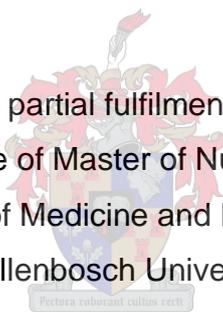


The development of a self-management intervention for adolescents living with HIV in a South African context: views of experts and key stakeholders

PETRA FRANCES ROCHER DE LANGE-CLOETE

Thesis presented in partial fulfilment of the requirements
for the degree of Master of Nursing Science
in the Faculty of Medicine and Health Sciences
Stellenbosch University



Supervisor: Dr Talitha Crowley

April 2022

DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third-party rights, and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Date: April 2022

Copyright © 2022 Stellenbosch University

All rights reserved

ABSTRACT

Background

Globally, many adolescents are living with human immunodeficiency virus (HIV). In South Africa, an estimated 360 000 adolescents were living with HIV in 2019. Adolescents also have poor health outcomes when compared to adults and children living with HIV. HIV is no longer recognised as an acute but rather a chronic condition involving lifelong medication and long-term holistic support and care. Self-management is an approach that may be helpful in changing behaviours, which could essentially lead to positive health outcomes. More research on self-management interventions is needed in the South African context to serve the unique needs of the adolescents to improve their treatment outcomes and quality of life. An adolescent HIV self-management intervention was developed in the context of South Africa using intervention mapping. As part of the development process, expert and stakeholder input is required.

Aim

The study aimed to explore the views of experts and key stakeholders as part of the development of a self-management intervention for ALWH in a South African context, to refine the intervention.

Methods

For this study, a descriptive qualitative design was used. The intervention's content validity was determined by consulting nine national and international experts. Moreover, the revised intervention was presented to 18 key stakeholders (11 adolescents living with HIV and 7 healthcare workers) during four focus groups in the Cape Metropole of the Western Cape to obtain further feedback. Data were analysed using the content validity index (CVI) and thematic analysis. Ethical approval was obtained from the Health Research Ethics Committee of the University of Stellenbosch, and permission was obtained from the Western Cape Department of Health. The researcher aimed to meet the four criteria of dependability, confirmability, credibility, and transferability to ensure trustworthiness.

Results

Item relevancy for all the components (outcomes, objectives, strategies, format, setting, timing, and facilitators) had a CVI rating of more than 0.8, indicating validity. Experts and key stakeholders agreed on the need for and importance of the intervention, emphasising the focus on ALWH's well-being, and objectives and content beyond HIV. The practical strategies appeared acceptable and feasible, but individual counselling/coaching may require additional human resource support. Components were revised based on the feedback, and several parameters for effective implementation were identified.

Conclusion

Progress in health outcomes among ALWH is lagging. Interventions and programmes that are showing promising results in supporting ALWH should be placed at the forefront of development. Following further refinement, this intervention might be a solution to ALWH in South Africa and the African context, which may support and guide them and healthcare workers in reaching treatment targets and ensuring a thriving population of ALWH.

Keywords

Adolescence, adolescents living with HIV (ALWH), HIV, self-management

OPSOMMING

Agtergrond

Wêreldwyd is daar heelwat adolessente wat met die menslike immuuniteitsgebrek virus (MIV) leef. Na raming het daar in 2019 360 000 adolessente met MIV (ALMM) in Suid-Afrika geleef. Adolessente het ontoereikende gesondheidsuitkomst in vergelyking met volwassenes en kinders wat met MIV leef. MIV word nie meer as 'n akute toestand beskou nie, maar eerder 'n chroniese toestand wat die gebruik van lewenslange medikasie en langtermyn holistiese ondersteuning en sorg behels. Selfbestuur is 'n benadering wat nuttig kan wees om gedrag te verander wat in wese tot positiewe gesondheidsuitkomst kan lei. Meer navorsing in selfbestuur-intervensies is nodig in die Suid-Afrikaanse konteks om in die unieke behoeftes van die adolessente te voorsien en sodoende hul behandelingsuitkomst en lewenskwaliteit te verbeter. 'n Adolessent MIV-selfbestuursintervensie is in die konteks van Suid-Afrika ontwikkel deur intervensiekartering te gebruik. As deel van die ontwikkelingsproses word insette van kundiges en belanghebbendes vereis.

Doel

Die studie het ten doel gehad om die sienings van kundiges en sleutelbelanghebbendes te verken as deel van die ontwikkeling van 'n selfbestuur-intervensie vir ALMM in 'n Suid-Afrikaanse konteks, om die intervensie te verfyn.

Metode

Vir hierdie studie is 'n beskrywende kwalitatiewe ontwerp gebruik. Die inhoudsgeldigheid van die intervensie is bepaal deur nege nasionale en internasionale kundiges te raadpleeg. Die hersiene intervensie is tydens vier fokusgroepe in die Kaapse Metropool van die Wes-Kaap aan 18 sleutelbelanghebbendes (11 adolessente wat met MIV leef en 7 gesondheidsorgwerkers) aangebied om verdere terugvoer te verkry. Data is ontleed deur die inhoudsgeldigheidsindeks (IGI) en tematiese analise te gebruik. Etiese goedkeuring is verkry van die Gesondheidsnavorsingsetiekkomitee van die Universiteit van Stellenbosch asook toestemming van die Wes-Kaapse Departement van Gesondheid. Om betroubaarheid

te verseker het die navorser daarop gemik om aan die vier kriteria van betroubaarheid, bevestigbaarheid, geloofwaardigheid en oordraagbaarheid te voldoen.

Resultate

Itemrelevansie vir al die komponente (uitkomst, doelwitte, strategieë, formaat, opset, tydsberekening en fasiliteerders) het 'n IGI-gradering van meer as 0.8 gehad wat geldigheid aandui. Kundiges en sleutelbelanghebbendes het saamgestem oor die behoefte aan en belangrikheid van die intervensie, met die klem op die fokus op die welstand van ALMM, en doelwitte en inhoud buite MIV. Die praktiese strategieë blyk aanvaarbaar en uitvoerbaar te wees, maar individuele berading/afrigting kan addisionele menslike hulpbronnondersteuning vereis. Komponente is hersien op grond van die terugvoer en verskeie parameters vir effektiewe implementering is geïdentifiseer.

Slotsom

Vordering in gesondheidsuitkomst van ALMM is agterweë. Intervensies en programme wat belowende resultate toon om ALMM te ondersteun, moet op die voorpunt vir ontwikkeling geplaas word. Na verdere verfyning, kan hierdie ingryping 'n oplossing vir ALMM in Suid-Afrika en die Afrika-konteks wees om hulle en gesondheidsorgwerkers te ondersteun en te lei om behandelingsteikens te bereik en 'n florerende bevolking van ALMM te verseker.

Sleutelwoorde:

MIV, adolesensie, adolessente wat met MIV leef, self-bestuur

ACKNOWLEDGEMENTS

This study would not have been possible without the financial support of the National Research Foundation (NRF) of South Africa.

Opinions expressed and conclusions arrived at are those of the author and are not attributed to the funders.

