and facilitate ASRH/HIV issues at home, mainly with a caregiver or parent and at ART/teen club clinics, community/religious gatherings, workshops, and retreats (Chapter Seven). Some ALHIV would not disclose their HIV status in public to peers or a partner, or request or initiate the use of condoms or contraception in a relationship. Instead, they would defer responsibility to partners or a health worker. Some female ALHIV opted out of making decisions about contraceptive use as part of preparing themselves for childbearing, as well as relying on their partner's ability to protect their relationship. Similarly, caregivers/parents reiterated the need to be calculating about what information on HIV/ASRH to disclose, with whom and when. This serves as a

subtle mechanism for ALHIV to make conscious decisions about the circumstances of their infections, negotiate childbearing and avoid STIs (Chapters Six and Seven).

Strategic silence has not been identified in previous literature exploring protective factors that contribute to ALHIV resilience in adolescents in Malawi and sub-Saharan Africa (Kaunda-Khangamwa, Kapwata et al. 2020). Most scholars argue that the continued silence on SRH/HIV related issues among adolescents exacerbates sexual taboos, gender inequalities, and closed communication across settings (Kajubi, Whyte, & Kyaddondo, 2016; Limaye et al., 2012; Skovdal & Belton, 2014; Undie et al., 2007). Partial disclosure, pretence, denial, concealment, or complete silence were common strategies adopted by caregivers when they feel unprepared for full disclosure to handle ASRH/HIV related questions (Kajubi 2016, p16). Pfeiffer et al. (2017) show how parents in Tanzania failed to improve adolescents' sexual and reproductive resilience because they could not discuss sexual matters openly. Similarly, in Malawi silence on sex and sexuality fosters taboos, negative discussions on rites of passage and adolescents' sexuality (Limaye et al. 2012, Undie et al. 2007, Makwemba et al., 2019). A deficit, 'disease and danger' based lens propagates a 'needy, vulnerable and needs fixing' public health approach (Singh, Both and Philport 2020, p 2, Bekker et al., 2015; Bhana et al., 2016; Luthar, 1990) (Chapters Six, Seven and Eight, and Kaunda-Khangamwa, Maphosa et al. 2020).

There is growing recognition that silence has mixed outcomes (Fielden et al., 2011; Shefer, 2015). Despite silence influencing gender inequalities, discrimination and stigma affecting vulnerable ALHIV, 'strategic silence' has the potential for open discussions with trusted people, in specific spaces and places to support ASRH and HIV related matters (Kaunda-Khangamwa, Kapwata, et al., 2020). Fielden and colleagues (2011) argue that silence takes many forms 'fluid and disembodied', protective against the deleterious effects of ignorance and discrimination. For others, silence promoted ' a neglected gendered phenomenon' to the understanding of not only HIV/AIDS but sexuality and the reproductive lives of persons living with HIV (Morrell, 2003; Samuels, 2020). A few have questioned whether 'truth', such as 'disclosure' of HIV status, while appearing to represent agency and voice,

may not always be beneficial (Shefer, 2015). Even where disclosure has taken place, ALHIV continue employing 'strategic silence' to manage their lives and matters related to sexuality. Hence, the findings on 'strategic silence' for ALHIV provides a nuanced account of resilience and HIV in Malawi and sub-Sharan Africa (Van Breda et al. 2018, Dulin et al. 2018, Bhana et al. 2016).

Income-Generating Activities and Resilience

Most young people mentioned that they tried to earn a living by engaging in small scale business at home, in the market-place, while others got temporally employment to earn them a small wage to improve their wellbeing (Chapter Six and Eight). Caregivers relied on ALHIV to help with managing their home-based tuckshops, where they sold groceries to community members as part of contributing to the family livelihood. Teen mentors with the help of guests facilitated life skills sessions on how to start a business, use Microsoft excel spread sheets for bookkeeping, and make profits. The life skills training workshops are run throughout the year. At least two sessions are for ALHIV, and both genders argued for the need to engage income generation as part of skills-building (shared in teen club meetings and workshops), showcasing their skills (recording music, running a small business including selling clothing, foodstuffs, cross-border trading, rearing chickens, growing vegetables) to attain money for individual use (buying fashionable clothes, phones, airtime and data bundles), maintaining 'love' relationships and family support (Chapter Six and Eight).

Both genders referred to themselves as 'hustlers' garnering for resources at varied space to enhance their lifestyle. Females mentioned that on top of attending school, they needed start-up business funding that allowed them to start work as distributors of health or skin products, while others hoped to run a hair salon or sell second-hand clothes to meet their daily needs and for savings. Male respondents shared their music skills and recorded music online to increase their fan base and downloads for profit. Others sold phone accessories, while others became agents for property selling and renting. Most ALHIV diversified their income to save more money to buy airtime or data bundles. In contrast, others spent the money with their girlfriends and a few boys reported that they bought better brands of condoms for

their sexual wellbeing (Chapter Six, Seven and Eight). Almost all ALHIV recommended financial start-up kits as part of the potential pathway to do well given their education challenges and lack of tuition (Chapters One, Eight and Nine).

It is evident that ALHIV wellbeing is not determined by support from the health sector alone, but rather they seek to access a diversity of opportunities to better their lives. Most studies have looked at the role of income generation in AIDS research through donations and grants support such as cash transfers programmes, with mixed reactions on livelihoods, schooling and STI/FP/pregnancy outcomes (Baird et al., 2012; Ferguson, Bender, & Thompson, 2018; George, Scott, Mehra, & Sriram, 2016; Panter-Brick, 2014). Similarly, the DREAMS study, as a package or linkage of programmes including cash transfers, is part of multifaceted and structural interventions to building resilient adolescent, keep adolescents girls in school and prevent early pregnancy and acquisition of HIV (Fleischman & Peck, 2015; Madurai et al., 2020; Saul et al., 2018). However, the DREAMS study is predominantly concerned with young women, and ignores the needs of young men. Income generation initiatives or child or adolescent labour, as alluded to earlier for ALHIV, are gendered and show how young people can take advantage of lessons learnt through life-skills at teen club clinics to strive to do well (Kaunda-Khangamwa, 2020; Liborio & Ungar, 2014; Skovdal, Ogutu, Aoro, & Campbell, 2009). ALHIV can request start-up kits which reveals their aspirations to be autonomous and empowered. Others manage to negotiate or navigate their experiences not only to build their financial freedom and wellbeing but to cater for their relationships. I acknowledge that this study did not discuss in-depth the role of income generation and businesses in ALHIV lives. Future research could explore how ALHIV leverage household productive activities, or entrepreneurship for their wellbeing.

8.5.3 In the Home, Community and Teen Club Clinic

Belonging to a family has been shown to mediate pathways to resilience. Family support was described as physical and psychological in the CYRM-28, and a parent/guardian or persons most knowledgeable (PMKs) about adolescents' lives (health care workers and mentors) in the qualitative data. In Malawi, most ALHIV

residing with their biological parents (PMKs) having access to ART, have improved health outcomes, as parents were able to engage with their adolescents to negotiate for material, monetary, entrepreneurial, clinical, educational support and resources directly. A few whose parents had died depended mainly on the extended family, aunts and uncles, and grandmothers. ALHIV divulged the depth of the relational support with guardians or caregivers through their drawings (ecomaps) (Figures 6.1 and 6.2) which were full of challenges and mistrust due to stigma or fear of accidental disclosure. Caregivers included grandmothers, siblings, guardians, relatives, and adoptive parents challenged the mediating role of extended families in ensuring a positive impact on ALHIV outcomes (Skovdal et al. 2014).

ALHIV engaged with parent/caregiver/guardian through guardian sessions held by the teen club clinic and promoted relational and multigenerational participation in one-to-one talks through guardian session, enhanced acceptance of living positively, ALHIV empowerment and autonomy in ART and teen-club clinic service use, and in particular SRH related matters (Chapters five-nine). For instance, most ALHIV had ongoing discussions with their PMKs to make decisions about the times to take medication or the frequency to attend teen-club clinic or seek a consultation and counselling session or to consider using condoms when the need arises. The ALHIV-PMKs communications are vital processes to strengthen personal connectedness, open communication and support networks. The open communication was not extended to other family members, including siblings, for fear of stigma and discrimination when the status is widely known, hence strategically protecting ALHIV.

At the community level, socio-cultural practices, values and beliefs were critical in preparing both caregivers and ALHIV to encompass open communication on sexual function and pleasure and reproductive aspirations, which ALHIV mentioned were essential for self-worth and positive outcomes. Findings from additive roles of institutional supports (homes, church and community) and rites of passage ceremonies transformed ALHIV lives, allowing them to express their pride to their culture, and to question their SRH needs and service provision. ALHIV and their caregivers/parents spoke together about attending either the church or community

rites of passage which paved the way for open communication on the need for male circumcision for boys and/or using condoms. For young women, sexual preparedness through talks with community/church role models and bodily enhancements, strengthened connectedness and informed decision making for both parties (Chapter seven-nine).

In light of the DSD approach and ASRH needs, the role of parents/caregivers can have a positive impact. My findings refer to guardian sessions and workshops as platforms which enhanced knowledge sharing and confidence to discuss sexual matters with their adolescents in their homes openly, refer to SRH topics in the school syllabus and encourage young people to attend rites of passage or initiation ceremonies. The comprehensive sexual education topics at school reflected on fewer topics on puberty, pregnancy, birth control and STIs to mention a few. ALHIV and PMKs reiterated the role of cultural and traditional practices such as rites of passage at the teen club clinics, community and church settings. The practices contributed to informed choices as sexual and reproductive beings and prepared them for sexual function and pleasure (Chapter Seven-nine), becoming responsible, and accessing services for counselling and contraceptive support.

Parental or caregivers' support of adolescents on HIV/SRH matters, in ways that might build resilience, in the broader literature on ASRH has been met with mixed or inconclusive evidence regarding positive outcomes and experiences. Young people can manage health issues and have choices when in a close relationship with at least one caring, competent and reliable adult who recognises, values and rewards pro-social behaviour (Sieving et al., 2017). Also, Gyan and colleagues (2016) and Bhana and colleagues (2016) claim relational support (parents, older siblings, friends, religious groups, schools and the community members) serves as a social control mechanism. It offers social support, which provides adolescents with skills to manage sex and pregnancies while strengthening relationships between family and health services, mainly focus on ART treatment outcomes, adherence and retention in care(Kajubi, Bagger, Katahoire, Kyaddondo, & Whyte, 2014; Phiri, Tweya, et al., 2017; Zgambo et al., 2018).

My research study contributes to the growing literature on positive framing of ASRH, as reflected by the work of Mkhwanazi (2006), Thompson (1990), Hodes and colleagues(2018), Pfeiffer and colleagues (2017), Bhana (2018). They discuss the relational supports, representation of teenage romance, love and pregnancy, and agency in research, and illustrate how youths living in poor resource settings made adaptive decisions not to delay pregnancy. Parental, familial, and social factors, including service delivery supports, have been discussed as protective in developing adolescent's strengths, resources and assets to meet SRH needs. The multilevel resources are aligned with an 'SRH paradigm shift' from sex or reproductive avoidance to open discussion, planning, and facilitation on whether or not to have a child (Leyva-Moral et al., 2018; Pfeiffer et al., 2017). The emphasis is on a 'multidimensional, ageless, continuous and connected' (Fortenberry, 2013, p. S131) approach for ALHIV and group experiences. ALHIV, become more comfortable with their sexuality, mediate positive engagement with SRH dialogues, relationships and outcomes overtime (Fortenberry 2013, Hensel and Fortenberry 2012, Bhana et al. 2016, Epstein and Mamo 2017, Toska et al. 2020). Service use and resilience are aligned with individual, family, clinic, community, cultural and religious practices, emphasising the diverse ways of linking up with ALHIV for their positive health-related outcomes and social well-being. Increased service use enhances resilience and resilience encourages service use. These are interconnected and evolving.

8.6 Strengths and Limitations

The strengths and limitations of this research study were identified in each chapter and they are extended here, including in relation to methodology, recall and social bias. The discussion is embedded in the study findings (Chapters 4-8).

This research study used mixed methods to explore different factors, dimensions and processes associated with resilience, service use and SRH to describe the complex and multilevel interactions between them as well as to capture the reasons for variations among ALHIV. The strength-based perspective helped to recognise facilitative spaces to ensure social, health and wellbeing for ALHIV. It was a challenge to elucidate the associations between levels of resilience and SRH service

among ALHIV because of low utilisation of STI care, contraception, gynaecology support and maternity facilities. However, low usage of SRH reflects not just a quantitative decrease but also variation in gendered needs, experiences and motivation (Papers I-V).

The application of a strength-based approach in this research study helped to reframe questions, analytical lens and interpretation to focus on positive outcomes (service use, sex positives), on which there has been little attention in Malawi and sub-Saharan Africa. I was able to relate with ALHIV as 'agentic beings' who have a 'voice, rights and choices' to actively participate in the access to social, economic and health care support (Mutambo et al. 2020, Liborio and Ungar 2009). Our interactions ultimately improved our dialogues and data collection sessions as they reflected on their life and service use experiences.

As alluded to earlier, this is the first study to measure resilience as a multidimensional construct for ALHIV and attending a teen club clinic in Malawi. The framing paved the way for understanding strength at multiple levels (individual, relational and context) and in relation to multilevel resources, while capturing the variations in ALHIV experiences of what it means to 'do well', despite adversity. Open-ended interviews provided ALHIV with opportunities to reflect on resilience, enabling them to reflect and draw on their real-life experiences, contextual resources towards accessing services, forming strategic relationships and decisions for their well-being and a bright future.

There were also certain limitations. SEM models presented in the results are from a homogenous sub-population - ALHIV aged 15-19 years old attending ART and teen club clinics. Measuring resilience scores for ALHIV was a once-off procedure due to logistical limitations which made it harder to measure at baseline and endline. This limits generalisability to other populations, communities, and context. The sample size was informed by previous studies conducted in a similar setting -- the teen club clinic -- which makes the study comparable to studies conducted in similar settings (Kim et al. 2014, 2015, MacKenzie et al. 2017). Wider sampling to enhance reliability would have included ALHIV who were not in care; we tried to reach them but failed due to changes in address or contact details.

ALHIV self-reported services used and drew some visuals (ecomaps) - an innovative graphic representation or visualisation ("picture") of people or resources in their lives as part of triangulating services and relational support they had received over time. However, it might be a challenge for ALHIV to report all the resources or relational supports they had used or experienced in the past year due to difficulties in recalling certain services in and outside the teen club clinic. In addition, some ALHIV might not have been confident in using pens or pencils to write or draw. Hence, I invited participants to pass by my make-shift office to remove or finish their ecomaps at a convenient time. The original drawings were not presented in the manuscript, hence losing the originality of the presentations. However, original copies of the ecomaps are attached in Appendix 19 to show examples from a few ALHIV and how they used this method to capture their aspirations.

Another limitation relates to my adaption and translation of the CYRM-28. ALHIV may have misinterpreted the statements, affecting the reliability of the instrument to measure resilience. A rigorous exercise was employed using cognitive interviews and feedback sessions with the advisory panel to ensure that questions were understood, and variables measured as intended (Heather et al. 2012, Ungar 2016).