I would like to express my sincere thanks to:

- Talitha Crowley, my supervisor, colleague and friend who has been by my side and available 24/7. Your compassion and patience with your students are remarkable. Your love for research and the profession of nursing is admirable.
- Louise Wilson, study participants, Beautiful Gate and Crossroads Clinic, who assisted in the organisation and planning around focus groups.
- Danine and Sr Mercia Cronje, who both played a pivotal role in me becoming a primary nurse specialist and following this academic career path as a proud nursing scholar.
- Tannie Elsje and the late Oom Paul, who played a valuable role in my formative years and who encouraged me on my journey to becoming a very proud nurse.
- My friends and family who have supported me with their kind words and numerous text messages of encouragement.
- My brothers, Nico and Schalk, who encouraged me to start my undergraduate studies as soon as I finished matric, and have supported me in ways they won't even realise.
- I dedicate this thesis to my mom Elsa and my late father, Pieter, who have always been enthusiastic about my career choices, and supported and encouraged me to become the best version of myself. You have always believed in me.
- And finally, by husband, Janes. For your love and support from the start. Thank you for always being positive and supporting me in my career and studies.

TABLE OF CONTENTS

| | |
|------------------------|-----|
| DECLARATION | i |
| ABSTRACT | ii |
| OPSOMMING | iv |
| ACKNOWLEDGEMENTS | iv |
| ABBREVIATIONS..... | xiv |

CHAPTER 1: FOUNDATION OF THE STUDY

| | |
|--|----|
| 1.1 INTRODUCTION | 1 |
| 1.2 BACKGROUND AND RATIONALE | 3 |
| 1.2.1 Self-management and self-management interventions | 3 |
| 1.2.2 Self-management interventions for adolescents living with HIV..... | 4 |
| 1.2.3 Intervention mapping | 5 |
| 1.2.4 Brief description of the developed intervention | 7 |
| 1.3 PROBLEM STATEMENT | 8 |
| 1.4 RESEARCH QUESTION..... | 8 |
| 1.5 RESEARCH AIM | 8 |
| 1.6 RESEARCH OBJECTIVES..... | 9 |
| 1.7 RESEARCH METHODOLOGY..... | 9 |
| 1.7.1 Research design | 9 |
| 1.7.2 Study setting..... | 10 |
| 1.7.3 Population and sample | 10 |
| 1.7.4 Pilot test and pilot interview | 11 |
| 1.7.5 Trustworthiness..... | 11 |
| 1.7.6 Recruitment and data collection | 11 |
| 1.7.7 Data analysis..... | 11 |
| 1.8 ETHICAL CONSIDERATIONS..... | 12 |
| 1.9 DEFINITIONS | 12 |
| 1.10 DURATION OF THE STUDY | 13 |
| 1.11 CHAPTER OUTLINE..... | 14 |
| 1.12 SIGNIFICANCE OF THE STUDY | 14 |
| 1.13 SUMMARY..... | 15 |

CHAPTER 2: LITERATURE REVIEW

| | | |
|-------|--|----|
| 2.1 | INTRODUCTION | 16 |
| 2.2 | ELECTING AND REVIEWING THE LITERATURE..... | 16 |
| 2.3 | OVERVIEW OF ADOLESCENTS LIVING WITH HIV GLOBALLY AND IN SOUTH AFRICA | 17 |
| 2.3.1 | Adolescents and HIV internationally..... | 17 |
| 2.3.2 | Adolescents and HIV in South Africa | 19 |
| 2.4 | SELF-MANAGEMENT PROCESSES, TASKS AND NEEDS OF Alwh..... | 20 |
| 2.4.1 | Self-management processes | 21 |
| 2.4.2 | Self-management tasks | 22 |
| 2.4.3 | Self-management needs..... | 24 |
| 2.5 | SELF-MANAGEMENT PROGRAMMES/INTERVENTIONS FOR ALWH | 26 |
| 2.5.1 | Type of interventions (methods and strategies)..... | 27 |
| 2.5.2 | Delivery format and duration..... | 28 |
| 2.5.3 | Setting | 29 |
| 2.5.4 | Facilitators | 30 |
| 2.6 | SUMMARY..... | 30 |

CHAPTER 3: RESEARCH METHODOLOGY

| | | |
|---------|-------------------------------|----|
| 3.1 | INTRODUCTION | 32 |
| 3.2 | AIM AND OBJECTIVES | 32 |
| 3.3 | STUDY SETTING | 33 |
| 3.4 | RESEARCH DESIGN..... | 35 |
| 3.5 | POPULATION AND SAMPLING..... | 36 |
| 3.5.1 | Population | 36 |
| 3.5.1.1 | Expert panel..... | 36 |
| 3.5.1.2 | Focus groups | 36 |
| 3.5.2 | Sampling and sample size..... | 37 |
| 3.5.2.1 | Expert panel..... | 37 |
| 3.5.2.2 | Focus groups | 37 |
| 3.5.3 | Inclusion criteria | 38 |
| 3.6 | RECRUITMENT..... | 39 |
| 3.6.1 | Expert panel | 39 |

| | | |
|----------|---|----|
| 3.6.2 | Focus groups..... | 39 |
| 3.6.3 | Data collection tools..... | 40 |
| 3.7 | PILOT TEST AND INTERVIEW | 41 |
| 3.7.1 | Expert panel | 41 |
| 3.7.2 | Focus groups..... | 42 |
| 3.8 | DATA COLLECTION..... | 42 |
| 3.8.1 | Expert panel | 42 |
| 3.8.2 | Focus groups..... | 43 |
| 3.9 | RIGOUR..... | 45 |
| 3.9.1 | Credibility..... | 45 |
| 3.9.2 | Transferability..... | 45 |
| 3.9.3 | Dependability..... | 46 |
| 3.9.4 | Confirmability..... | 46 |
| 3.10 | DATA ANALYSIS..... | 47 |
| 3.10.1 | Expert panel | 47 |
| 3.10.2 | Focus groups..... | 48 |
| 3.10.2.1 | Phase one: Familiarising yourself with your data..... | 49 |
| 3.10.2.2 | Phase two: Generating initial codes | 49 |
| 3.10.2.3 | Phase three: Searching for themes | 49 |
| 3.10.2.4 | Phase four: Reviewing themes..... | 50 |
| 3.10.2.5 | Phase five: Defining and naming themes..... | 50 |
| 3.10.2.6 | Phase six: Producing the report | 50 |
| 3.11 | ETHICAL CONSIDERATIONS..... | 50 |
| 3.11.1 | Right to self-determination..... | 51 |
| 3.11.2 | Right to confidentiality and anonymity..... | 51 |
| 3.11.3 | Right to protection from discomfort and harm..... | 52 |
| 3.11.3.1 | COVID-19 specific measures | 52 |
| 3.12 | SUMMARY..... | 53 |