SRH issues among ALHIV are sensitive issues, and respondents may have felt obliged to adjust their views or to avoid giving information about their behaviour. The low reporting on STI, family planning, and pregnancy might have led to data incompleteness (Chapter four, eight and Paper III). ALHIV reported having easy access to condoms that were placed in the public toilets around the clinic and the frequency of access was not documented, leading to further gaps on condom use in the registers. In addition to the convenience of placing condoms in the public toilets, there is a need to develop an innovative method by which adolescents can be involved in collecting or accounting for SRH related data. In addition, ALHIV might feel embarrassed or fearful to talk about services that they used for SRH, sex, pregnancy, and HIV-related issues outside the teen club clinic. To cater for social desirability bias, and the general trend of significantly underreporting by females

and overreporting by males (Desmond et al., 2018), all interviews were held away from health workers, teen-club clinic facilities and community members who might eavesdrop on discussions. In addition, multiple interview sessions were held with ALHIV who had consented to attend follow-up sessions as part of triangulation.

CHAPTER NINE

RESILIENCE, RECOMMENDATIONS & CONCLUSION

9.0 Introduction

In this chapter, I briefly revisit the aims of the study, then discuss the key outcomes and my contributions to knowledge and research processes with working adolescents in research. I set out my recommendations, which I have divided into two topics at programmatic levels. The first is working with lay persons in research; this includes adapting the CYRM-28 in low-income countries and enhancing teen club support under the DSD platform. The second is policy-related issues, including in relation to health, education sectors, improving capacity building and entrepreneurial skills. I conclude with ideas on further analysis, publications and future research.

The overall aim of this study was to describe and analyse protective factors and resources that influence SRH service utilisation of ALHIV in Malawi. Using a socio-ecological framework, I explored SRH service use and the notion of 'resilience' to understand the multi-level interactions of ALHIV accessing the teen club clinic and other resources and supports. The research study adds to the emerging literature on strength-based perspectives on SRH, service use and resilience as well as the narrative on ALHIV experiences within ARV clinic ethnographies. The validation of CYRM-28 for ALHIV confirmed the capacity to develop a model for monitoring and evaluation of service use, SRH and resilience in a low resource setting. The complex interactions within the home, community, and institutions have inherent strength in the form of resources and relational sources of support and processes that contribute to ALHIVs' positive social, economic and health outcomes. ALHIV experience complex needs but have protective factors and aspirations that can be used to enhance their self-worth, the will to live, and the opportunity to achieve, attain financial autonomy and appreciate their sexuality.

The multivariate findings confirmed ALHIV as multiple service users of three or more services and the dimensions that inform their resilience: individual (personal and social skills, relational (parental support) and contextual (spiritual and cultural). ALHIV were satisfied and valued the resourcefulness of the teen club clinic, while continuing to utilise community, traditional and religious supports, taking into account the dynamics and fluidity of relationships and institutional alternatives for their well-being. However, at the teen club clinic, ALHIV low utilisation of STI and family planning failed to confirm SRH service use and associations across the 15-19 year old. The low SRH records suggests that ALHIV are accessing SRH related services (STI, family planning, emergency pills, condoms) from other service providers (private clinics, grocery stores, YFHS) as suggested in chapter four, eight and Paper III and IV (Kaunda-Khangamwa et al. 2020a).

Another key outcome was the value of the socio-ecological perspective in relaying strategic silence and relationships, and the use of multiple service institutions, including the rites of passage ceremonies to confirm that ALHIV have varied supports as indicated in the framework. The facilitative spaces of homes, teen club clinic, cultural and religious resources continue to evolve to promote positive ASRH outcomes. These outcomes include an increase in knowledge, having an informed choice and decision making, as well as extending a sex-positive approach. Culturally meaningful processes such as rites of passage ceremonies at community and church level have resilience enhancing potential. Rites of passage were reframed as supporting informed choices about abstinence and contraception use. Peers and school support were reported as potential barriers to ALHIV well-being which affirms that risks, protective factors and resilience are variable and dynamic.

The qualitative accounts provided more complex data from ALHIV and PMK on the notion of 'doing well' despite adversity, seeking autonomy, financial stability, health and social services, acceptance of SRH as normative and part of the development process, romantic and sexual desires, and conflicts and negotiations on SRH issues.

The ecomap is a methodological contribution to participatory research with adolescents. Young people provided visualised maps of the individual, relational

and institutional resource connections to the external world, providing a way to discover young people's intricate webs of social and health systems. By reflecting on the four cases and ecomaps, I was able to illuminate the fluid nature of relationships and interactions with resource supports, unravelled strategic silence and choices among ALHIV; including documenting mixed outcomes ranging from isolation, stigmatisation and discrimination (mainly in homes, school, with peers), on the one hand, to being empowered and strengthened through health facility support on the other.

The spaces and reframing of sexuality and responsibilities that arise in adolescents' sexual and reproductive lives were emphasised as part of a complex reality. The findings demonstrated a nuanced and multidimensional understanding of SRH as involving dialogues leading to 'self-love', sexual self-esteem, pleasure, informed choice and consent (Harden, 2014; WHO, 2006a). I add to the emergent literature on the sex-positive framework for research on ALHIV. I consider that ALHIV have a right to a voice, informed choices and decision making over their sexuality, as developmentally normative and potentially healthy (Harden, 2014; Hensel & Fortenberry, 2013). Most parents, caregivers and ALHIV echoed their talks about living positively, accounting for 'sexual readiness' and providing tangible support as well as offering alternate sexual and reproductive support. Sexual readiness included the ability to express needs, desires, and to be able to access and build their knowledge on sexuality and reproductive preparedness, including the desire or the need have a child or not, choices available, and preparations made. Harnessing a strength-based focus allowed for an exploration of the effects of support systems for adolescents to not only make 'healthy' choices on reproduction and contraception but to plan for positive future goals (Hodes et al., 2018; Kaunda-Khangamwa, Kapwata, et al., 2020; Mkhwanazi, 2006; Pfeiffer et al., 2017).

9.1 Recommendations for ALHIV Programs

9.1.1Working with Adolescents in Research Workshops & Parent/Guardian Sessions

As a contribution to the involvement of ALHIV in the research process, I reflect on results from the different objectives and gaps learnt throughout *Working with adolescents in Research Workshop & Parent/Guardian Session.* I developed the workshop that was funded externally by Blantyre Health Research Training Trust (BHRTT) as part of capacity building, aiming to improve participation in health research under teen club clinics and giving back to the community. The workshop was run alongside this PhD with recommendations from supervisors and members of the advisory panel to reach out to health workers, caregivers and adolescents as part of the fieldwork preparation, informing and validating the CYRM-28, data analysis and interpretation processes and capacity building. The workshop also provided a platform for adolescents, mentors, parents and health workers to learn about and voice their opinions on the research, implementation processes including service usage, and improvements needed. The sessions allowed for diverse group participation (adolescents, parents and health workers), the formation of relationships, and sharing their accomplishments, and challenges. This included recommendations for better health outcomes.

9.1.2 Working with ALHIV as Mentors and Research Workshops.

Linking mentors (role models who had graduated from the teen club) with health workers are part of the motivation and allowed for adolescents to realise their endeavours, potential and opportunities. Mentors coordinated teen club activities with fellows' (ALHIV). At the programmatic level, working together with young people, mentors, health workers and community members can create a successful pathway to support those living with HIV, which enhance their relationships, access to services and care, uphold ethical practice, participate in monitoring and evaluation exercises, and enhance their empowerment, leadership roles and their voices. I recommend that graduating ALHIV to mentorship roles should continue as part of strengthening their involvement and skills workmanship and trust across the programme.

Involving ALHIV in workshops as part of the research process should become a routine activity, with support from both internal and external funding to continue motivating participants to learn and inspire everyone to learn from each other's

work. Given that some SRH related data are incomplete in the clinic, it is critical to advance ALHIV engagement in generating local interventions that support them in different ways. Adolescents may get involved in the process of research as a community resource and to conduct or contribute to need assessments, and to guide the design, monitoring, adaptation and evaluation of targeted initiatives, programmes and services (Ozer & Piatt, 2017, p. 2). This is part of integrating and strengthening health workers', caregivers', research teams' and teen mentors' capacities in understanding research, upholding ethics, and safeguarding vulnerable populations. I highlight that 'adolescent lives matter' as presented by Patton et al. (2016) with respect to health equity and justice; increasing global (and regional, national, district and community) visibility, monitoring and accountability for adolescents; scaling up sustainable and effective actions among adolescents; and engaging and empowering adolescents (Ozer & Piatt, 2017, p. 2).

9.2 Adapting the Child Youth Resilience Measure- CYRM-28 in Poor Resource Settings

To understand how adolescents, develop resilience, including reporting positive health and social outcomes, various tests and scales have been used over time. I chose the CYRM-28 as a recommended culturally and contextually relevant measure of resilience in this thesis. The tool was validated and predominantly used by Ungar and Liebenberg (2011) among multicultural youths (1451 youths facing adversities in 11 countries (South Africa, Tanzania, Gambia, Israel, Palestine, Russia, India, China, Colombia, USA and Canada) in both the global north and south (Windle et al., 2011). The CYRM-28 has the potential to be adopted for monitoring and evaluation of programmes across communities and intervention programmes. However, there is a need to design or adapt youth resilience measures that capture HIV/SRH specific conceptual psychometric characteristics (infecting others, or children, becoming ill, consequences for sexual life, SRH service use) for individual and programme evaluation. Such resilience measures can track social, health and clinical outcomes and factors as necessary for evidence-based recommendations across adolescence.

9.3 Differentiated Service Delivery Platform: Enhanced Teen Club Clinic Support.

Adolescents, girls and young women continue to bear the brunt of HIV, although more young men die of AIDS-related illnesses (SADC, 2019). The current increase in the prevalence of HIV among young people requires that services be comprehensive and strengthened, with the same service providers, mentors and social supports. Aligned to the comprehensive and rigorous support for ART and the teen club clinic is the timely monitoring and evaluation of individual, health facility and policy interventions to track progress and inform decision making. I maintain that the DSD/teen club clinic has the potential to support adolescents' links from HIV diagnosis to ART initiation, retention on ART and adherence to ART, including the provision of comprehensive psychosocial support on SRH related matters (Kaunda-Khangamwa, Kapwata et al. 2020). Therefore, when designing monitoring and evaluation under DSD, studies need to take account of patient-centred approaches and enhanced support and resources available within health systems. DSD support is likely to enhance ART uptake and retention, as well as multiple other SRH and social and economic outcomes in a teen-club clinic setting. Teen-club clinic, parental and guardian support has evolved through patient-centred-care and should be enhanced for planning, designing and implementation processes.

9.4 Recommendations for Policy

This work carries a few implications and recommendations for adolescents, service use and SRH policy and programming. The research study is informed by a range of global goals and commitment to national policies and initiatives to ensure health and well-being for adolescents aged 10-24. Malawi is recognised for adopting and implementing progressive policy frameworks for young people under youth, health, education, entrepreneurship and labour policies, but there is a disconnect in the implementation of ASRH (Chirwa et al., 2018; UNFPA, 2017). There is wide recognition of linkages between risk and protective factors for HIV and ASRH (Hopkins & Collins, 2017) including the programmatic responses such as the provision of health resources and service delivery to be intertwined. However,

service integration alone for SRH and HIV is not sufficient for ALHIV to do well, despite highlighting the enhanced teen club clinic support under the patient-centred care and its potential to transform ALHIV representation, their voice and access to multiple services. The non-availability of structures or pathways to let ALHIV have basic information and awareness of available resources under different policies, hinders their overall wellbeing. Policy level interventions for ALHIV need to be adapted for those with low levels of education, experiencing high levels of poverty as part of increasing access to equitable and relevant quality resources to all (Government of Malawi, 2017b; Malawi Government, n.d.). Hence, policy recommendations are presented by sector and as part of a holistic approach to social and ASRH programming and strategic interventions.

9.4.1 Policy Recommendation for the Health Sector

With the advent of DSD or adolescent centred care, this thesis confirmed that about 97% of ALHIV were satisfied with teen club clinic service provision due to the provision of a conducive environment, free and open to all young people seeking SRH services, friendly health workers and mentors, and convenient opening and closing hours, including opening after school hours. However, despite meeting all the needs and preferences of ALHIV, still few make use of the family planning, STI care, and specialist services from the gynaecologist as part of their reproductive preparedness to have a child. In addition, most ALHIV in this study were diagnosed with HIV at birth. There may be challenges related to onwards transmission partners and children, including reinfection, which affects their choices and decision making over time (Eshun-Wilson et al., 2019; Kanyangarara et al., 2019; Toska, Pantelic, Meinck, & Keck, 2017).

Hence, I recommend that more emphasis should be placed on messages to curb re-infection, efforts to achieve positive pregnancy outcomes through health education, and prevention of mother-to-child transmission programme activities (Callahan et al. 2017). As the teen club clinic is recognised as a ‘one-stop shop’, it is a key delivery platform to continue offering routine health education, care and support. Since adolescence is a transition period, I suggest that cross-departmental support should be strengthened from the HIV/AIDS & ART care, STI & Family Planning,

pharmacy, and nutrition, as well as PMTCT teams, to meet the complex needs of ALHIV. Another option is to integrate service provision as part of 1) increased advocacy of family planning as a human right, 2) ensuring easy access to contraception, 3) prevention of secondary HIV transmission, and 4) joint monitoring and evaluation of SRH outcomes at district and community levels under the Ministry of Health directorates: HIV and AIDS Department, Reproductive Health Directorate, and the Department of Preventive Health Services, with support from established partners such as PEPFAR, USAID, UNFPA, WHO, UNICEF/Malawi.

Teen club clinic and parental and guardian support have evolved through an adolescent-centred care approach. Multiple groups need to be involved in planning, designing and implementation processes using participatory and learner-centred methods such as simulations, adult, and experiential learning. There is need to consider unique needs of diverse groups and relationships in multiple spaces (workshops, seminars, monthly meetings including one-to-one sessions) as part of mainstreaming SRH in health education, promotion, prevention across ALHIV everyday lives. By involving multiple perspectives, diverse spaces and support fit well within the call to put adolescents at the centre to allow for self-appraisal, participation, and empowerment, and as influencing and enhancing gender equity in health programmes.

In addition, multisectoral coordination to provide comprehensive sexuality education at facility levels including private hospitals, clinic, businesses, philanthropy, civil society organisations, academia, media, communities, and schools – in the Life Skills (primary) and Life Skills (secondary) series – will encourage service use and attract ALHIV to existing and alternative service use. School curricula discussions and church programming of sex, condoms, contraception, and pleasure among young people can be made possible by adopting a sex-positive approach (Malawi Government, n.d.; Singh, Both, & Philpott, 2020). Integration of family planning, SRH and SRHR initiatives will enhance information and services across sectors and improve quality of care and access to contraception

and family planning for youth while supporting them to make informed choices and decision making.

9.4.2 Policy recommendations for the Education Sector

School and education support was identified as a barrier to ALHIV 'doing well' under findings for the validation of the CYRM-28. The result can be due to lack of money to attend school, and stigma, discrimination and negative representations of people living with HIV in the textbooks and curricula as well as in the classroom, which leads to fear and social exclusion. A ten-country review of school curricula in East and Southern Africa reiterates the limitations of the school curricula as lacking depth and sensitivity in representations of safe sex or missing essential information related to human development, reproduction, sexuality, and details about STI and HIV risk (OECD Development Centre, 2018; UNESCO & UNFPA, 2012). The policy recommendation relate to the two directorates under Ministry of Education Science and Technology (MoEST): the Directorate of Inspection and Advisory Services Supervision and inspection of teaching and learning processes responsible for curriculum development, and the Directorate of Nutrition, HIV and AIDS managing the HIV programmes which are cross-cutting in all departments and sections of the MoEST (Government of Malawi, 2018). The two directorates need to revise the curricula and monitor the implementation of comprehensive sexual education curriculum for both primary and secondary school levels. The revision needs to recognise that adolescents are living positively, as healthy, active participants in society, with the autonomy to protect their health and others in their relationships.

9.4.3 Lack of Capacity to Pay for Tuition

Poverty levels in Malawi continue to rise, which affects the income of young people and their families. Primary education has been free up to Standard 8 since 1994, but for secondary education, families must pay tuition fees and often transport and accommodation costs. Most caregivers and ALHIV reported that they were forced out of secondary and post-secondary education due to financial constraints. I received phone calls and WhatsApp messages, as mentioned in my piece on

positionality and reflexivity in Chapter Two (Kaunda-Khangamwa, 2020), requesting support for tuition fees or referral to social welfare or an NGO for support. Aligned with the increase of several children asking for school fees for secondary or college education and trade skills (carpentry, brick layering, tailoring), the UFC health care and mentorship team set up a social welfare fund, into which staff remit about 3% of their monthly allowances when attending teen club clinic to help raise tuition funds for ALHIV. To strengthen this innovative local initiative, which sometimes runs out of funds when there is no funding, I recommend ALHIV should be linked to the district welfare office for continued support. In addition, cross-sectoral support between the Ministries of Health and Education, and bursary programmes of established NGOs, can be tapped on for vocational and college fees.

Cross-sectoral support in service provision for ALHIV may include initiatives such as Keeping Girls in School (KGIS) project that provides cash transfers, bursaries and improved sanitation support to girls in primary and secondary schools. Similarly, the MoEST offers bursaries and cash transfers for young people, and the National Inclusive Education Strategy (NIES) (2017-2021) enhances education for all through learner diversity, partnerships and community engagement. The National Girls Education Strategy empowers girls by keeping them in school, using by-laws in each traditional authority across the country (Government of Malawi, n.d.-b, 2013, 2018; Hardin, Trumbo, & Wiest, 2020; Malawi Government, n.d.; OECD Development Centre, 2018). Request for referrals to educational support by ALHIV and their caregivers show the limitations of the provision of practical information on cross-sectoral initiatives that will not only strengthen social and health outcomes but also enhance their education and well-being.

9.5 Capacity Building and Entrepreneurial Initiatives

The UFC Teen Club Clinic continues to open its doors and facilitate capacity building and ongoing mentoring for ALHIV, parents and caregivers, including mentors. Given the diversity of programmes and activities within the clinic, most ALHIV reported having lower levels of education. A few had self-taught experiences in computers, farming, mechanics and entrepreneurship while others

attended vocational training to become electricians, plumbers, accountants or administrators. Despite lack of capacity to pay for tuition or to get financial support and poverty, many ALHIV used their savings to get involved in petty business ventures to meet their own and family daily needs. Health workers, mentors and invited professionals played an instrumental role in motivating ALHIV to learn social and technical skills to stay in school or run their businesses. Alternatively, we may consider incorporating already existing structures and partnerships with NGOs like Youth Net and Counselling, BIPAI, Camp Hope and teen club clinics across the district to hold school/business/career advise meetings, exhibitions as part of awareness programmes for young people to know support structures at the community, district and national levels.

In addition, information related to savings, business plans or proposals, social welfare programmes, tuition and educational support, and internship programmes can be shared using inexpensive channels of communication as part of increasing awareness of their presence. Some of the ways to link up with the adolescents with information may include information boards at the clinic, SMS messaging or WhatsApp as means of reaching out to many adolescents.

9.6 Further Analysis and Publications

I have plans for further analysis and publication from this study in the remaining part of the year and early next year. The analysis will focus on the remaining data from in-depth interviews with health workers and mentors; policy-related discourses on sustainable goals and differentiated service delivery; and integrating SRH and HIV care. The purpose of the publications is to extend space to discuss additional areas of functioning of ALHIV, beyond the teen club clinic and health policies. Continuing to incorporate multiple perspectives from health workers, policymakers and ALHIV with co-morbidities will add insights on experiences that most promote positive functioning over time. The list of possible publications include:

The first paper will look at ‘Promoting resilience among ALHIV: Lessons for Malawian health care workers and mentors. This paper will focus on ALHIV

reflections on how health workers and mentors as crucial stakeholders in the ART or teen club clinic facilitate resilience, including lessons learnt to inform strategies for health-workers and mentors promoting resilience when working with ALHIV and other vulnerable populations.

'A narrative of sexual and reproductive health in Malawi: A case study of adolescents within the differentiated service delivery/patient-centred care.' This second paper will illuminate experiences, discourses and implications to practice under the SDGs and DSD/patient-centred era. Findings gleaned from the translation of global goals, commitment to regional and national policies, and initiatives will help to account for national realities. Such knowledge could contribute to lessons learnt under the implementation of progressive policy frameworks for SRH among adolescents.

'A comparative ethnographic study of adolescents with co-morbidities - cancer, diabetes and HIV/AIDS -- attending ART clinics in Blantyre, Malawi' is another paper in the pipeline. In this third paper, I aim to highlight protective factors and barriers exhibited in the different chronic illnesses, complex patterns of service use, and experiences while contributing to guidelines for integrated care and support for ALHIV.

9.7 Future Research

Research on adolescents' resilience and HIV is sparse in Malawi, as elsewhere in Sub-Saharan Africa, and complementary and new areas for research have been identified from this study. Recommendations for future studies are described in detail below.

This study was a first attempt to measure resilience for ALHIV, and measures and scales are refined through repeated studies (Windle et al. 2011, Ungar 2016). As presented in the paper on validation of CYRM-28, a longitudinal study to capture not only adolescents' needs but protective resources, values and aspirations among adolescents accessing SRH services, with larger samples, will be critical to determine the causality of resilience pathways in Malawi. Understanding causal

pathways are essential to decide on barriers and facilitating factors and to gain further insight into processes that foster resilience across different communities or among other chronically vulnerable young people. It is essential to follow up on resilience data and disaggregate it by age, gender, and status in school or out-of-school, to explore the variability of resilience within individual and groups over time. Future research could also include a longitudinal or comparative study with larger samples to understand protective factors and resilience pathways for adolescents in rural as well urban Malawi.

The multiple perspectives (parents, caregivers, mentors and health workers) is warranted using data from the adult supplement version of the CYRM (PMK-CYRM-28) about adolescents' life. The data will be triangulated with data from other methods, caregivers and health workers to investigate differences in how adults and adolescents perceive risks, service usage and satisfaction. In addition, it will be critical for adolescents to be involved in the research process so that the gathered data provides a meaningful direction to prevention and intervention plans. Furthermore, stakeholders from specific departments under the Ministry of health: reproductive health, preventive services, HIV units and NGOs are overlooked in resilience studies, yet they serve key life-saving roles at the community, district and national level.

Future research should also explore the patterns of service use, health worker supports and resilience outcomes among adolescents living in other poor resource settings. Questions of the roles of multiple services (child welfare, education, juvenile corrections, mental health) in making a difference in the lives of adolescents are critical at a time when the COVID-19 pandemic is impacting on all health care. Despite fewer COVID-19 cases in sub-Saharan Africa including Malawi, there is concern due to the disproportionately large number of people living with HIV (PLHIV). There are inconclusive reports that having an underlying condition, such as HIV (advanced HIV or poorly controlled HIV) increases the chance to acquire COVID -19 (Hogan et al., 2020; UNAIDS, 2020b), or in contrast, the protective effect of ART on severity of infection from coronavirus. There is also growing recognition that strategies used to mitigate the pandemic such as social

distancing, quarantines, and closure of geographic areas disrupts routine care and affects PLHIV and ALHIV access to medication, engagement with health workers and peer support for clinical and psychosocial services (Jewell et al., 2020; Nkengasong & Mankoula, 2020). This warrant further investigation in countries which are resource-constrained such as Malawi.

9.8 Concluding Comments.

The ages of 15-19 represent a window of opportunity to explore, support and cater to adolescents' multiple vulnerabilities and complex needs as they work to establish themselves as young adults. Building on a strength-based perspective, I place adolescents at the centre, particularly of service provision (WHO 2016, 2017, 2018, Kok et al. 2018, The Lancet, 2015). I draw on recent insights to frame 'resilience' as a multidimensional construct (Ungar & Liebenberg 2011, Masten 2007, 2015, Ungar 2004, 2008), which is critical to ALHIV health outcomes and well-being. It is clear that ALHIV may demonstrate positive functioning in certain areas while struggling in others. Socio-ecological resource supports and processes such as adolescent centredness or differentiated service delivery, and parental support, help ALHIV gain a sense of self-worth and negotiate for 'healthy' or positive outcomes.

Taking an adolescent development view, I show how the home, community and teen-club clinic interactions foster resilience. ALHIV sexual and reproductive lives continue to evolve, allowing both genders to embrace and voice their peer, romantic and sexual relationships, the responsibilities that flow from these, and their struggle to maintain them. Parenthood and sexuality are valued and aspired by both genders, which inform young people’s decisions to abstain, use Norplant or condoms, and choose or avoid early marriages as part of either short- or long-term strategy for well-being. Most ALHIV voiced their concerns about having 'healthy babies' with romantic partners living with HIV, their aspirations to attain an education and then gain employment or run a business and adhere to ART. Because stigma is persistent, I show too how they strategically stay silent while they work to these goals, as part of the nuanced understanding of 'doing well despite adversity'.

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11. APPENDICES

Appendix 1: Human Research Ethics Committee Certificates, The University of Witwatersrand

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Ms B Kaunda

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M180465

NAME: (Principal Investigator)	Ms B Kaunda
DEPARTMENT:	School of Public Health Medical School University
PROJECT TITLE:	Sexual and reproductive health, service use and resilience among adolescents in urban Blantyre, Malawi
DATE CONSIDERED:	04/05/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Professor L Manderson
APPROVED BY:	Professor CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	17/08/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **April** and will therefore be due in the month of **April** each year. Unreported changes to the application m e given by the HREC (Medical).

Principal Investigator Signature — Date: 18 August 2018

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 1.1 Faculty Approval of PhD Thesis Title

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

15 May 2018
Person No: 1487823
PAG

Ms BN Kaunda
College Of Medicine, Malaria Alert Centre
Private Bag 360. Chichiri, Blantyre Malawi
265
Malawi

Dear Ms Kaunda

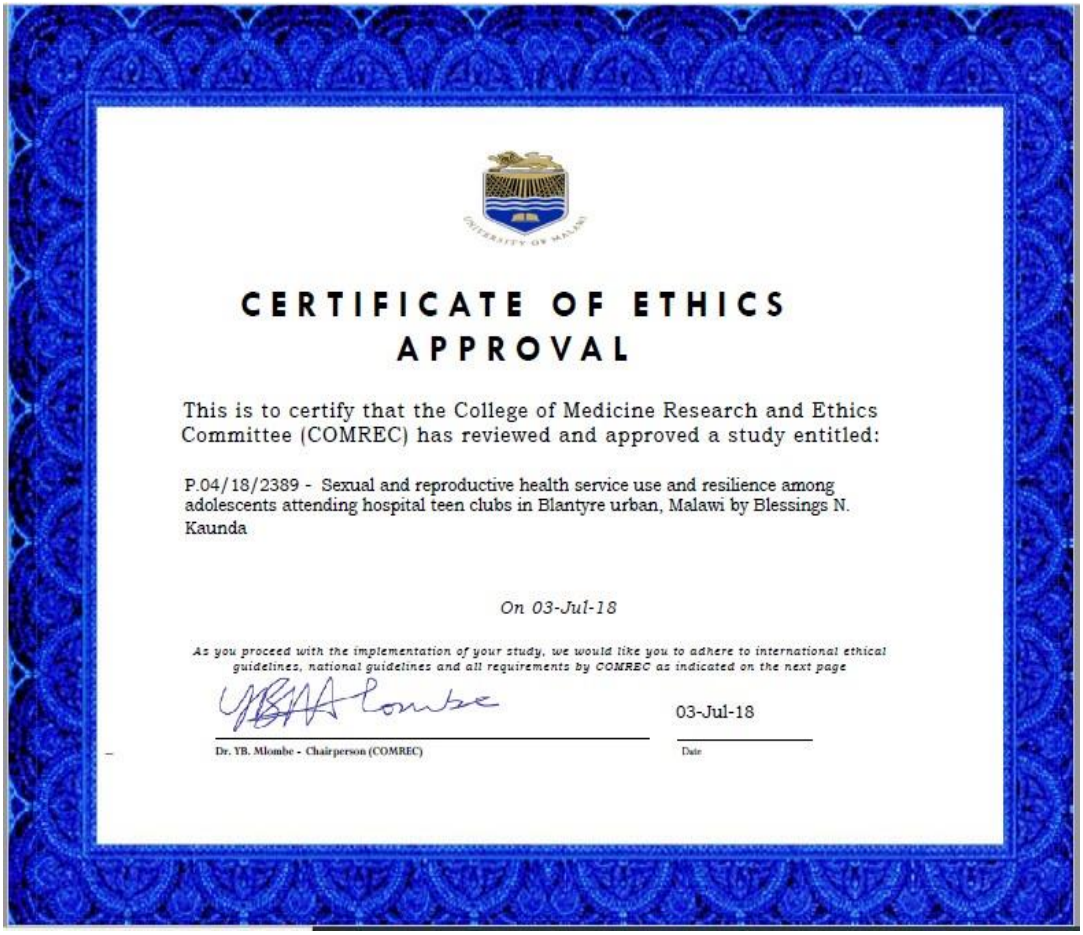
Doctor of Philosophy: Approval of Title

We have pleasure in advising that your proposal entitled *Sexual and reproductive health service use and resilience among adolescents attending hospital teen clubs in urban Blantyre, Malawi* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Appendix 2: College of Medicine Research Ethics Committee Certificate, University of Malawi



CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.04/18/2389 - Sexual and reproductive health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi by Blessings N. Kaunda

On 03-Jul-18

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page

Dr. YB. Mlombe - Chairperson (COMREC)

03-Jul-18

Date

Appendix 3. Letter of Research Approval: Tiyanjane Teen Club: Zomba

DIGNITAS

March 1, 2018

TO: **All National and International Ethics Review Committees**

RE: **Support Letter to Conduct Study at Tisungane Clinic, Zomba Malawi**

I write to confirm Dignitas' support for Blessing Kaunda, a PhD Student at the University of the Witwatersrand, Johannesburg, South Africa who is planning to conduct a pilot study at Tisungane Teen Club.