CHAPTER 4: FINDINGS

| | | |
|-------|------------------------------------|----|
| 4.1 | INTRODUCTION | 55 |
| 4.2 | EXPERT PANEL..... | 55 |
| 4.2.1 | Biographical data of experts | 55 |

| | | |
|---------|---|----|
| 4.2.2 | Results of expert feedback | 56 |
| 4.2.2.1 | Content clarity and validity indexes..... | 56 |
| 4.2.2.2 | Qualitative feedback and revisions | 58 |
| 4.3 | FOCUS GROUPS..... | 65 |
| 4.3.1 | Section A: Biographical data..... | 65 |
| 4.3.2 | Section B: Themes emerging from the data analysis | 65 |
| 4.3.2.1 | Theme one: Programme aim and outcomes | 66 |
| 4.3.2.2 | Theme two: Programme content, format, and practical strategies .. | 70 |
| 4.3.2.3 | Theme three: Programme facilitators, duration and setting | 74 |
| 4.4 | SUMMARY..... | 77 |

CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

| | | |
|-------|---|----|
| 5.1 | INTRODUCTION | 78 |
| 5.2 | DISCUSSION | 78 |
| 5.2.1 | Objective 1: To explore if the objectives and outcomes of the intervention are relevant and clearly defined | 78 |
| 5.2.2 | Objective 2: To determine if the theoretical methods and practical strategies of the intervention are relevant and feasible | 80 |
| 5.2.3 | Objective 3: To establish if the format, setting, programme duration, and leaders/facilitators of the intervention are relevant and feasible | 83 |
| 5.2.4 | Objective 4: To explore if the intervention contents are clearly described and relevant..... | 86 |
| 5.3 | LIMITATIONS OF THE STUDY | 87 |
| 5.4 | CONCLUSIONS | 88 |
| 5.5 | RECOMMENDATIONS | 88 |
| 5.5.1 | Recommendation 1: Further development of the intervention's components..... | 88 |
| 5.5.2 | Recommendation 2: Development of training guides..... | 88 |
| 5.5.3 | Recommendation 3: Piloting and development of implementation guidelines | 89 |
| 5.6 | DISSEMINATION | 89 |
| 5.7 | CONCLUSION..... | 90 |
| | REFERENCES | 91 |

LIST OF TABLES

| | |
|--|----|
| Table 2.1: Specific self-management tasks..... | 23 |
| Table 3.1: Example of initial code generation..... | 49 |
| Table 3.2: Example of a theme and sub-themes..... | 50 |
| Table 4.1: Summary: Biographical data of experts | 55 |
| Table 4.2: Results of expert feedback | 57 |
| Table 4.3: Demographic details of focus group participants | 65 |
| Table 4.4: Themes and sub-themes | 66 |

LIST OF FIGURES

| | |
|--|----|
| Figure 1.1: Intervention Logic Model..... | 7 |
| Figure 1.2: Overview of Research Methodology | 10 |
| Figure 2.1: Self-management processes applied to ALWH..... | 22 |

APPENDICES

| | |
|---|-----|
| Appendix 1: Ethical approval from Stellenbosch University | 101 |
| Appendix 2: Ethics Progress report from Stellenbosch University | 103 |
| Appendix 3: Permission obtained from Western Cape Department of Health..... | 103 |
| Appendix 4: Consent Forms | 104 |
| Appendix 5: Legal Guardian/Parent Participation Consent Form | 108 |
| Appendix 6: Expert Questionnaire..... | 112 |
| Appendix 7: Interview Guide..... | 131 |
| Appendix 8: Summary of changes based on expert feedback..... | 136 |
| Appendix 9: Facilitator guide frontpage..... | 166 |
| Appendix 10: Workbook frontpage..... | 167 |
| Appendix 11: Language editing certificate..... | 168 |

ABBREVIATIONS

| | |
|----------|--------------------------------------|
| AIDS | Acquired Immune Deficiency Syndrome |
| ALWH | Adolescents Living with HIV |
| ART | Antiretroviral Therapy |
| ARV | Anti-Retro Viral |
| CBT | Cognitive Behavioural Therapy |
| CD4 | Cluster of differentiation 4 |
| HIV | Human Immunodeficiency Virus |
| HRQL | Health Related Quality of Life |
| ICT | Information-communication technology |
| IM | Intervention Mapping |
| NGO | Non-governmental Organisation |
| PLWH | People Living with HIV |
| SM | Self-Management |
| Stats SA | Statistics South Africa |
| STI | Sexually Transmitted Infection |
| UNAIDS | United Nations Program on HIV/AIDS |
| UNICEF | United Nations Children's Fund |
| VL | Viral Load |
| WHO | World Health Organisation |
| YLWH | Youth Living with HIV |

CHAPTER 1

FOUNDATION OF THE STUDY

1.1 INTRODUCTION

“When a child is diagnosed with HIV, a journey begins. Throughout this journey, children, families, and caregivers will need information and support.” (Nsaba et al. 2018:2)

There are approximately 1.75 million adolescents (aged 10–19 years) globally living with the human immunodeficiency virus (HIV) (United Nations Children’s Fund [UNICEF], 2021). In Africa, acquired immune deficiency syndrome (AIDS) is the leading cause of death amongst adolescents (United Nations Program on HIV/AIDS [UNAIDS], 2015), and an estimated 740 000 adolescents could become infected with HIV/AIDS between 2016 and 2030 (UNICEF, 2016:6).

In 2020, South Africa reported an estimated 7.8 million adults (15 years +) and 360 000 adolescents were living with HIV in 2019 (UNAIDS, 2019; UNAIDS, 2020). Moreover, the prevalence of adolescents infected both perinatally and behaviourally accounts for 11% of South Africa’s total number of people living with HIV (Zanoni, Archary, Buchan, Katz & Haberer, 2016:1-2).

Significantly, lower retention and viral suppression rates were found amongst adolescents in a systematic review of several South African studies compared with adults (Zanoni et al., 2016:4). With these statistics in hand, there is a dire need to focus research on HIV management amongst this vulnerable population group in South Africa. Increasing adolescents living with HIV’s (ALWH) chronic disease self-management (SM) skills might have a positive effect on their healthcare outcomes and well-being (Crowley, Van der Merwe, Kidd & Skinner, 2019:1).

Self-management in people with chronic conditions entails a person’s ability to daily manage the symptoms and treatment of their chronic condition and the effect of the illness on their physical and psychosocial well-being (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002:178; Grady & Gough, 2014:e26). In this study, SM is defined as

“the processes and behaviours adolescents engage in, to take care of their chronic illness with the assistance of their caregivers, health workers, family, friends, peers and educators” (Crowley, 2018:217).

ALWH’s SM needs are complicated and include adherence to lifelong medication regimes (Mutumba, Mugerwa, Mussiime, Gautam, Nakyambadde, Matama & Stephenson, 2019:1). Most research amongst ALWH focused on medication adherence and medical management, which is only one domain of SM (Sattoe, Bal, Roelofs, Bal, Miedema & van Staa, 2015:704). A gap in research was thus identified during the review of literature regarding adolescent HIV management and interventions that may improve and promote positive care outcomes for this population group (Armstrong, Nagata, Vicari, Irvine, Cluver, Sohn, Ferguson, Caswell, Njenga, Oliveras, Ross, Puthanakit, Baggaley & Penazzato, 2018:S19; Mutumba et al., 2019:1).