The main study site for Blessings study is Umodzi HIV Clinic at Queen Elizabeth Hospital, Blantyre. Blessings study on **"Sexual and Reproductive health, service use and resilience among adolescents in rural and urban Malawi"** has potential to inform the growing need to provide better sexual and reproductive health services and better adolescent HIV care services. Her research is timely especially at this time when research evidence is scanty and lacking in this area that could help inform evidence based policy making in Malawi.

Please do not hesitate to contact us if you need further information.

Yours sincerely,

Megh Raj Nagriti
COUNTRY DIRECTOR

DIGNITAS INTERNATIONAL
Malawi Office
P.O. Box 1071
Zomba, Malawi

Tel +265 (0) 1 525 420
Fax +265 (0) 1 527 558
Dignitasinternational.org

Appendix 3.1: Letter of Research Approval: Lighthouse Trust: Blantyre

LIGHTHOUSE

Tel: (265) 1 758 940 ext 211
Fax: (265) 1 758 941
Cell: (265) 8 88 892 523
Email: samphiri@lighthouse.org.mw

Kamuzu Central Hospital (Area 33)
P.O. Box 106
Lilongwe
Malawi

Our Ref: **LH/SP/elk/0305533** **27th March 2018**

To whom it may concern

RE: **APPROVAL TO CONDUCT RESEARCH AT QUEEN ELIZABETH CENTRAL HOSPITAL, UMODZI FAMILY CENTRE - ADOLESCENT CLINIC (BLANTYRE, MALAWI)**

Reference is made to the subject mentioned above.
This is to confirm that Blessings N. Kaunda, a postgraduate student at the University of the Witwatersrand has been granted an approval to conduct research at Queen Elizabeth Central Hospital (Umodzi Family Centre) Adolescent Clinic, the research title is: *Sexual and reproductive health, service use and resilience among adolescents in urban Blantyre, Malawi.* This is a requirement for her Ph.D. degree in Public Health and Medical Anthropology.

Blessings N. Kaunda will be working with Adolescents Living with HIV (ALHIV) aged 15-19 attending the ART clinic and Umodzi Teen club. The aim of this study is to describe and analyse how adolescents access and utilize sexual and reproductive services in extremely risk contexts characterized by poverty, high HIV prevalence, early sexual debut, child marriages and childbirth.

Lighthouse has reviewed the protocol and the following are the objectives of her research:

1. Determining factors associated with resilience among ALHIV at the individual, family, institutional and structural levels
2. Explore adolescents' perceptions of resilience-promoting resources across age groups, including
3. Elucidate the associations between levels of resilience and SRH service-utilization among ALHIV
4. Explore formal and informal pathways of adolescent service use that promote positive outcomes,

Records to be examined are ART, STI, family planning, maternity register, and BAOBAB system and the participants will be recruited from the ART Clinic – Adolescent Club meetings at community level.

Thank you for trusting in Lighthouse Trust

Yours faithfully

Dr. Sam Phiri, PhD (UK), MSc (UK), DCM (MW)
CLINICAL EPIDEMIOLOGIST AND EXECUTIVE DIRECTOR

Appendix 4: Invitation Letters for Adolescents, Parents and Guardians.

18-19 year olds

We would like to invite you to the clinic. We have set out time and space to discuss adolescents related issues on **25 November 2018**. The discussion will begin at 1300-1400. Your presence will make a difference!

Signed by the PI and contact details.

Invitation to parent or guardian and their adolescent.

For 15, 16 and 17 year olds

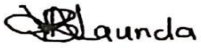
We would like to invite you and your child to the clinic. We have set out time and space to discuss adolescents related issues on **9 December 2018**. As a parent or guardian, you are being encouraged to attend. The discussion will begin at 1300-1400. Your presence will make a difference!

Signed by the PI and contact details.

Appendix 5: Co-Author Agreement Form

Declaration: Student's contribution to article (s) and Co-authorship Agreement Form

I, **Blessings Nyasilia Kaunda,** student number **1487823,** declare that this Thesis is my own work and that I contributed adequately towards research findings published in the article (s) stated below which are included in my thesis.

Student's Signature:  Date: 03/11/2020

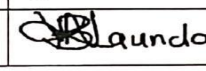
Name of Primary Supervisor: Prof. Lenore Manderson

Signature of Primary Supervisor Date: 8 November 2020

Agreement by co-authors: By signing this declaration, the co-authors listed below agree to the use of the article(s) by the student as part of her Thesis. In cases where the student is not the 1st author of a published article, the primary supervisor must explain (under comments) why the student is entitled to use the paper for his degree purposes.

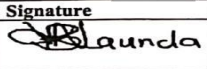
Article 1: Title: 'A volunteer for life.' Interactions in resilience and service use research in Malawi. A volunteer for life.' Interactions in resilience and service use research in Malawi was published in the Journal of Medicine Anthropology Theory (MAT) p296–302. https://doi.org/10.17157/mat.7.2.5030, http://medanthrotheory.org/index.php/mat/article/view/5030

Journal name, year: *Medical Anthropology Theory*, 2020 (Status: Published).

Author	Name	Signature	Date
Author	Blessings N. Kaunda-Khangamwa		03/11/2020

Article 2: Title: Validating a Child Youth Resilience Measurement (CYRM-28) for Adolescents Living with HIV (ALHIV) in Urban Malawi. Frontiers Psychology. doi:10.3389/fpsyg.2020.01896.

Journal name, year: *Frontiers Psychology*, 2020 (Status: Published).

Authors	Name	Signature	Date
1st author	Blessings N. Kaunda-Khangamwa		03/11/2020

1

Scanned with CamScanner

2nd author	Innocent Maphosa		04/11 2020
3rd author	Rosalia Dambe	Rosalia Dambe	03/11/2020
4th author	Kennedy Malisita		03/11/2020
5th author	Emmanuel Mtagalume		03/11/2020
6th author	Lario Chigaru		03/11/2020
7th author	Alister Munthali		05/11/2020
8th author	Effie Chipeta		05/11/2020
9th author	Sam Phiri		05/11/2020
10th author	Lenore Manderson		08/11/2020

Article 3: Title: Service use and resilience among adolescents living with HIV (ALHIV) in Blantyre, Malawi.

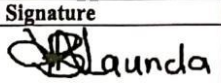
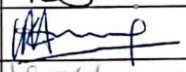
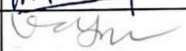
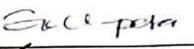
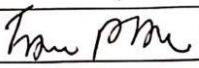
Journal name, year: *International Journal of Integrated Care*. 2020 (Status: Under review).

Authors	Name	Signature	Date
1st author	Blessings N. Kaunda-Khangamwa	Kaunda	03/11/2020
2nd author	Innocent Maphosa		04/11/2020
3rd author	Moffo Phiri		4/11/2020
4th author	Kennedy Malisita		03/11/2020
5th author	Alister Munthali		05/11/2020
6th author	Effie Chipeta		05/11/2020
7th author	Sam Phiri		05/11/2020
8th author	Lenore Manderson		08/11/2020

Article 4: Title: Adolescents living with HIV, complex needs and resilience in Blantyre, Malawi. *AIDS Research Therapy*. 17, 35 (2020). https://doi.org/10.1186/s12981-020-00292-1

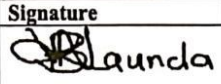
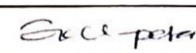
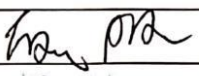
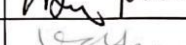
Journal name, year: *AIDS Research Therapy*. 2020 (Status: Published).

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Authors	Name	Signature	Date
1st author	Blessings N. Kaunda-Khangamwa		03/11/2020
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7th author	Lenore Manderson		03/11/2020

Article 5: Title: Spaces and places: Sexual and Reproductive Health and HIV care for adolescents in Blantyre, Malawi

Journal name, year: *Journal of Adolescent Health*. 2020 (Status: Submitted on 28 October).

Authors	Name	Signature	Date
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Comments: Primary Supervisor

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Appendix 6: Information Sheet and Consent Form for the ALHIV Survey

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi.

Introduction

My name is Blessings N. Kaunda. I am a student at the University of Witwatersrand, School of Public Health and University of Malawi, College of Medicine, Blantyre Malawi. I would like to ask you to take part in a research study organised as part of the student thesis and is funded by Consortium for Advanced Research Training for Africa (CARTA). The study is voluntary and will take one year including reviewing your clinical records, service and resource use. However, you can leave the research at any time from today.

Your taking part in this study is entirely voluntary. Please read the information below and ask questions about anything you do not understand, before deciding whether or not to participate.

Purpose of Study

I am organising research on adolescents accessing services in Blantyre at Umodzi clinic or community level. We would like to understand how adolescents' access and use services or resources in their environment. We are also interested in types of services you use for sexual reproductive health needs. We would like to understand how using the different resources/services improves their lives or not. If you agree to participate, I will be conducting an interview using a survey.

Study design and Procedures (What you will be asked to do)

I have survey questions that I prepared for the interviews. The questions will be read out to you by the research study organisers. You will be expected to answer on the papers placed in-front of you. The study will invite 406 adolescents to complete questions on (Child Youth Resilience Measure) adolescents of your age groups 15-19.

The survey will take place at College of Medicine, Lecture hall 1. The estimated time to complete the exercise is between 45-90 minutes. If at any time, you want to stop, I will do so without any penalty. You are free to refuse to answer any question I pose to you at any time.

We would like to meet some of you again (10-20) to conduct individual and group interviews. Therefore, we will invite some of you back to participate in a second round of the interviews.

Study Participants/ Who can participate in the study

You are being invited to participate in the study:

1. Male or female
2. If you are between the ages of 15-19
3. In school or out-of-school
4. Attending or not attending a teen club
5. Facing any challenges in your life

Possible risks

When I ask you questions, you might feel embarrassment or upset. I would like to ask you to inform me. If you continue to feel upset, please tell me, and I will take you to skilled personnel to get appropriate support.

Possible Benefits

The information I collect from you and the community will help address the challenges adolescents face when using or not using services. The findings will be shared with local service providers and key stakeholders at community and national level for better programme planning.

Compensation and Reimbursement

I am not providing any compensation for any participants in this research study. Transport reimbursement is amounting to MK 1000 for travelling to Collge of Medicine or Malaria alert centre to take part in the study.

Confidentiality and Anonymity

All the information from this study will be kept a secret. Your name will not be used at any time in the data. I will use a number or fictitious name to protect you when I am talking or writing about you throughout my study. All data will be owned by the School of Public Health, University of the Witwatersrand and MAC-CDAC, College of Medicine. Recorded information (written and digitally-recorded) will be kept in a secure place under lock and key for a period of five years at the MAC-CDAC offices. Thereafter all information will be destroyed. No one other than the researcher and her supervisors will have access to the recorded material and the transcripts.

If you have any questions about this study, your rights, safety and wellbeing or any complaint, please contact Blessings N. Kaunda at Malaria Alert Center on 0888554052, The COMREC Secretariat on 01 871 911 ext 334.

This information sheet is for you to keep.

Consent Form

SIGNATURE PAGE FOR STUDY PARTICIPANT FOR ADOLESCENTS' CYRM QUESTIONNAIRE

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi.

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily. I understand that I can change my mind at any stage and it will not affect me in any way.

☐ **Yes (**please *tick) I* **agree to be interviewed.**

_____ _____

Full name of Participant Signature &Date

Thumbprint: ----------

Participant's name and date written by: _____

Signature & Date

Witness name, signature and date are required only when the consenting participant is illiterate

_____ _____

Name of Witness Signature & Date

I certify that s/he apparently understood the nature and the purpose of the study and consents to the participation in the study. S/he has been given opportunity to ask questions which have been answered satisfactorily.

Signature: _____ Date: _____

Designee/investigator's name _____ Time: _____
Name ***(please print name)***

Thank you for agreeing to participate in this study.

Appendix 7: Focus Group Interview Guide for Cognitive Interviews

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi.

Focus Group Guide

For office use only.
Participant Number:
Site ID:
Data number:
Date of administration:

Introduction

My name is Blessings N. Kaunda. I am a student at the University of Witwatersrand, School of Public Health and the University of Malawi, College of Medicine, Blantyre Malawi. The study is being organised as part of the student thesis and is funded by the Consortium for Advanced Research Training for Africa (CARTA). I would like to understand how adolescents' access and use services or resources in their environment. I am also interested in the types of services you use for sexual and reproductive health needs. I would like to understand how using the different resources/services improves your lives or not.
I would like to ask you to take part in a focus group, which will take between 45-90 minutes. A focus group is a meeting when a number of people come together to talk about a specific topic.

I would like us to introduce ourselves to each other. Confidentiality cannot be guaranteed when taking part in a focus group. However, I would like to encourage everyone in this the group to maintain confidentiality by not sharing any information on what we have discussed today. It is very important that we can speak freely here, without concern that what we sat will be shared with others. The study is voluntary, and you have the right to withdraw from participation at any point with no negative consequences.

DIRECTIONS
The guide is for advisory committee and 15-19 year olds in group discussions.
The guide will inform questions that make sense to people locally in Section A of the CYRM.

ADMINISTRATION

The research organiser will guide the group discussions at a central venue. The following prompts may help generate conversation and questions.

FGD #: **District:**

Facility:

Date: **Start time:** **End time:**

	Age	Gender	Education	Males and/or females' groups
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

Education:

1= None, 2=Junior primary, 3= Senior primary, 4=Junior secondary, 5=Senior secondary, 6=University degree, 7=Other certificates and diplomas (specify), 8=Other (specify)

FGD Moderator:

Instructions for FGD Moderator:

- This guide should help you to initiate and moderate the discussion, which should flow like a normal discussion rather than a question-answers session.
- The guide is designed for a group of 6-10 ALHIV, to be conducted at a convenient chosen by the group.
- Participants must be aware that focus group discussions will take around 60 minutes (reschedule if this is not possible)
- Ask another member of the research assistants to take notes about interactions, group dynamics, and the content of discussions.
- Ensure privacy (including audio-privacy) for the discussion. Participants are likely to know each other already. Establish some ground rule about the confidentiality of what is discussed within the group.

General question on life as an adolescent.

1. Tell me about growing up as an adolescent here.
2. "What kinds of things are most challenging for you growing up here?"
3. "What do you do when you face difficulties in your life?"
4. "How do you describe people who grow up well here despite the many problems they face?"

5. “What does it mean to you, your family and your community when bad things happen to you?”