There are no interventions known to the researcher that focus on improving the SM skills of ALWH in South Africa. Therefore, this study is part of a larger study that aims to develop an SM intervention for ALWH. The larger study uses intervention mapping (IM) as an approach to develop the intervention. IM is a theory- and evidence-based approach to intervention design that helps programme planners (through a set of steps) identify changeable determinants of risk behaviours, select appropriate intervention methods, and develop implementation strategies. According to the IM approach, key stakeholders’ opinions need to be considered when developing new interventions (Fernandez, Robert, Markham & Kok, 2019:2).

In the larger study, the researchers have already identified preliminary programme outcomes, objectives, methods, and practical strategies to implement the intervention, based on the literature and theory. The researcher is a master’s degree student and part of a team working on the development of this SM intervention. This present study thus focused on exploring experts’ (such as researchers working with ALWH and academics familiar with SM science) and key stakeholders (such as adolescents and healthcare workers) views and opinions of a SM intervention that was developed for ALWH. This data will be used to revise the intervention to ensure selected methods and strategies are appropriate for the context and population of ALWH in South Africa.

1.2 BACKGROUND AND RATIONALE

1.2.1 Self-management and self-management interventions

According to seminal work of Ryan and Sawin (2009:217-223), SM skills and abilities are associated with improved health behaviours, outcomes, and quality of life, which could be of great benefit to ALWH. SM interventions may also be more effective than traditional patient education. Interventions designed to improve SM usually focus on improving SM processes, such as knowledge and beliefs, self-regulation, and social facilitation, as these are the most amenable to change (Ryan & Sawin, 2009:226).

A systematic review by Bal, Sattoe, Roelofs, Bal, van Staa and Miedema (2016:1293) found SM interventions to be effective in chronic conditions in young people, irrespective of the diagnosis. Another scoping review by Bernardin, Toews, Restall and Vuongphan (2013:314) reported that SM interventions might be an effective approach for improving outcomes, specifically in people living with HIV.

However, there is also a need for SM interventions for particular population groups across different geographical locations (Mutumba et al., 2019:6). A cross-sectional study has shown that SM is associated with better health outcomes (adherence, health-related quality of life, and viral suppression) in the South African context (Crowley et al., 2019:1). However, no SM intervention for adolescents was identified in the South African context. It was therefore decided to develop an SM intervention that will focus on the needs of ALWH in a South African context, with the overall aim of improving adolescent outcomes, including their quality of life and well-being.

SM programmes or interventions help individuals improve the skills, abilities, and behaviour needed to manage their chronic condition by means of self-empowerment (Sawin, 2017:170). In a scoping review by Bernardin et al. (2013:321) on SM interventions for people living with HIV, the authors identified the following knowledge, skills and attitudes taught in SM programmes: 1) self-care; 2) interpersonal skills; 3) technical knowledge; 4) cognitive skills; 5) positive attitudes; and 6) planning for future roles. However, these skills were not specific to ALWH.

One well-known SM programme is the Stanford Chronic Disease Self-Management Programme (CDSMP), developed by Kate Lorig and colleagues in the early 1990s. The programme is peer-taught and based on self-efficacy theory. Participants enhance their SM skills through skills mastery, modelling, reinterpretation and social persuasion (Lorig, 2015:1-3). This programme has improved health outcomes and has been translated and used globally and adapted for people living with HIV (Positive Self-Management Programme for People Living with HIV). However, to the researcher's knowledge, it has not yet been adapted or used for ALWH.

1.2.2 Self-management interventions for adolescents living with HIV

As stated, at the time of this study, there were no specific SM interventions for ALWH. However, several programmes and resources were identified as potential best practices for adolescent and youth-friendly HIV services (Gage, Do & Grant, 2017) that may also assist adolescents in acquiring SM skills and transition to adult care. Some interventions that have been implemented in the African context are summarised in the sections that follow. Other interventions found in the literature with the potential for adaptation are discussed in more detail in Chapter 2.

The Toolkit for the Transition of Care and other Services for ALWH provides resources to support adolescents and families to build resilience and SM skills during their transition from adolescent care to adult care. The toolkit was implemented in Kenya and focused on healthcare providers and adolescents (Gage, Do & Grant, 2017:190). The toolkit provides a framework to track adolescents' progress to self-care and adult services, and is intended to enhance healthcare workers' and caregivers' knowledge of adolescents' needs during the transition process (Duffy, Bergmann & Sharer, 2014:5-104; Gage, Do & Grant, 2017:190). The toolkit's acceptability was tested through interviews with healthcare and community workers. Currently, certain aspects of the toolkit are being implemented and researched in Zambia (Sharer, 2019).

The Supporting Youth and Motivating Positive Action (SYMPA) project in the Democratic Republic of Congo was developed with the aim of helping ALWH cope with HIV in the context of their emerging independence and sexuality (Gage, Do & Grant, 2017:98). The intervention consists of six 90-minute group sessions over six weeks,

with 5–10 participants in each group (same-sex groups). Psychosocial counsellors and one nurse teach the sessions. A qualitative feasibility study was conducted on this intervention and showed promise, but the intervention has not been sustained over time (Parker, Maman, Pettifor, Chalachala, Edmonds, Golin, Moracco & Behets, 2013; Gage, Do & Grant, 2017:102).

The Wits Reproductive Health Institute (RHI) adolescent toolkit for healthcare workers in the South African context is a handbook and toolkit meant to support healthcare workers working with adolescents. However, no specific implementation plan could be identified (Fick, Fairlie, Moultrie, Woollett, Pahad, Thomson & Pleaner, 2015). Similarly, an integrated teen club curriculum has been developed in Swaziland (Strengthening High-Impact Interventions for AIDS-free Generation [AIDSFree] Project, 2017) that has not yet been evaluated scientifically.

Since no existing adolescent SM intervention could be identified in the South African context, a theory-informed and evidence-based intervention was developed using the IM approach. The IM approach allows researchers to use the literature and draw from existing theory, evidence-based methods, and best practices to tailor an intervention for a specific target group.

1.2.3 Intervention mapping

IM comprises six steps, and on completion of each step, the product guides the researcher to the next step. When all the steps are completed, the results guide the design, implementation, and evaluation of the SM intervention (Kok, 2014:157). The six steps include: 1) Needs assessment, literature review, and focus groups; 2) Identification of outcomes, performance objectives and change objectives; 3) Selecting methods and practical strategies; 4) Creating an organised programme plan; 5) Creating an adoption and implementation plan; and 6) Creating an evaluation plan (Detaille, Van Der Gulden, Engels, Heerkens & Van Dijk, 2010:2-5).

For the intervention under study, the first step of IM was informed by data from a PhD study conducted in the Cape Metropole of the Western Cape on the development of an instrument to measure adolescent HIV SM (Crowley, 2018), theory and a literature

review. This assisted the researchers of the larger study in creating a logic model of the problem (see Figure 1.1).

The IM's preliminary methods, practical strategies, programme structure and content (Steps 2 and 3) are derived from known adolescent transition/SM programmes (Parker et al., 2013; Duffy, Bergmann & Sharer, 2014), adolescent toolkits (Fick et al., 2015), adolescent curriculums (AIDSFree Project, 2017) and guidelines (Cincinnati Children's Hospital, 2007), adult SM programmes (Lorig, 2015), qualitative studies (Adams, 2019; Mutumba et al., 2019), a scoping review of component interventions to promote SM in adults (Bernardin et al., 2013), and a systematic review of effective interventions to enhance SM among ALWH (Crowley & Rohwer, 2021).

Certain aspects, such as the target group, need to be considered when designing an intervention for ALWH, which in this case, can be adolescents who are either perinatally or behaviourally infected. Perinatally infected adolescents acquire HIV through mother-to-child transmission and are now surviving to adolescence and beyond (Sherr, Cluver, Toska & He, 2018:93). Behaviourally infected adolescents acquired the virus through sexual exposure (Sherr et al., 2018:93). These two sub-populations could have different needs that may need to be considered when designing an SM intervention. For this study, both sub-populations were included. The intervention focused on older adolescents (aged 15–19) as they were preparing for or in the process of transitioning to adult care and may benefit greatly from acquiring SM skills.

The contextual factors that may influence SM, for example, the condition-specific factors (complex medication regimes in HIV), social and physical environment (including healthcare services), and individual and family factors (including the age of the adolescent and family structure and functioning) had to be considered when planning the intervention (Swendeman, Barbara, Ingram & Rotheram-Borus, 2009:1324). Other aspects that needed to be contemplated were the challenges and stressors this vulnerable group face every day. Some challenges include living with a lifelong illness, stigma, discrimination, managing the disclosure of their condition, and social isolation or rejection (Swendeman et al., 2009:1326; Crowley, Van der Merwe & Skinner, 2019).

Although the preliminary intervention objectives, methods, practical strategies, programme structure, and content were developed based on sound methods, the IM approach suggested that experts and key stakeholders be consulted to ensure the intervention is methodologically sound and contextually relevant and sustainable. Experts' and key stakeholders' opinions ensured a positive outcome that would increase the likelihood of an effective and successful intervention (Fernandez et al., 2019:1). The experts' and key stakeholders' opinions were used to further refine the intervention and develop materials for implementation. After this study, the intervention will be piloted to test its acceptability, feasibility, and preliminary efficacy.

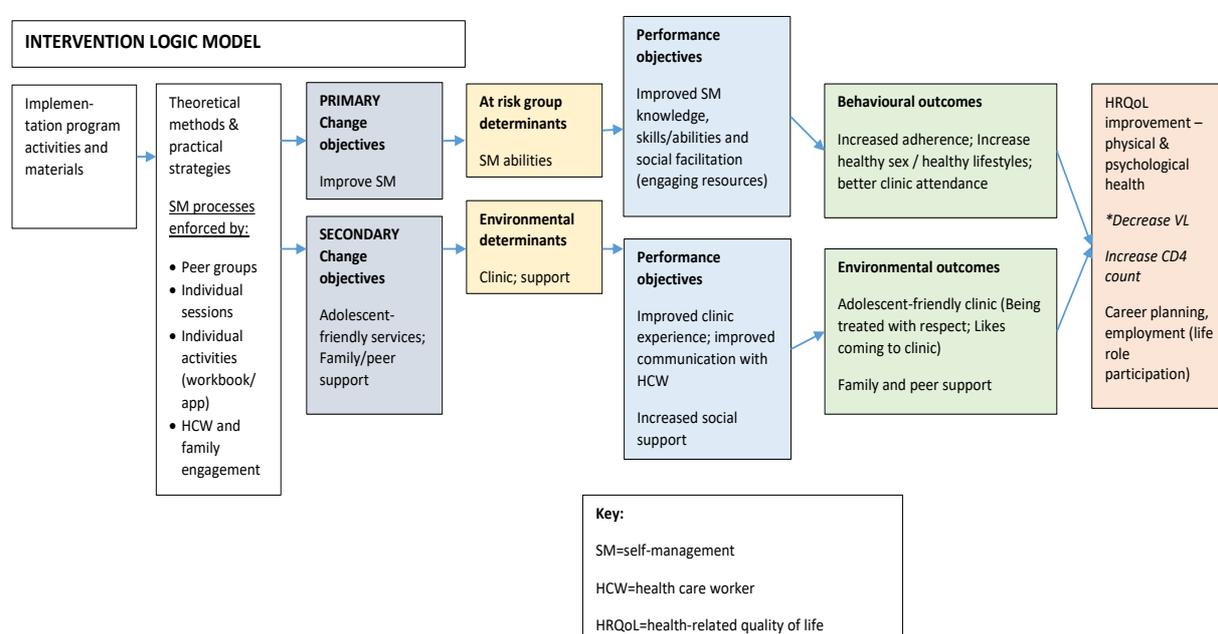


Figure 1.1: Intervention Logic Model

1.2.4 Brief description of the developed intervention

The developed intervention is focused on adolescents aged 15–19 and aims to improve their SM skills, adherence to treatment, clinic attendance, feelings of support from health workers, family and peers, and satisfaction with health services. It also aims to reduce risky behaviours and improve treatment (increased viral suppression and CD4 counts) and health (mental/psychological health and quality of life) outcomes.

The intervention consists of a 12-week programme that includes peer-group sessions led by older youth living with HIV (YLWH) (19–24). Individual counselling sessions are conducted using coaching or motivational interviewing techniques. Adolescents have to complete activities focused on the following SM components: 1) knowledge and beliefs; 2) goals and facilitation; 3) participation; 4) biomedical management; and 5) coping and self-regulation. It is envisioned that activities be completed in a workbook or via a smartphone application.

Family and healthcare worker engagement is realised through healthcare workers attending one peer-group session to discuss adolescent-friendly services with adolescents, and a family member attends the last individual counselling session with the adolescent to engage with them in future planning and support.

1.3 PROBLEM STATEMENT

Currently, there are no SM interventions known to the researcher for ALWH in South Africa. A preliminary intervention was thus designed based on the IM approach, but experts' and key stakeholders' views on the development of the SM intervention for ALWH have not yet been explored. Their views are critical to refining the intervention and ensuring that it is implementable, sustainable, and effective (Fernandez et al., 2019: 1).

1.4 RESEARCH QUESTION

How can the views of experts and key stakeholders contribute to the development of an SM intervention for ALWH in a South African context?

1.5 RESEARCH AIM

To explore the views of experts and key stakeholders as part of the development of an SM intervention for ALWH in a South African context, to refine the intervention.

1.6 RESEARCH OBJECTIVES

1. To explore if the objectives and outcomes of the intervention are relevant and clearly defined.
2. To determine if the theoretical methods and practical strategies of the intervention are relevant and feasible.
3. To establish if the format, setting, programme duration, and leaders/facilitators of the intervention are relevant and feasible.
4. To explore if the intervention contents are clearly described and relevant.

1.7 RESEARCH METHODOLOGY

Figure 1.2 illustrates an overview of the methods used in this study. The research methodology is discussed in more detail in Chapter 3.

1.7.1 Research design

The researcher explored experts' and key stakeholders' views in the development of an SM intervention for ALWH in a South African context by following a qualitative exploratory-descriptive approach. Firstly, an expert panel was consulted, and their views were incorporated in a revised draft of the intervention. Moreover, based on their feedback, an adolescent workbook and facilitator guide (see Appendices 9 and 10 for an excerpt) was developed. Secondly, the revised proposed intervention and materials were presented to key stakeholders in focus groups.