General Questions on health

1. How do you keep healthy?
2. “What does being healthy mean to you and others in your family and the community?”
3. “What do you and peers you know do to keep healthy?”
    a. Probe on mental,
    b. Probe on physical,
    c. Probe on emotional,
    d. Probe on spiritual
    e. Probe on sexual relationships
    f. Probe on reproduction

Personal Questions

4. Have you ever heard about sexual and reproductive health? Probe on What and Why?
5. What are some of the services that you have used in your life-time?
6. Where do you seek these services?
7. Have you ever sought SRH services? Probe on what and where?

Conclusion

Are there any final questions or issues that you want us to discuss?
If not, thank you for taking part in this discussion.

Appendix 7.1 In-Depth Interview Guide for Cognitive Interviews

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

QUESTIONNAIRE FOR ADOLESCENCE RESILIENCE IN ZOMBA

Participant ID No:
District:
Site:
Date of administration:

Administration Instructions
The following will be read out loud by me (principal investigator) at the beginning

Thank you for coming today. Today's task has 3 steps.

Step 1. I will read the questions out loud.
Step 2. I will give you a minute to think and discuss the answer.
Step 3. You are allowed to discuss your answers with me or your peers.
Remember they are no wrong answers.
Please answer the questions as honestly as possible
I would like to learn from you.

Explaining what it is about: "Please say "out loud" anything that comes into your head whilst you are answering…"

1. I have people I want to be like.
2. I share/cooperate with people around me.
3. Getting an education is important to me.
4. I know how to behave/act in different situations, at home, teen club clinic and school.
5. My parent(s) or caregiver(s) watch me closely, they know where I am and what I am doing most of the time.
6. My parent(s) or caregiver(s) know a lot about me (like what Ido)
7. There is enough to eat at home when I am hungry.
8. I try to finish activities that I start.
9. Spiritual beliefs are a source of strength to me (e.g., believing in God)
10. I am proud of ethnicity (Tonga, Tumbuka, Lhlomwe)
11. People think I am fun to be with.
12. I talk to my family about how I feel (sad, happy).
13. When things don't go my way, I can fix it without hurting myself or other people.
14. I feel supported by my friends.
15. I know where to go to get help.

16. I feel that I belong at my school.
17. I think my family cares about me when times are hard.
18. I think my friends care about me when times are hard.
19. I am treated fairly.
20. I have chances to show that I am growing up and can do things by myself.
21. I know what I am good at.
22. I participate in religious activities (e.g., church youth group)
23. I think it is important to help out in my community.
24. I feel safe when I am with my family.
25. I have chances to learn skills that will be useful when I am older.
26. I like the way my family celebrates things (e.g., holidays or learning about my culture)
27. I like the way my community celebrates things (initiation or rites ceremony)
28. I am a proud Malawian.

"Probe on what ALHIV are thinking…" what is going through your mind as you are considering each of your answers…"

Appendix 8: CYRM-28 & Global Early Adolescent Survey (GEAS) tools

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

QUESTIONNAIRE FOR ADOLESCENCE RESILIENCE IN BLANTYRE

Participant ID No:
District:
Site:
Date of administration:

Administration Instructions
The following will be read out loud by me (principal investigator) at the beginning

Thank you for coming today. Today's task has 3 steps.

Step 1. I will read the questions out loud.
Step 2. I will give you a minute to circle or write the answer.
Step 3. You are not allowed to discuss your answers with anyone.
Remember they are no wrong answers
Please answer the questions as honestly as possible
I would like to learn from you.

---

1. I am interested in the services that you have used. Please look at the list below and tick on the ones that you are now using or have you used in the past 12 months.

Youth Friendly Health Service	☐
Community Outreach Clinic	☐
Family planning Clinic	☐
One Stop Centre	☐
Traditional healer	☐
Educational Support	☐
Teen Club	☐
Teen Club Clinic	☐
Sexual Transmitted Infection (STI) clinic	☐
Youth Centre	☐
Maternity Clinic (Ante-natal Clinic, Labour ward)	☐
Anti-retroviral Treatment (ART) clinic	☐
Mental Health Service (e.g seen a counsellor, psychologist)	☐
Correctional Service (e.g., questioned by police, put on probation, been in jail)	☐
None of the above	☐
Other	☐

CIRCLE YOUR ANSWER

Section A: Background

2. How old are you now? **10** **11** **12** **13** **14**

15 **16** **17** **18** **19**

3. **Are you a boy or girl?** □Boy □Girl □Don't Know

4. **What is your tribe?** □Chewa, □Tonga □Sena
□Lhlomwe

□Ngoni □Tumbuka □ Don't Know □Other.

(Specify_____)

5. **What is your religion?** □ Anglican, □ CCAP □Catholic
□SDA

□Moslem □Baptist □ No religion □Other

6. Are you currently enrolled in school?
□Yes, if Yes, Circle the standard, grade/form.

Standard / Grade: 1 2 3 4 5 6 7 8

Form 1 2 3 4 5 6

□No
□Other (Specify_____)

7. If No, what is the last grade you passed?
_____

I would like to ask you about where you live and your family.

8. **Have you changed homes?** □Yes □No
If yes, how many times:
□ once □twice □three times or more □ don't know □ other

9. Including you, how many people typically sleep in the same room as you?
□I sleep alone □1 other person □2 or 3 other people.

□4 or more other people □ don't know □Other

10. Whom do you live with?

□ Mother □Father □Brother □Sister
□Friends □Grandparent □Another family member
□Teacher □Boyfriend □ Girlfriend · Health center
□Doctor □Nurse, □Police □Social-worker
□Health workers □ Religious leader or pastor
□Someone at a school clinic □ Adolescent home □Other (specify_____)

11. How long have you lived with these people?

□ all my life □for the past 5 years □ for past two years □ don't know
□ other_____.

12. **Who takes care of you?**

□ Mother □Father □Brother □Sister
□Friends □Grandparent □Another family member
□Teacher □Boyfriend □ Girlfriend · Health center
□Doctor □Nurse, □Police □Social-worker
□Health workers □ Religious leader or pastor
□Someone at a school clinic □ Adolescent home □Other (specify_____)

13. How many brothers do you have?

□one □two □three □ none
□don't know □ other

14. How many sisters do you have?

□one □two □three □ none
□don't know □ other

15. **Have any members of your immediate family died, like a parent, or a brother or sister**?

□Yes □No

[If Yes to14] Who died?

□ Mother □ Father □Brother □ sister
□don't know □other

16. **How many meals do you eat per day**?

□ one meal □two meals □ three meals □don't know □other

17. **Please describe whom you consider to be your family**?
_____
_____

I want to ask just a few more personal questions:

18. **Have you ever had a baby?**

□Yes □No □don't know □other

[If Yes to 17] how many do you have?

□ one □ two □three and more □ don't know
□other (Specify_____)

19. **Are you caring for this child at the moment**?

□Yes □No □Sometimes □don't know
□other specify_____

20. **If you are not taking care of the baby, please specify the person who does**_____
_____
_____

SECTION B: Skills, Friends & social support

21. Circle one answer for each statement.

	Not at All	A Little	Sometimes	Quite A Bit	A lot
1.I have people I look up to.	1	2	3	4	5
2. I have people I look up to.	1	2	3	4	5
3. I cooperate with people around me.	1	2	3	4	5
4.Getting an education is important to me.	1	2	3	4	5
5. I know how to behave in different social situations.	1	2	3	4	5
6. My parent(s)/caregiver(s) watch me closely.	1	2	3	4	5
7. My parents/caregivers know a lot about me	1	2	3	4	5
8. If I am hungry, there is enough to eat.	1	2	3	4	5
9.I try to finish what I start	1	2	3	4	5
10. Spiritual beliefs are a source of strength for me.	1	2	3	4	5

11.I am proud of my ethnic background.	1	2	3	4	5
12. I talk to my family/caregiver(s) about how I feel.	1	2	3	4	5
13. I can solve problems without harming myself or others (for example by using drugs and/or being violent).	1	2	3	4	5
14. I feel supported by my friends	1	2	3	4	5
15. I know where to go in my community to get help.	1	2	3	4	5
16. I feel I belong at my school.	1	2	3	4	5
17. My family stands by me during difficult times.	1	2	3	4	5
18. My friends stand by me during difficult times.	1	2	3	4	5
19.I am treated fairly in my community.	1	2	3	4	5
20. I have opportunities to show others that I am becoming an adult and can act responsibly.	1	2	3	4	5
21. I am aware of my own strengths	1	2	3	4	5
22. I participate in organised religious activities	1 1	2 2	3 3	4 4	5 5
23. I think it is important to serve my community	1	2	3	4	5
24. I feel safe when I am with my family/caregivers.	1	2	3	4	5
25. I have opportunities to develop skills useful in life, like job skills and skills to care for others).	1	2	3	4	5
26. I enjoy my family's/caregiver's cultural and family traditions.	1	2	3	4	5
27. I enjoy my community's tradition.	1	2	3	4	5
28. I am proud to be from _____ethnic _____group (Insert)	1	2	3	4	5

SECTION C. SERVICE-USE

22.How often have you used this service?

	How often have you used this service	**Never**	**Needed it, but could not get it**	**Once in month**	**A couple of times**	**3 times or more in a month**
Teen club	Peer counselling					
	Peer support					
	Nurse counsellor					
	Support group					
	Referred to nurse					
	Referred to counsellor					
	Referred to a specialist					
ART Clinic	Nurse					
	Doctor					
	Specialist (gynaecology)					
	Counsellor					
	STI counsellor					
	Referred to OPD					
	Skin specialist					
	Referred to family planning					
Educational services		**Never**	**Needed it, but could not get it**	**Once in month**	**A couple of times**	**3 times or more in a month**
	Support from teacher					

	Support from psychologist					
	Special school					
	Teen club					
	Support from counsellor					
Child welfare		**Never**	**Needed it, but could not get it**	**Once in month**	**A couple of times**	**3 times or more in a month**
	Social worker					
	Child headed home					
	Foster home					
	Drop-in centre					
	Home based care					
	Street-kid support					
	Monthly allowance					
YFHS		**Never**	**Needed it, but could not get it**	**Once in month**	**A couple of times**	**3 times or more in a month**
	Nurse					
	Counselling services					
	Doctor					
	Specialist (gynaecology)					
	Counsellor					
	STI counsellor					
	Referred to OPD					
	Skin specialist					

	Referred to family planning					
Mental Health service		**Never**	**Needed it, but could not get it**	**Once in month**	**A couple of times**	**3 times or more in a month**
	Psychologist					
	Group therapy					
	Substance abuse or addiction service					
	Support group					
	Medication					
	Referred to hospital					
	Referred to traditional healer					
Correctional services/Justice system		**Never**	**Needed it, but could not get it**	**Once in month**	**A couple of times**	**3 times or more in a month**
	Been questioned by the police					
	Gone to court as charged					
	Gone to court as a witness					
	Been put in jail					
	Been on a probation					
	Served on community service					

Cultural or Spiritual services		**Never**	**Needed it, but could not get it**	**Once in month**	**A couple of times**	**3 times or more in a month**
	Traditional healer					
	Pastoral counselling					
	Religious leader					
	Spiritual healer					

Other services that you have used. Please list below and specify by <u>circling</u> how often you have used them			
	Once in my life	**A couple of times**	**3 times or more**
a.			
b.			
c.			

SECTION D: Using Services

23. State the service/programme/adolescent club that you currently have a lot of contact with_____

Rate the above named service /programme/adolescent club ----------	Very helpful 		Somewhat helpful 	Not helpful at all 	
I helped choose this service	Strongly Agree	Agree	Undecided	Agree	Strongly agree
People helping me, stood by me	Strongly Agree	Agree	Undecided	Agree	Strongly agree
This is a service I needed	Strongly Agree	Agree	Undecided	Agree	Strongly agree
I am now able to cope when things go wrong	Strongly Agree	Agree	Undecided	Agree	Strongly agree
Staff spoke in the way that I understood	Strongly Agree	Agree	Undecided	Agree	Strongly agree
Staff respected my religious and spiritual beliefs	Strongly Agree	Agree	Undecided	Agree	Strongly agree
I felt I had someone within the service to talk to when I was in trouble	Strongly Agree	Agree	Undecided	Agree	Strongly agree
I had a say over how this service was delivered to me	Strongly Agree	Agree	Undecided	Agree	Strongly agree
I received a service that I wanted and was right for me	Strongly Agree	Agree	Undecided	Agree	Strongly agree
I could get the service when I needed it	Strongly Agree	Agree	Undecided	Agree	Strongly agree

The location of the service was convenient and easy to get to	Strongly Agree	Agree	Undecided	Agree	Strongly agree
Staff was sensitive to my cultural background and values	Strongly Agree	Agree	Undecided	Agree	Strongly agree
Overall, I am satisfied with the service I received	Strongly Agree	Agree	Undecided	Agree	Strongly agree
There was a service I needed but could not get……..	Strongly Agree	Agree	Undecided	Agree	Strongly agree
	Strongly Agree	Agree	Undecided	Agree	Strongly agree

23. What has been helpful about this service?_____
_____
_____

24. What could have made this service better?_____
_____
_____

SECTION E: FRIENDS

25. **How many close friends (boys and/or girls) do you have**? (By close friends, I mean those that you can talk about feelings and share secrets.) Write down the numbers.
□Male friends □Female friends` □Don't know □None

26. During a normal week, how often do you spend time hanging out with your closest friends outside of school?
□ Very often (nearly every day) □Often (3-4 times a week) □Not very often (1 or 2 times a week) □Never (no times per week)

27.**How many of your close friends think that it is important to…**

Issues	All	Most	Few	None	Don't Know

Attend school regularly					
Study hard					
Be good in sports					
Be popular with people your age					
Have boyfriend or girlfriend					
Have sexual intercourse					
Smoke cigarettes					
Drink alcohol					
Use drugs					
Dropping out of school permanently					
Become pregnant					
Use condoms					
Use family planning pills					
Seek STI care					
Go for HIV test					

SECTION K: Out of school

29. Have you ever been to school?

□Yes □No □Don't know □Not sure

30. **What is the highest grade or class you completed?**

_____ □Don't know

31. How long has it been since you left school?

□Less than 1 year □Between 1 to 2 years □Between 2 to 3 years □ More than 3 years

32. What are some of the main reasons you are not in school?

□ Lack of school fees, uniforms, materials □ Got pregnant/made girlfriend pregnant.

□ Got married □Sickness.

□Needed/wanted to earn money □Not a good student/failed in school

□Not interested □Other_____ (specify)

□ Don't know

33. SECTION L: Community

The following questions are about adults in your Community.