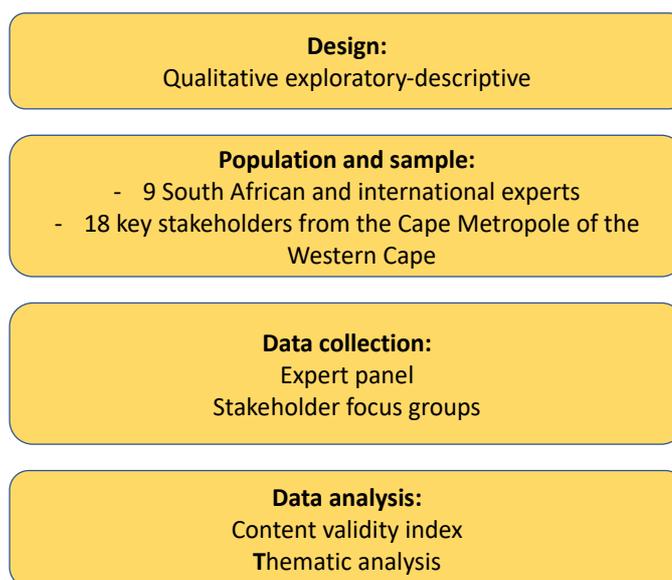


Figure 1.2: Overview of Research Methodology

1.7.2 Study setting

The expert panel included national and international researchers and academics. They reviewed the intervention and provided electronic feedback via a questionnaire. An online focus group was then held to provide feedback to the experts about revisions made. Focus groups with the key stakeholders were conducted in the Cape Metropole of the Western Cape.

1.7.3 Population and sample

The expert panel consisted of nine South African and international experts (academics and researchers) in the field of adolescent care, HIV management, SM, and intervention mapping. The focus groups were conducted by consulting 18 key stakeholders from the Cape Metropole of the Western Cape, including 11 ALWH/YLWH and seven healthcare workers or NGO representatives with experience working with adolescents. Youth aged 19–24 were included in the study as the intervention aims to use them as peer facilitators.

1.7.4 Pilot test and pilot interview

The questionnaire was piloted with one expert to ensure the instructions were clear, and the questionnaire was revised according to the feedback provided by the expert.

The interview guide was piloted with one stakeholder who was not part of the focus groups. The researcher's supervisor was also present during the pilot interview.

1.7.5 Trustworthiness

The researcher implemented the four criteria of trustworthiness, namely dependability, confirmability, credibility and transferability to ensure the study is rigorous and of high quality (Grove, Gray & Burns, 2015:392; Polit & Beck, 2017:557-573).

1.7.6 Recruitment and data collection

Experts were recruited via email, and data were collected online. Experts reviewed the intervention and rated the clarity and relevancy of its components. Only one round of review was required, followed by an online feedback session in which the experts were presented with the revisions and had an opportunity to give further suggestions.

The key stakeholders were recruited via email/telephone contact with community gatekeepers who work in the public sector and have direct contact with all the stakeholders. For the key stakeholders, data were collected through four focus groups (two focus groups with the ALWH/YLWH aged 15–24, and two with healthcare workers and NGO representatives).

1.7.7 Data analysis

After the expert panel completed the electronic questionnaire, the researcher established the measure of agreement between individual participants' responses by using the content validity index (CVI) for items (I-CVI), as described by Polit and Beck (2017:311). Data from the feedback session were transcribed and analysed

thematically (Braun & Clarke, 2006:77). Similarly, focus group discussions were transcribed and analysed using thematic analysis.

1.8 ETHICAL CONSIDERATIONS

Ethics approval was obtained from the Health Research Ethics Committee of the University of Stellenbosch, reference number: S20/01/011. Permission was also obtained from the Western Cape Department of Health, reference number: WC_202008_019, for the researcher to conduct the study.

In order to protect human subjects during research, all research studies should follow ethical principles (Grove et al., 2015:98). For this study, the ethical principles of the declaration of Helsinki were adhered to, which serves as a comprehensive guide for the conduct of ethical research (World Medical Association Declaration of Helsinki, 2013). Moreover, the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (formed in 1978) identified three vital ethical principles:

- Firstly, respect for persons, which includes individuals' autonomy and whether they want to participate in the study.
- Secondly, beneficence, which motivates the researcher to do good and do no harm.
- Thirdly, justice, which stipulates that a participant should be treated rightfully in terms of the benefit-to-risk ratio of the research (Grove et al., 2015:98).

For this study, the researcher followed the above-mentioned principles. The ethical considerations and COVID-19 protocol are unpacked and further discussed in Chapter 3.

1.9 DEFINITIONS

Adolescence: the period between 10 and 19 years, one of the most rapid phases in human development (World Health Organisation, 2019). In this study, the intervention was developed for older adolescents aged 15–19 years.

Youth/young people: persons between the ages of 15–24 (United Nations, 2008).

Self-management: is defined as “the processes and behaviours adolescents engage in, to take care of their chronic illness with the assistance of their caregivers, health workers, family, friends, peers and educators” (Crowley, 2018:217).

Self-management interventions: SM interventions enhance the development of SM skills (Ryan & Sawin, 2009:218). It promotes behaviour change, decreases healthcare costs, and increases individuals’ quality of life or well-being. SM education transcends traditional knowledge-based patient education and includes processes that develop problem-solving skills and improve confidence or self-efficacy (Van Staa, 2012:180).

Intervention mapping: IM is a protocol for behaviour change based on systematic theory and evidence. It describes the process from identifying the problem to solving or reducing it (Kok, 2014:156).

1.10 DURATION OF THE STUDY

Ethics approval was obtained from the Health Research Ethics Committee (HREC) at the University of Stellenbosch on the 25th of March 2020. As expert data collection did not require provincial approval, the expert panel data collection commenced in April 2020 and was completed in August 2020. Due to the embargo on face-to-face research during the COVID-19 pandemic, focus group data collection commenced in March 2021. HREC extension/renewal for the study was obtained from the 25th of March 2021 until the 24th of March 2022.

Approval from the Western Cape Department of Health was obtained on the 12th of December 2020. Data for the focus groups were collected from March to June 2021. Data analysis started in March 2021 and continued until November 2021. The thesis was submitted for examination on 1 December 2021.

1.11 CHAPTER OUTLINE

Chapter 1: Foundation of the study

The foundation of the study introduces the study topic, aim and objectives, and gives a brief overview of the research methodology.

Chapter 2: Literature review

An overview of the literature on ALWH and their SM needs is described in this chapter. Also, SM methods and strategies that can be used in interventions focused on ALWH are highlighted.

Chapter 3: Research methodology

The chapter provides an in-depth description of the research methodology applied in the study and includes the design, population, data collection strategies and data analysis.

Chapter 4: Findings

In this chapter, the findings are presented and interpreted based on the data collected during the study.

Chapter 5: Discussion, conclusions, and recommendations

The chapter includes a discussion of findings related to the study's objectives. The conclusions drawn from the research and recommendations made by the researcher are also presented.

1.12 SIGNIFICANCE OF THE STUDY

The significance of the study was to gain insight into experts' and key stakeholders' views and opinions regarding the development of the SM intervention for ALWH in a South African context. The insight and views presented in this study will be helpful in the further development and refinement of the SM intervention. The SM intervention could have a positive effect on the health outcomes and well-being of ALWH.

1.13 SUMMARY

The reviewed literature revealed a lack of research about SM interventions for ALWH, specifically in the South African context. There is evidence that improved SM among adolescents with a chronic illness may have a direct positive effect on their healthcare outcomes and overall well-being.

Therefore, it was important and of great value to explore experts' and key stakeholders' views as part of the development of an SM intervention for ALWH in a South African context. The acquired information from the study's findings may be of great support in the development of an SM intervention for ALWH. In Chapter 2, the literature review provides relevant information on ALWH and their SM needs. The chapter also highlights some SM methods and strategies that can be used in interventions focused on ALWH.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter provided a background and introduction to the study and a brief overview of the research methodology. In this chapter, an in-depth literature review is presented. A literature review is an analytical review of theoretical and pragmatic sources to generate a picture of the known and unknown about a specific problem. The literature is then arranged to put the identified research problem or gap in context (Grove, Gray & Burns, 2015:506; Polit & Beck, 2017:733).

The aim of the literature review was to identify scientific articles that would provide relevant information on ALWH and their SM needs. Secondly, the literature review was conducted to highlight and explore SM methods and strategies that can be used in interventions focused on ALWH.

The literature review is organised under the following headings:

- Overview of ALWH globally and in South Africa
- SM processes, tasks and needs of ALWH
- SM programmes/interventions for ALWH

2.2 ELECTING AND REVIEWING THE LITERATURE

For this study, databases such as MEDLINE via PubMed, CINAHL and Google Scholar were utilised. Keywords and the Medical Subject Headings (MESH) used in this search included: 'self-management'; 'intervention'; 'programme'; 'self-care'; 'chronic conditions'; 'HIV'; 'adolescents'; and 'young people'. Articles selected were in English and not older than ten years, except for the original articles published on adolescent behaviour and SM, including SM education and SM interventions.

In addition to the peer-reviewed articles, statistics from the UNICEF, The Joint United Nations Programme on HIV and AIDS (UNAIDS), The World Health Organisation (WHO), and Statistics South Africa (Stats SA) were reviewed that highlighted the global dilemma of HIV.

2.3 OVERVIEW OF ADOLESCENTS LIVING WITH HIV GLOBALLY AND IN SOUTH AFRICA

In 2020, a total of 37.7 million people worldwide were living with HIV (UNAIDS, 2021:1), of which 1.75 million were adolescents aged 10–19 years (UNICEF, 2021). Since the large-scale implementation of antiretroviral therapy (ART) as a long-term treatment for HIV, there has been a paradigm shift in recognising HIV as a chronic condition rather than an acute condition. ART has resulted in the decrease in HIV-associated morbidity and mortality; people diagnosed with HIV are currently living longer and require long-term holistic health care (Côté, Godin, Ramirez-Garcia, Rouleau, Bourbonnais, Gueheneuc, Tremblay & Otis, 2015:1; Panel on Antiretroviral Guidelines for Adults and Adolescents, 2018:A-1; Swendeman et al., 2009:1321).

As described in Chapter 1, ALWH consists of two groups. The first is adolescents who contracted HIV through mother-to-child transmission either during pregnancy, labour or breastfeeding (perinatally infected or vertically infected). The second is adolescents who contracted HIV through sexual intercourse (behaviourally or horizontally infected) (Zungu, Naidoo, Hodes, North, Mabaso, Skinner, Gittings, Sewpaul, Takatshana, Jooste, Moyo, Ramlagan, Cloete & Toska, 2021:1).

2.3.1 Adolescents and HIV internationally

Adolescence is a vulnerable stage in one's life, with psychological and biological changes taking place, reflecting the transition from childhood to adulthood (Jaworska & MacQueen, 2015:291). Adolescence is also associated with increased impulsivity and risk-taking, causing adolescents to be at a higher risk of contracting HIV, poor ART adherence, drug resistance, viral failure, loss to follow-up, and risky sexual behaviour (Anderson, Muloiwa & Davies, 2020:1). These factors correspond with the transformation and development in adolescents' social and school settings, where they

will be spending more time with their peers and less time with their parents/caregivers (Jaworska & MacQueen, 2015:291). ALWH face many challenges worldwide. They experience the complexities of change and development during adolescence, and need to direct their way through this life stage dealing with a chronic disease that is sexually transmittable with a large degree of internal stigma (Slogrove & Sohn, 2018:2).

Adolescents have unique needs and deserve special acknowledgement, distinct from children and adults (Shaw & Rivet Amico, 2016:387). However, ALWH are globally underserved in national HIV programmes (Armstrong et al., 2018:S16; Munyayi & Van Wyk, 2020:1). Dick and Ferguson (2015:3) conducted an overview that focused on a global and regional analysis of adolescent loss of life and disability-adjusted life-years. They also collected data on health-related matters among adolescents and found evidence of low levels of retention in care and poor quality services for ALWH. These findings highlight the need to focus on improved service delivery in this group.

A qualitative study and narrative literature review by Armstrong et al. (2018:S16) similarly highlighted a gap in interventional research for ALWH; although research in the area is expanding, it is still not optimal. Researchers thus need more information and evidence on ALWH to inform policy and intervention development to improve overall health outcomes for ALWH globally.

Treatment goals for HIV programmes were set by the UNAIDS programme coordinating board to help end the AIDS epidemic by 2030, called 90-90-90. These ambitious targets were that by 2020:

- 90% of all people living with HIV (PLWH) will know their status;
- 90% of all people who know their status will receive sustained ART; and
- 90% of all people receiving ART will have viral suppression.

According to the 2021 Global AIDS update (UNAIDS, 2021), there has been some progress in this domain, although targets were not met. Globally, at the end of 2020:

- 84% CI [67 – 98%] of all PLWH knew their HIV status;
- 87% CI [67 – 98%] of PLWH who knew their status were receiving sustained ART; and
- 90% CI [70 – 98%] of people receiving ART were virally suppressed.

Ultimately, the 90-90-90 targets were adjusted to 95% to be reached by 2030 (UNAIDS, 2015). The Fast Track by UNAIDS drives these targets, focusing on the 95-95-95 goals. These are more appropriate as we are fast approaching 2030. South Africa's progress in reaching these targets is discussed next.

2.3.2 Adolescents and HIV in South Africa

South Africa is the country with the highest number of HIV infections globally, with 7.8 million people living with HIV in 2020 (Stats SA, 2020; UNAIDS, 2021:1). In South Africa in 2019, there were 360 000 ALWH from the total 1.5 million ALWH in sub-Saharan Africa (UNICEF, 2019). These adolescents face various challenges in the communities in which they live. They are surrounded by extreme poverty and high unemployment rates, violence (specifically gender-based violence), substance use and abuse. Healthcare facilities are also not easily accessible and often not adolescent-friendly (Zungu et al., 2021:XVII). These challenges further contribute to onward transmission, non-adherence and viral failure. All of these factors should be focused on at the national health level for these adolescents to live a normal life and thrive.