Tell me how much you think that the following is true**:**

Issues	**True**	**Sometimes**	**Not very true**	**Never**	**Don't Know**
People in my community look out for and help their neighbours					
People in my community look out for and help their neighbours					
People in my community know who I am					
People in my community care about me					
There are a lot of safe places where people my age can spend time outdoors					
Girls in my community are involved in abortion.					
Boys or girls are harassed in my community					

34. Adults and the community

How likely is it that an adult in your neighborhood would do something like intervene if adolescents or teenagers were…**?**

Issues	**Very likely**	**Somewhat likely**	**Not very likely**	**Very unlikely**	**Don't Know**
Damaging property					
Bullying or threatening others					
Fighting with another person					
Selling drugs in the community					
Taking alcohol					
Girl-boy relationship					
Boy-girl relationship					
Seeking sexual health services					
Not seeking sexual health					
Seeking reproductive health					
Not seeking reproductive services					
Girls becoming pregnant					
Boys having sex					

35. Can you tell me where you feel unsafe or threatened? (Select all that apply)

□In your community □On the way to school □At the teen club
□At the Saturday teen club □In your classroom □At the ART Clinic
□At family planning clinic □At labour ward □At the STI clinic
□On the playground, gym, or sports field in school

36. Who or what makes you feel unsafe or threatened in your community? (Select all that apply)

□Adults □Boys or girls your age □Health workers □Other things (example: dogs, other animals, car accidents) □ Don't Know □Other

---

Please specify what makes you feel unsafe or threatened.

37. Who or what makes you feel unsafe or threatened in school? (Select all that apply)

□ Teachers or other adults □Classmates or other students □Other things

(example: dogs, other animals, car accidents) □Don't Know □other

---

Please specify what makes you feel unsafe or threatened.

38. Is there a person whom you would go to if you felt threatened or unsafe?

□Yes □No □Don't know

39. Who would you go to for help or advice if you felt unsafe or threatened?

(Select all that apply)

□ Mother □Father □Brother □Sister
□Friends □Grandparent □Another family member
□Teacher □Boyfriend □ Girlfriend · Health center
□Doctor □Nurse, □Police □Social-worker
□Health workers □ Religious leader or pastor
□Someone at a school clinic □ Adolescent home □Other
(specify_____) □I do not feel threatened or unsafe

40. Do you ever carry a weapon like a gun, razor, club for protection?

□ Often □ Sometimes □ Rarely □ Never □Don't know

Conclusion

Are there any final questions or issues that you want us to discuss?
If not, thank you for taking part in this survey.

Appendix 9: In-depth Interview Guide for ALHIV

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

In-depth guide to discussing an ecomap

1. **Defining Family**
   - Who are the members of your family? Probe on their ages.
   - Whom do you discuss issues within this family?
   - Whom do you share information with this family?
   - Whom do you talk to about SRH? Probe, whom? Why?

2. **Identifying informal supports**
   - Who is important to your family? Probe on support networks.
   - Who else, besides your family is important to you? Probe why?
   - Whom do you call for help?
   - How do they help you, other members of your family?
   - Whom do you talk to about SRH? Probe, whom? Why?
3. **Identify formal supports.**
   - What forms of service organisations do you use?
   - Who do you interact with in the services above?
   - Who do you see or talk with regularly?
   - How does the [individual, agency, or organisation] help support you?
   - Are any of the supports we have talked about particularly helpful for you, your family, or your child?
   - Are any of the supports we have talked about not particularly helpful for you, your family, or your child?
   - Are any of the supports we have talked about stressful for you, your family, or your child?
   - Which service-organisation do you like? Why?
   - Which service organisation provides SRH support for you?

Conclusion

- Summary
- Are they any other burning issues that need to be discussed before we close?

Thank you very much for taking part in this discussion

Appendix 9.1: Adolescents' Ecomapping Execise Information Sheet and Consent Form

Adolescents Focus Group Discussions Pilot_Ecommaping: Version 1.0

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

Introduction

My name is Blessings N. Kaunda. I am a student at the University of Witwatersrand, School of Public Health and University of Malawi, College of Medicine, Blantyre Malawi. I would like to ask you to take part in a research study organised as part of the student thesis and is funded by Consortium for Advanced Research Training for Africa (CARTA). The study is voluntary and will take one year including reviewing your clinical records, service and resource use. However, you can leave this study at any time from today.

Your taking part in this study is entirely voluntary. Please read the information below and ask questions about anything you do not understand, before deciding whether or not to take part.

Purpose of Study

I am organising research on adolescents accessing services in Blantyre at Umodzi clinic or community level. We would like to understand how adolescents' access and use services or resources in their environment. We are also interested in types of services you use for sexual reproductive health needs. We would like to understand how using the different resources/services improves their lives or not. If you agree to take part, I will be conducting drawing sessions and interview discussion.

Study design and Procedures (What you will be asked to do)

I have a drawing exercise (ecomapping) and questions prepared for this exercise. This drawing exercise will include 7 adolescents in a focus groups. The group will meet at the Zomba Central Hospital (outside Blantyre) to see if the instructions on the drawing exercises will work in the real world.

We will use pencils, permanent marker and paper to draw patterns or roads that you use to receive assistance when you face challenges in your life. The drawings will also show the resources, people and buildings that you go to, to discuss the challenges in your life. The estimated time for the drawing exercise between 45-90 minutes.

We will have a break time between the drawing exercise and discussing your pictures. During the break-time, you will receive a drink and a bun. We will talk about the drawings with you and share your thoughts, discuss issues openly your diagrams. As we continue in our talking more questions will arise. Where I do not understand I will ask you to elaborate.

Also, I would like to record all qualitative data collection exercises to help me remember what participants tell me, and so that the information can be used later for writing my report.

Study Participants/ Who can participate in the study

You are being invited to participate in the study:

1. Male or female
2. If you are between the ages of 15-19
3. In school or out-of-school
4. Attending or not attending a teen club
5. Facing any challenges in your life

Possible risks

When I ask you questions, you might feel embarrassment or upset. I would like to ask you to inform me. If you continue to feel upset, please tell me, and I will take you to the skilled person to get appropriate support.

Possible Benefits

The information I collect from you and the community will help address the challenges adolescents face when using or not using services. The findings will be shared with local service providers and key stakeholders at community and national level for better programme planning.

Compensation and Reimbursement

I am not providing any compensation for any participants in this research study. Transport reimbursement is amounting to MK 1000 for travelling to Collge of Medicine or Malaria alert centre to take part in the study.

Confidentiality and Anonymity

All the information from this study will be kept a secret. Your name will not be used at any time in the data. I will use a number or fictitious name to protect you when I am talking or writing about you throughout my study. All data will be owned by the School of Public Health, University of the Witwatersrand and MAC-CDAC, College of Medicine. Recorded information (written and digitally-recorded) will be kept in a secure place under lock and key for a period of five years at the MAC-CDAC offices. Thereafter all information will be destroyed. No one other than the researcher and her supervisors will have access to the recorded material and the transcripts.

If you have any questions about this study, your rights, safety and wellbeing or any complaint, please contact Blessings N. Kaunda at Malaria Alert Centre on 0888554052, The COMREC Secretariat on 01 871 911 ext 334.
This information sheet is for you to keep.

Consent Form
SIGNATURE PAGE FOR STUDY PARTICIPANT FOR ECOMAPPING EXECISE

Sexual and Reproductive health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily. I understand that I can change my mind at any stage and it will not affect me in any way.

☐ **Yes** (please *tick) I* **agree to be interviewed.**
☐ **Yes** (please *tick) I* **agree to take part in the drawing exercise.**

_____ _____
Full name of Participant Signature &Date

For those that cannot write:

Thumbprint: ----------

Participant's name and date written by: _____ _____

Signature & Date
Witness name, signature and date are required only when the consenting participant is illiterate

_____ _____
Name of Witness Signature & Date

I certify that s/he apparently understood the nature and the purpose of the study and consents to the participation in the study. S/he has been given opportunity to ask questions which have been answered satisfactorily.

Signature: _____ _____

Designee/investig _____ _____
Name ***(please print name)***

Thank you for agreeing to participate in this study.

Appendix 10. Guide on the Ecomapping Exercise

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

Guide on the instructions to draw an ecomap

For office use only
Participant Number:
Site ID:
Data number:
Date of administration:

DIRECTIONS
The research organiser will lead the drawing sessions. Each participant invited to take part in this session would be required to sit alone on a desk. He/She needs to be supplied with enough paper, pens, permanent marker, pencils and a rubber.

ADMINISTRATION
The research organiser will guide the selected participants for ecomapping exercise at a central venue. The following prompts may help generate drawings for further discussion in the second round of in-depth interviews

Instructions to draw an ecomap
The eco-map will help to identify and mobilise resources, support systems including connections for the adolescents SRH service-use and wellbeing.

1. Participants need to consent to take part in the study.
2. Need for a pencil, permanent marker, rubber and blank white sheet of paper
3. Draw your family in the middle of the paper
    a. Start by placing yourself in the middle of the paper (□) if you are a boy and
    (O) if you are a girl.
    b. Draw members of your family close to you. A square box represents the male caregiver □ and places their age in the middle of the square.
    c. A circle O represents a mother figure and place their age inside the circle.

d. If you do not have any family, place your source of support in a rectangle 

i. Use the rectangles to mention some of the resources that you use for sexual needs.
ii. Use another rectangle to mention some of the resources you use for reproductive (contraception) needs.
iii. Use another rectangle to mention some of the resources you use for STI needs.

4. Circle the whole family.
5. Add the connections between the family and the different parts of the health services that you have accessed in the past.
6. Connections between the family and the services above are indicated by drawing lines between the family and those systems.
7. The nature of the connection can be expressed in the type of line drawn:
    a. *Solid lines with varying degrees of thickness to connect the informal and formal supports to the family circle.
    b. * A solid or thick lines represent a great deal of support between the informal or formal support and the family. 
    c. *Slightly thinner lines represent moderate support.
    d. * A dotted line a tenuous connection
    e. Thinnest lines represent individuals, agencies, or organisations identified by the family to be part of their informal or formal network that does not provide much support.
    f. *A support relationship is identified as stressful; hatch marks can be placed on the support line.
    g. *Hatch marks on a thick support line represent a stressful relationship with an individual who provides significant support to a member of the family. 
8. It is useful to indicate the direction of the flow of resources, energy, or interest by drawing arrows along the connecting lines: 

Conclusion

Are there any final questions or issues that you want us to discuss?
If not, thank you for taking part in this discussion.

Appendix 10.1: In-depth Guide to Discussing Eco-Mapping Exercise

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

Guide: IDI Discussing the Ecomaps

For office use only
Participant Number:
Site ID:
Data number:
Date of administration:

DIRECTIONS
The research organiser with the help of research assistant will hold face-to-face interviews with respondents at comfortable places far from disturbances.

ADMINISTRATION
The research organiser with the help of research assistants will use the guide below to engage in a conversation stimulated by the drawings.

In-depth guide to discussing an ecomap

4. **Defining Family**
   - Who are the members of your family? Probe on their ages.
   - Whom do you discuss issues within this family?
   - Whom do you share information with this family?
   - Whom do you talk to about SRH? Probe, whom? Why?

5. **Identifying informal supports**
   - Who is important to your family? Probe on support networks.
   - Who else, besides your family is important to you? Probe why?
   - Whom do you call for help?
   - How do they help you, other members of your family?
   - Whom do you talk to about SRH? Probe, whom? Why?

6. **Identify formal supports.**
   - What forms of service organisations do you use?
   - Who do you interact with in the services above?
   - Who do you see or talk with regularly?
   - How does the [individual, agency, or organisation] help support you?
   - Are any of the supports we have talked about particularly helpful for you, your family, or your child?
   - Are any of the supports we have talked about not particularly helpful for you, your family, or your child?
   - Are any of the supports we have talked about stressful for you, your family, or your child?

- Which service-organisation do you like? Why?
- Which service organisation provides SRH support for you?

Conclusion

- Summary
- Are they any other burning issues that need to be discussed before we close?
- Thank you very much for taking part in this discussion.

Appendix 11: Focus Group Interview Guide for ALHIV

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi.

FGD #: **District:**

Facility:
Date: **Start time:** **End time:**

	Age	**Gender**	**Education**	**Males and/or females' groups**
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

Education:
1= None, 2=Junior primary, 3= Senior primary, 4=Junior secondary, 5=Senior secondary, 6=University degree, 7=Other certificates and diplomas (specify), 8=Other (specify)

FGD Moderator:

Instructions for FGD Moderator:

- This guide should help you to initiate and moderate the discussion, which should flow like a normal discussion rather than a question-answers session
- The guide is designed for a group of 6-10 ALHIV, to be conducted at a convenient chosen by the group.
- Participants must be aware that focus group discussions will take around 60 minutes (reschedule if this is not possible)
- Ask another member of the research assistants to take notes about interactions, group dynamics, and the content of discussions.
- Ensure privacy (including audio-privacy) for the discussion. Participants are likely to know each other already. Establish some ground rule about the confidentiality of what is discussed within the group.

TOPIC/THEME	Example of opening questions
Doing well Health and wellbeing Relational support Formal and alternative support (Personnel, institutions, resources, service provision)	• Tell me about growing up as an adolescent here. • "What kinds of things are most challenging for you growing up here?" • "What do you do when you face difficulties in your life?" • "How do you describe people who grow up well here despite the many problems they face?" • "What does it mean to you, your family and your community when bad things happen to you?" • How do you keep healthy? • "What does being healthy mean to you and others in your family and the community?" • "What do you and peers you know do to keep healthy?" • Probe of mental, Probe on physical, emotional and spiritual support • Probe on sexual relationships, Probe on reproduction • Whom do you live with? Probe on people who takes care of him/her. • Do you have any friends? Probe ages, gender, meetings • Are you involved in any relationship? Probe • Probe on friendships, romantic or sexual relationships • What services are available for you? • What forms of service organisations do you visit? • Whom do they interact with in the services above? • Who do they see or talk with regularly? • What do they see or talk about at the organization? • How does the [individual, agency, or organisation] support you? • Are any of the supports we have talked about particularly helpful for you in the community? • Are any of the supports we have talked about not particularly helpful for you in the community? • Are any of the supports we have talked about that are stressful to you? • Which service-organisation do you like? Why? • Which service do you not like? Why?

Appendix 12: Information Sheet for Parents, Caregivers and Health workers

Parents/Guardian Information Sheet and Assent Form

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi.

Introduction

My name is Blessings N. Kaunda. I am a student at the University of Witwatersrand, School of Public Health and University of Malawi, College of Medicine, Blantyre Malawi. I would like to ask you to take part in a research study organised as part of the student thesis and is funded by Consortium for Advanced Research Training for Africa (CARTA). Your taking part in this study is entirely voluntary. We would like to understand adolescent service use, review their records and assess service-use overtime. Please read the information below and ask questions about anything you do not understand, before deciding whether or not to participate.

This document provides information about the study. We would like to speak to your child (boy or girl) aged 15-17. Please read the information below, or you can listen as I read to you to understand the research study. Your child's participation in this study is entirely voluntary. As a parent, you can ask questions about anything you do not understand, before deciding whether to allow your child to participate. However, you have the right to leave the study at any time from today.

The purpose of Study

I am organising research on adolescents accessing services in Blantyre at Umodzi clinic or community level. We would like to learn and understand how adolescents' access and use services or resources in their environment. We are also interested in types of services they use for sexual reproductive health needs. We would like to understand how using the different resources/services improves their lives or not.

Your child will be requested to decide whether she wants to participate in the study. If your child wishes not to participate, his/her decision will be respected.

Study Participants/ Who can participate in the study

Adolescents invited to participate in the study:

1. Male or female
2. If they are between the ages of 15-17
3. In school or out-of-school
4. Attending or not attending a teen club
5. Facing any challenges in your life

Why has my child been invited to take part

Your child was selected to take part because she is an adolescent (boy or girl) aged between 15-19 and might be accessing one or two services at Queen Elizabeth Central Hospital. We would like to request that your child participates in this study.

What will happen if my child takes part?

When you agree for your child to take part in this study, you will be requested to either sign or provide a thumb-print as proof that you voluntarily allowed your child to be involved in the study. Your child will be informed that you allowed them to participate and they will also be given a chance be informed about the study and ask for their approval to participate.

I have questions that I prepared for your child during our discussions. The estimated time to complete the exercise is between 45-90 minutes. We will discuss services and support that they have used and received in the past year. I will discuss some of the challenges and opportunities that the adolescent encounters in their life. The discussions and drawing exercise will take place at College of Medicine-lecture hall and boardrooms. You will not be part of the discussion. For privacy and confidentiality, I will speak to the child alone. His/her responses will not be shared with you.

Your child will be requested to decide whether to use either paper forms or digital recorder. Your child's responses will be recorded on a paper or digital recorder by the interviewer. Your child has the right to refuse to continue with the discussion, answer a certain question, or using the recorder. Please note that we will not use your child name in all our discussion, rather a secret number or fictitious name will be used to keep track of our participants. This number will not be shared with anyone except my supervisors at the university.

The study will take place in one year and will involve a survey, drawing exercise and record reviews. You will be requested to allow your child to participate. Also, we might have follow-up discussions and drawing exercise at College of Medicine. You are being requested if we can invite your child for the second-round of discussions. You have the right to refuse to allow your child to participate at any stage.

Possible risks

During data collection, some questions might be difficult to understand, personal and one might experience embarrassment or discomfort. As a participant, your child has the right to refuse some questions, stop the survey or drawing exercise at any time without any problems. Also, your child is encouraged to let me know whenever they continue to feel the discomfort and embarrassment and I will stop our discussion. I will take your child to skilled personnel to get appropriate support.

Possible Benefits

There are no direct benefits to participating in this study. However, the information I collect from you and the adolescents will help address the issues, values and struggles adolescents face when accessing services. The findings are significant to us and will be shared with local service providers and key stakeholders at community and national level for better programme planning.

Compensation and Reimbursement

I am not providing any compensation for any participants in this research study. Your child will receive a bun and juice during a health break. Transport

reimbursement is MK 1000 for traveling to take part in the study at College of Medicine or Malaria Alert Centre.

Confidentiality and Anonymity
All the information from this study will be kept private and confidential. Your child's name will not be used at any time in data analysis, report writing or manuscripts. An identifier in the form of a number or fictitious name will be used in the survey and qualitative data collection exercises.

Also, I would like to record all qualitative data collection exercises to help me remember what participants tell me, and so that the information can be analysed later for writing my thesis. I assure you that all the recordings will be kept confidential and no one in the community or any authority will have access to the recordings. I will only share the recordings with my supervisors in local supervisor at College of Medicine and the School of Public Health- The University of Witwatersrand in South-Africa. If you decide during the discussion that you do not want the recorder on, it can be turned off.

All data will be owned by the School of Public Health, University of the Witwatersrand and MAC-CDAC, College of Medicine. Recorded information (written and digitally-recorded) will be kept in a secure place under lock and key for a period of five years at the MAC-CDAC offices. Thereafter all information will be destroyed. No one other than the researcher and her supervisors will have access to the recorded material and the transcripts.

If you have any questions about this study, your rights, safety, and wellbeing or any complaint, please contact Blessings N. Kaunda at Malaria Alert Center on 0888554052, The COMREC Secretariate on 01 871 911 ext 334.
This information sheet is for you to keep.

Assent Form
SIGNATURE PAGE FOR PARENTAL/GUARDIAN ASSENT

Sexual and Reproductive health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

I have had the study explained to me and know what is needed from my child. I have understood all that has been read and had my questions answered satisfactorily. I understand that my child will voluntarily take part in this study. He/she can change his/her mind at any stage and it will not affect him/her in any way.

□ **Yes** (please *tick) I* **allow my child to take part in this study, to link up with the researcher, have access to my child's hospital and teen club records.**

_____

Full name of Participant Signature &Date

For those that cannot write:

Thumbprint: ----------

Participant's name and date written by:_____

Signature & Date
Witness name, signature, and date are required only when the consenting participant is illiterate

_____ _____

Name of Witness Signature & Date

I certify that s/he understood the nature and the purpose of the study and consents to the participation in the study. S/he has been given the opportunity to ask questions which have been answered satisfactorily.

Signature: _____ _____

Designee/investigator Name _____ _____
(please print name)

Thank you for agreeing to participate in this study

Appendix 13: FGD Guide for Parents/Caregivers and Key Informants

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi.

FGD #: **District:**

Facility:
Date: **Start time:** **End time:**

	Age	Gender	Education	Males and/or females Groups
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

Education:
1= None, 2=Junior primary, 3= Senior primary, 4=Junior secondary, 5=Senior secondary, 6=University degree, 7=Other certificates and diplomas (specify), 8=Other (specify)

FGD Moderator:

Instructions for FGD Moderator:

- This guide should help you to initiate and moderate the discussion, which should flow like a normal discussion rather than a question-answers session
- The guide is designed for a group of 6-10 parents or caregivers, to be conducted at a convenient chosen by the group.
- Participants must be aware that focus group discussions will take around 60 minutes (reschedule if this is not possible)
- Ask another member of the research assistants to take notes about interactions, group dynamics, and the content of discussions.

- Ensure privacy (including audio-privacy) for the discussion. Participants are likely to know each other already. Establish some ground rule about the confidentiality of what is discussed within the group.

Defining Family/relational support

- Whom do adolescents aged 15-19 talk to about their lives?
- Whom do adolescents aged 15-19 talk to about their problems
- Whom do adolescents aged 15-19 talk to about SRH? Probe, whom? Why

Identifying informal supports

- Where else do adolescents seek SRH at home, community levels? Probe 15-19) age groups
- Whom do they call for, when in need of SRH services?

Identify formal supports.

- What formal services are available for adolescents?
- What forms of service organisations do they use?
- Whom do they interact with in the services above?
- Who do they see or talk with regularly?
- How does the [individual, agency, or organisation] help support them?
- Are any of the supports we have talked about particularly helpful for adolescents in this community?
- Are any of the supports we have talked about not particularly helpful for them in this community?
- Are any of the supports we have talked about that are stressful to adolescents?
- Which service-organisation do you like? Why?
- Which SRH service do you not like? Why?

Conclusion

- Summary
- Are they any other burning issues that need to be discussed before we close?

Thank you very much for taking part in this discussion

Appendix 14: Focus group interview guide for health-workers

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

FGD #: **District:**

Facility:
Date: **Start time:** **End time:**

	Age	Gender	Education	Males and/or females' groups
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

Education:
1= None, 2=Junior primary, 3= Senior primary, 4=Junior secondary, 5=Senior secondary, 6=University degree, 7=Other certificates and diplomas (specify), 8=Other (specify)

FGD Moderator:

- This guide should help you to initiate and moderate the discussion, which should flow like a normal discussion rather than a question-answers session
- The guide is designed for a group of 6-10 parents or caregivers, to be conducted at a convenient chosen by the group.
- Participants must be aware that focus group discussions will take around 60 minutes (reschedule if this is not possible)
- Ask another member of the research assistants to take notes about interactions, group dynamics, and the content of discussions.
-

- Ensure privacy (including audio-privacy) for the discussion. Participants are likely to know each other already. Establish some ground rule about the confidentiality of what is discussed within the group.

Defining Family/relational support

- Whom do adolescents aged 15-19 talk to about their lives?
- Whom do adolescents aged 15-19 talk to about their problems
- Whom do adolescents aged 15-19 talk to about SRH? Probe, whom? Why

Identifying informal supports

- Where else do adolescents seek SRH at home, community levels? Probe 15-19) age groups
- Whom do they call for, when in need of SRH services?

Identify formal supports.

- What formal services are available for adolescents?
- What forms of service organisations do they use?
- Whom do they interact with in the services above?
- Who do they see or talk with regularly?
- How does the [individual, agency, or organisation] help support them?
- Are any of the supports we have talked about particularly helpful for adolescents in this community?
- Are any of the supports we have talked about not particularly helpful for them in this community?
- Are any of the supports we have talked about that are stressful to adolescents?
- Which service-organisation do you like? Why?
- Which SRH service do you not like? Why?

Conclusion

- Summary
- Are they any other burning issues that need to be discussed before we close?
- Thank you very much for taking part in this discussion

Appendix 15: Digital Recording: Information sheet & Consent form

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

Introduction

My name is Blessings N. Kaunda. I am a student at the University of Witwatersrand, School of Public Health and University of Malawi, College of Medicine, Blantyre Malawi. I would like to ask you to take part in a research study organised as part of the student thesis and is funded by Consortium for Advanced Research Training for Africa (CARTA). The study is voluntary and will take one year including reviewing your clinical records, service and resource use. However, you can leave it at any time from today.

Your taking part in this study is entirely voluntary. Please read the information below and ask questions about anything you do not understand, before deciding whether or not to participate.

Purpose of Study

I am organizing research on adolescents accessing services in Blantyre at Umodzi clinic or community level. We would like to understand how adolescents' access and use services or resources in their environment. We are also interested in types of services you use for sexual reproductive health needs. We would like to understand how using the different resources/services improves their lives or not. If you agree to take part, I will be conducting interview discussion.

Study design and Procedures (What you will be asked to do)

I would like to record the focus group (FGD) data collection exercises to help me remember what participants tell me so that I can use the data later for writing my revising the data collection tools. The estimated time to complete the exercise is between 45-90 minutes.

I promise you that all the recordings will be kept a secret and no one in the community or any authority will have access to the recordings. I will only share the recordings with my supervisors at College of Medicine and the School of Public Health- The University of Witwatersrand in South-Africa. If you decide during the research exercise that you do not want the recorder on, it can be turned off.

If at any time, you want to stop, I will do so without any penalty. You are free to refuse to answer any question I pose to you at any time.

Study Participants/ Who can participate in the study

You are being invited to participate in the study:

1. Male or female
2. If you are between the ages of 15-19
3. In school or out-of-school
4. Attending or not attending a teen club
5. Facing any challenges in your life

Possible risks
When I ask you questions, you might feel embarrassment or upset. I would like to ask you to inform me. If you continue to feel upset, please tell me, and I will take you to skilled personnel to get appropriate support.

Possible Benefits
The information I collect from you and the community will help address the challenges adolescents face when using or not using services. The findings will be shared with local service providers and key stakeholders at community and national level for better programme planning.

Compensation and Reimbursement
I am not providing any compensation for any participants in this research study. Our discussions will inform planning of programmes in our communities in the future.

Confidentiality and Anonymity
All the information from this study will be kept a secret. Your name will not be used at any time in the data. I will use a number or fictitious name to protect you when I am talking or writing about you throughout my study. All data will be owned by the School of Public Health, University of the Witwatersrand and MAC-CDAC, College of Medicine. Recorded information (written and digitally-recorded) will be kept in a secure place under lock and key for a period of five years at the MAC-CDAC offices. Thereafter all information will be destroyed. No one other than the researcher and her supervisors will have access to the recorded material and the transcripts.

If you have any questions about this study, your rights, safety and wellbeing or any complaint, please contact Blessings N. Kaunda at Malaria Alert Centre on 0888554052, The COMREC Secretariat on 01 871 911 ext 334.
This information sheet is for you to keep.

CONSENT FORM
Digital Recording
SIGNATURE PAGE FOR STUDY PARTICIPANT

Sexual and Reproductive health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily. I understand that I can change my mind at any stage and it will not affect me in any way.

***I* agree to be interviewed.**

- **Yes (tick) *I* agree to be interviewed.**
- **Yes (tick) I agree to use a digital recorder.**

_____ _____

Full name of Participant Signature &Date

For those that cannot write:

Thumbprint: ----------

Participant's name and date written by: _____ _____

Signature & Date
Witness name, signature and date are required only when the consenting participant is illiterate

_____ _____

Name of Witness Signature & Date

I certify that s/he apparently understood the nature and the purpose of the study and consents to the participation in the study. S/he has been given opportunity to ask questions which have been answered satisfactorily.

Signature: _____ _____

Designee/investig _____ _____
Name ***(please print name)***

Thank you for agreeing to participate in this study.

Appendix 16: Data Abstraction form

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

ALHIV in the study pool.

	10-14		**15-19**	**20- 24**	**25+**		**Totals**
Gender Male							
Female							
Age at ART Enrolment							
Current Age							
Treatment line on 2nd Line							
Art Duration Less than 1year							
Art Duration More than 1year							
Adherence Performance							
Good Adherence							
Poor Adherence							
Cumulative outcomes Transferred out							
Defaulters							
Died							

Stopped Retained and on ART							
Not retained							
STI status Infection							
Confirmed Infection							
Pregnancy Status							
Confirmed status							
Pregnancy outcome							
Miscarriage							
Live birth							
Abortion							
Contraception disbursed							

Appendix 17: Semi-structured observation guide

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi

Event name:
Place
Event Date
Event Participant

1. Observation

The observations will be used to establish rapport, with clinic staff and for sampling purposes to send out invitation and negotiate times for interviews with adolescents. An intensive observation will be done on a few adolescents during consultation sessions and SRH workshops.

2. Topic lists

2.1 At the ART clinic

- Attending clinic personnel's
- Attending adolescents
- How are the participants interacting?
- Is there dialogue?
- Who is talking/listening?
- What is their body language/non-verbal information?
- How is the atmosphere?
- Space's adolescents occupy during the sessions?
- Sitting plans, conversations and questions raised?

Question time	Person posing Questions	Context

2.2 At the Teen club

- Who attends the club? (Personnel? mentors? adolescents? formal speakers?)
- Are the same people attending the meetings of each month (age, gender)?
- Observations, from the moment an individual presents themselves at the club.
- Inquiries about SRH
- Interactions with staff
- The description of the environment, space and clinic atmosphere
- Description of the attitude of the participants
- Group dynamics

2.3 During consultations sessions

- Sit in on some consultations.
- What is being discussed? How often?
- How is the dialogue?
- Reference to SRH?
- Adolescent-Provider relationship

Other
Notes

Appendix 18: Information sheet and consent form for all study participants

Sexual and Reproductive Health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi.

Introduction

My name is Blessings N. Kaunda. I am a student at the University of Witwatersrand, School of Public Health and University of Malawi, College of Medicine, Blantyre Malawi. I would like to ask you to take part in a research study organised as part of the student thesis and is funded by Consortium for Advanced Research Training for Africa (CARTA). The study is voluntary and will take one year including reviewing your clinical records, service and resource use. However, you can leave it at any time from today.

Your taking part in this study is entirely voluntary. Please read the information below and ask questions about anything you do not understand, before deciding whether or not to participate.

Purpose of Study

I am organising research on adolescents accessing services in Blantyre at Umodzi clinic or community level. We would like to understand how adolescents' access and use services or resources in their environment. We are also interested in types of services you use for sexual reproductive health needs. We would like to understand how using the different resources/services improves their lives or not. If you agree to participate, I will be conducting an interview using a survey.

Study design and Procedures (What you will be asked to do)

I have to find out if the survey questions that I prepared for the interviews can be understood and answered by people in the same age group as you. The questions will be read out to you by the research study organisers. You will be expected to take part in a discussion with the researchers or in a group. The interview questions will be discussed out loud to find out if the CYRM questions make sense in the real world. You will sit and discuss the questions in groups depending on your age group15-16, 17-18 and 19.

The talks on survey or qualitative questions will take place in a conference room at Zomba/ Queen Elizabeth Central Hospital. The estimated time to complete the exercise is between 45-90 minutes. If at any time, you want to stop, I will do so without any penalty. You are free to refuse to answer any question I pose to you at any time.

Study Participants/ Who can participate in the study.

You are being invited to participate in the study:

1. Male or female
2. If you are between the ages of 15-19
3. In school or out-of-school

4. Attending or not attending a teen club
5. Facing any challenges in your life

Possible risks
Confidentiality cannot be guaranteed when taking part in focus group. When I ask you questions, you might feel embarrassment or upset. I would like to ask you to inform me. If you continue to feel upset, please tell me, and I will take you to the skilled person to get appropriate support.

Possible Benefits
The information I collect from you and the community will help address the challenges adolescents face when using or not using services. The findings will be shared with local service providers and key stakeholders at community and national level for better programme planning.

Compensation and Reimbursement
I am not providing any compensation for any participants in this research study. Transport reimbursement is amounting to MK 1000 for travelling to take part in the study at a central venue (College of Medicine or Malaria Alert Centre).

Confidentiality and Anonymity
All the information from this study will be kept a secret. Your name will not be used at any time in the data. I will use a number or fictitious name to protect you when I am talking or writing about you throughout my study. All data will be owned by the School of Public Health, University of the Witwatersrand and MAC-CDAC, College of Medicine. Recorded information (written and digitally-recorded) will be kept in a secure place under lock and key for a period of five years at the MAC-CDAC offices. Thereafter all information will be destroyed. No one other than the researcher and her supervisors will have access to the recorded material and the transcripts.

If you have any questions about this study, your rights, safety and wellbeing or any complaint, please contact Blessings N. Kaunda at Malaria Alert Center on 0888554052, The COMREC Secretariat on 01 871 911 ext 334.

This information sheet is for you to keep.

CONSENT FORM ADOLESCENTS PARTICIPATING IN FGD TO INFORM CYRM

SIGNATURE PAGE FOR STUDY PARTICIPANT

Sexual and Reproductive health service use and resilience among adolescents attending hospital teen clubs in Blantyre urban, Malawi.

I have had the study explained to me. I have understood all that has been read and had my questions answered satisfactorily. I understand that I can change my mind at any stage and it will not affect me in any way.

☐ **Yes** (please *tick) **I* agree to be interviewed.**

_____ _____

Full name of Participant Signature &Date

For those that cannot write:

Thumbprint: ----------

Participant's name and date written by: _____

Signature & Date

Witness name, signature and date are required only when the consenting participant is illiterate.

_____ _____

Name of Witness Signature & Date

I certify that s/he apparently understood the nature and the purpose of the study and consents to the participation in the study. S/he has been given opportunity to ask questions which have been answered satisfactorily.

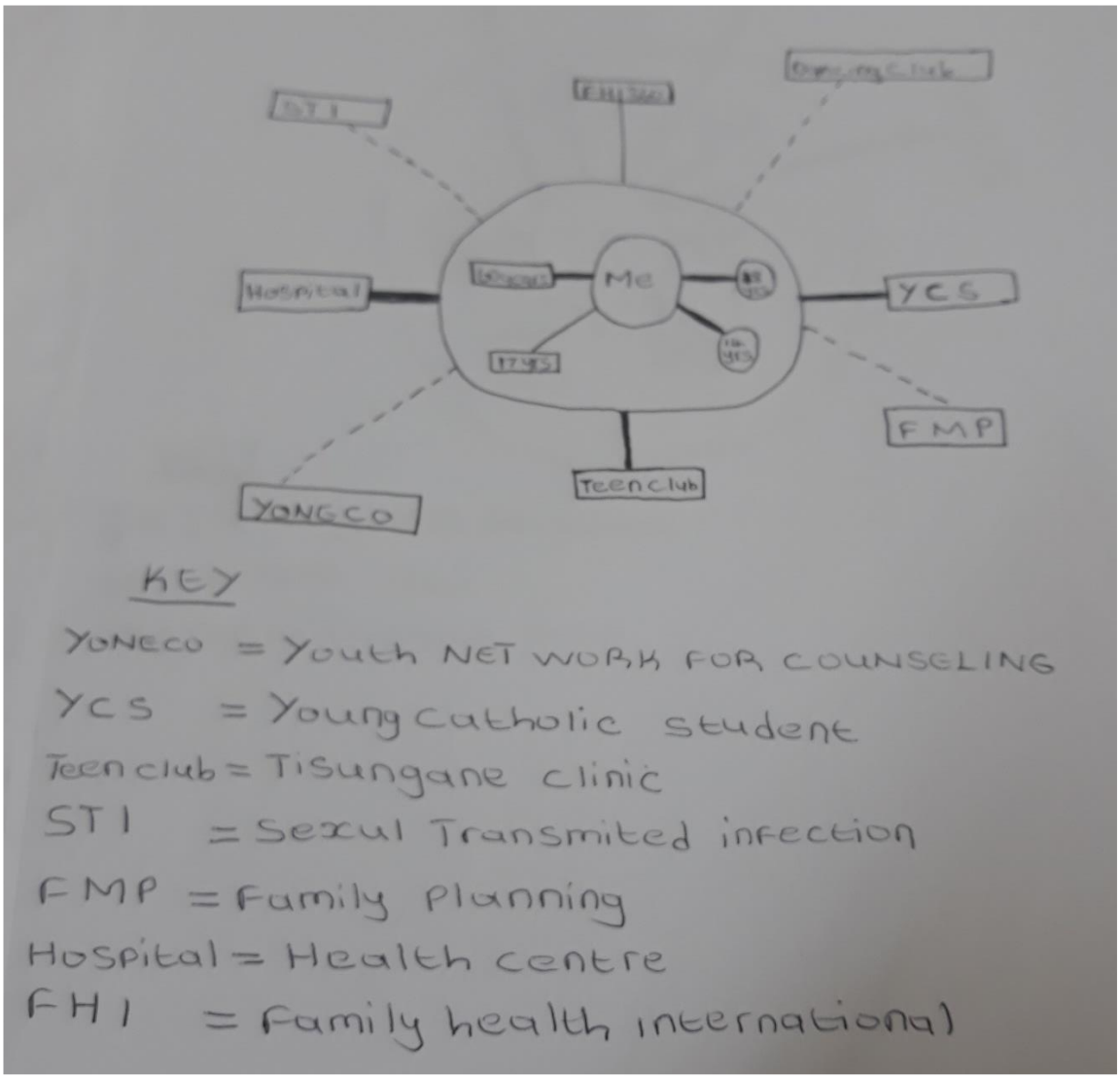
Signature: _____ _____

Designee/investigator _____ _____

Name ***(please print name)***

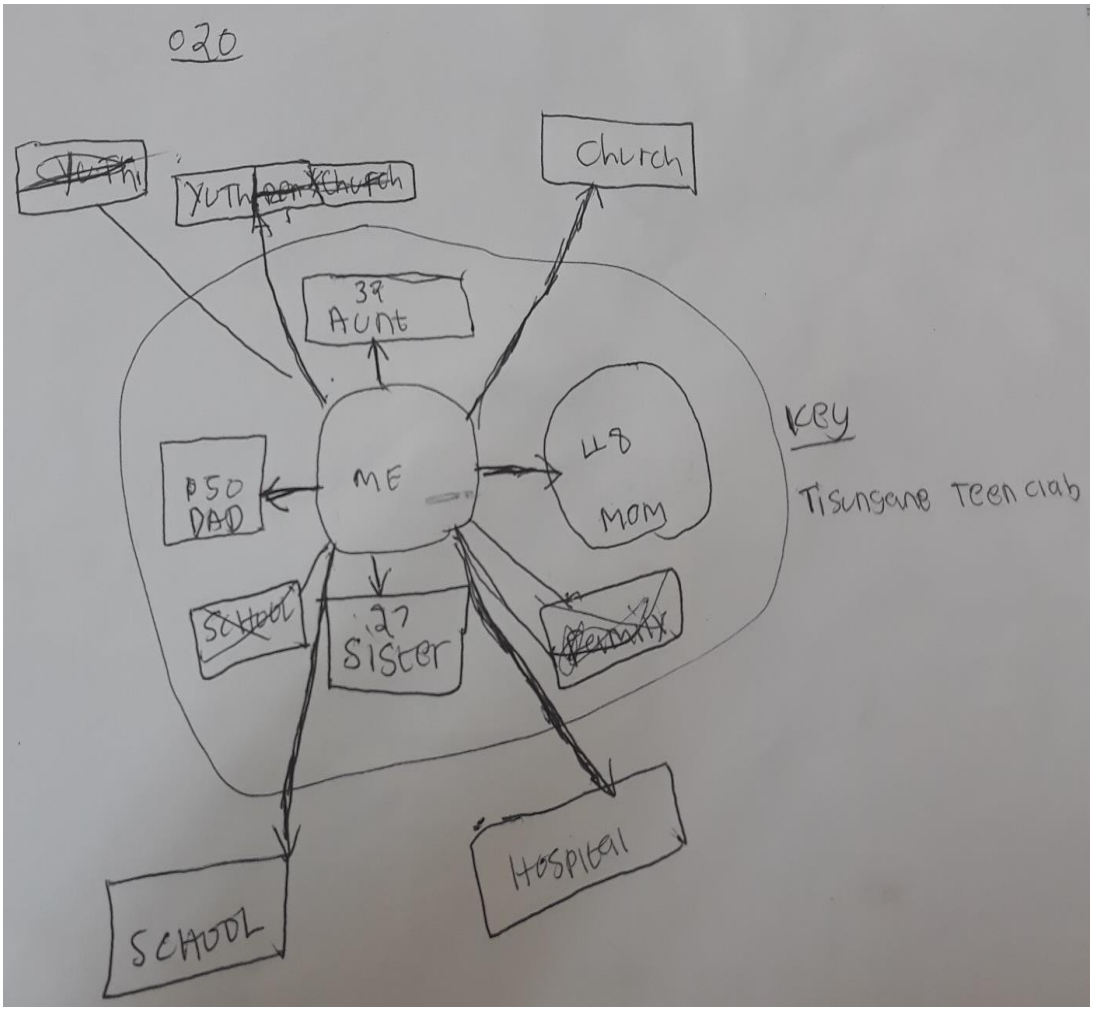
Thank you for agreeing to participate in this study

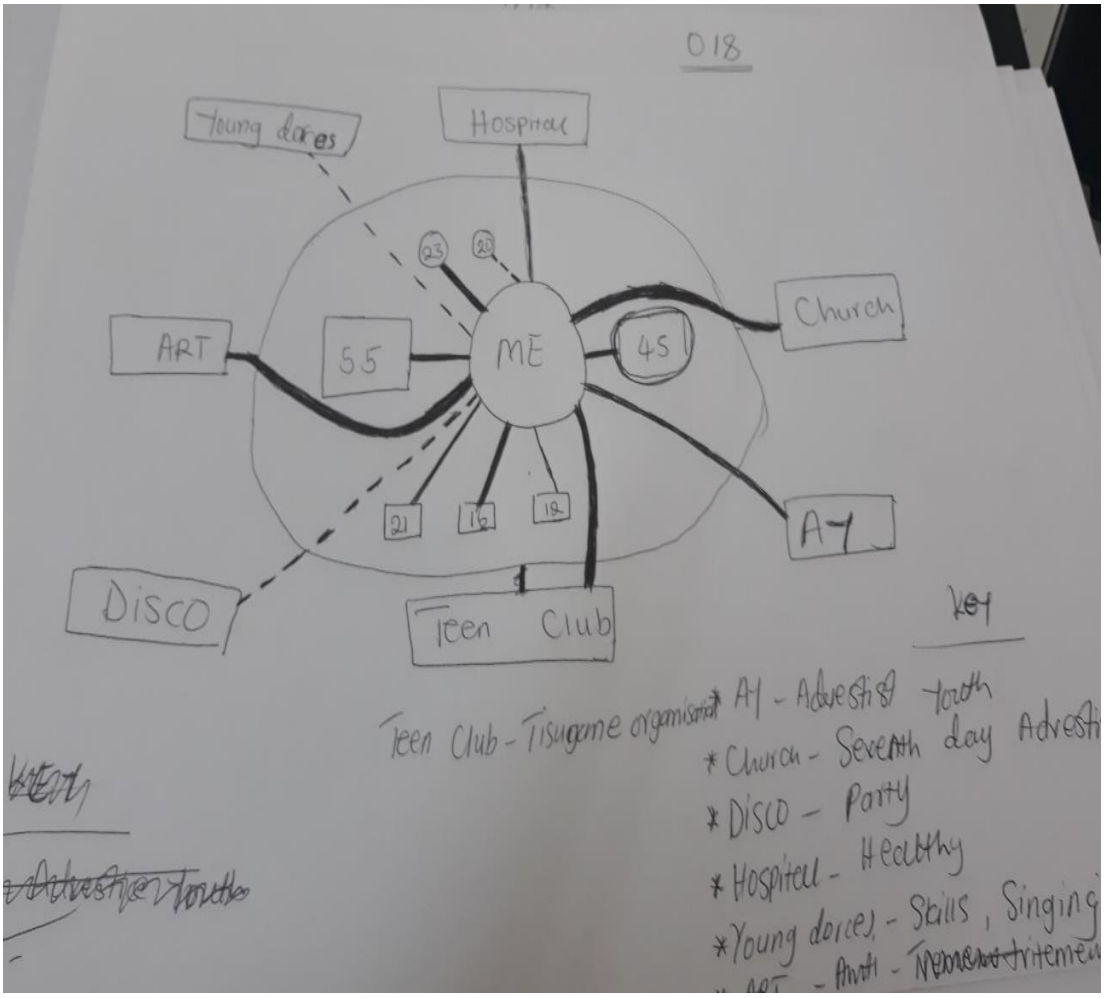
Appendix 19: Ecomaps drawn by ALHIV showing their resource support.



18-year old, striving to become an advocate for adolescents.

17-year old, dreaming of becoming a nurse.





16-year old, who frequents the disco to have fun and relax

Appendix 20: Plagiarism declaration and Turnitin cover page

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

I Blessings N. Kaunda (Student number: 1487823) am a student registered for the degree of Doctor of Philosophy, Public Health in the academic year 2017.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: Kaunda Date: 3 November 2020

1487823:Sexual_and_reproductive_health,_service_use_and_re.

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