A systematic review by Zanoni, Sibaya, Carins and Haberer (2018:957) highlighted some barriers to retention in care. These included attending the clinic during school time, fear of HIV status disclosure, fear of loneliness, and animosity towards clinic staff. Unsuccessfully transitioning from paediatric to adult care has also been identified as a hurdle in the care of ALWH. Some of the causes may include the absence of sufficient infrastructure (referring to a lack of dedicated spaces in clinics for adolescents and overcrowded and impersonal environments); a lack of staff guidance, training, and communication between adult and paediatric services; as well as the fear of stigma (Dahourou, Gautier-Lafaye, Teasdale, Renner, Yotebieng & Desmond, 2017:2-3).

The 95-95-95 targets are one area of focus to improve the outcomes of ALWH in South Africa. Progress is seen, but targets are not being met. In addition, it is clear that adolescent targets lag far behind those of adults. By 2017, adolescent males living with HIV who knew their status reached 60%, the male adolescents on ART reached 42%, and those who were virally suppressed reached 30% of the 90% target. Adolescent females living with HIV who knew their status reached 64%, the female adolescents on ART reached 40%, and those who were virally suppressed reached 33% of the anticipated 90% target (Zungu et al., 2021:15).

Ultimately, adolescence is a critical stage in a person's life to adopt healthy behaviours, especially in light of substance abuse, sexual behaviour, diet and exercise. Adolescence is also a vital time to engage in the SM of chronic disorders (Viner, Ozer, Denny, Marmot, Resnick, Fatusi & Currie, 2012:1641). More interventions are needed to support adolescents through this life stage and in managing numerous challenges as they learn to live with a lifelong chronic illness. SM was found to be a good strategy to support young people with chronic conditions (Sattoe et al., 2015:704-715), and is discussed in more detail in the following sections.

2.4 SELF-MANAGEMENT PROCESSES, TASKS AND NEEDS OF ALWH

Adolescents face many challenges and obstacles during this life stage, where they take on a new social role and enter the process of transitioning into adulthood; in turn, this might affect an adolescent's self-efficacy (Bandura, 2005:6). Together with the normal challenges, adolescents living with a chronic disease have to take on additional responsibility in managing their condition (Slogrove & Sohn, 2018:2).

Adolescents need guidance from their families and healthcare professionals in learning to self-manage their condition. SM may enhance health outcomes and quality of life, as well as reduce healthcare expenses (Sawin, 2017:169). However, there was a lack of appropriate literature when the researcher reviewed data concerning SM among ALWH. In one recent study conducted in the Western Cape of South Africa on the development of an instrument measuring adolescent SM, higher SM was linked to better HIV-related health outcomes (Crowley et al., 2019:1).

SM interventions may also play a role in increasing adherence and viral suppression, although more evidence is needed (Crowley & Rohwer, 2021:1). In a qualitative study conducted in the Eastern Cape, the SM needs of ALWH were identified in the domains of knowledge and beliefs, self-regulation skills, and SM resources. As mentioned in Chapter 1, SM is defined as “the processes and behaviours adolescents engage in, to take care of their chronic illness with the assistance of their caregivers, health workers, family, friends, peers and educators” (Crowley, 2018:217). SM processes generally lead to SM behaviours and, ultimately, positive health outcomes (Ryan & Sawin, 2009:220-221; Sawin, 2017:172-173). Some studies and guidelines have additionally referred to SM tasks. Both these concepts are discussed below and can be used to identify SM needs.

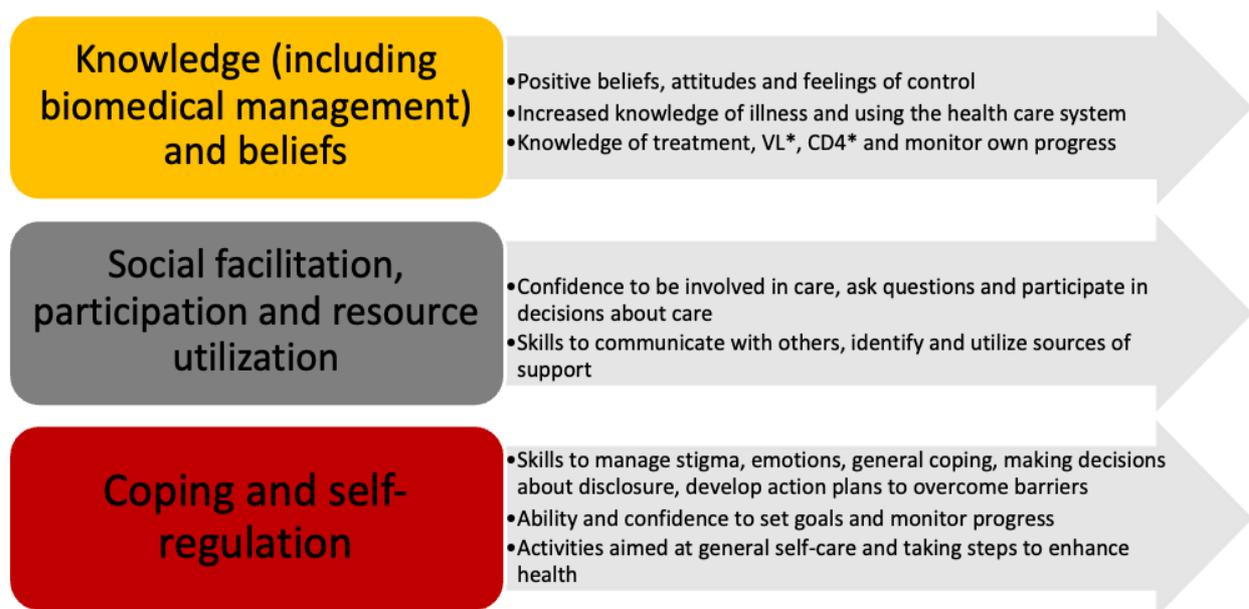
2.4.1 Self-management processes

The Individual and Family Self-Management Theory (IFSMT) describes SM as an intricate phenomenon affecting individuals and families who all have to be invested in participating in the SM process to achieve health outcomes (Ryan & Sawin, 2009:225-226). According to Ryan and Sawin (2009:226), people are more likely to participate in necessary preventative health behaviours when they have the correct knowledge, have health beliefs consistent with healthy behaviour, when they develop self-regulating abilities to adjust their behaviours, and if they encounter social facilitation that favourably influences and encourages them. ALWH and their families therefore use SM processes such as knowledge and beliefs, self-regulation skills and abilities, and social facilitation specific to HIV management to achieve health outcomes and healthy behaviours. These processes span beyond medical management of the condition (Ryan & Sawin, 2009:217; Crowley et al., 2019:11).

When the processes of SM are applied to ALWH (Figure 2.1), knowledge and beliefs include the adolescents’ positive beliefs and attitudes, knowledge about their condition, the importance of ART, feelings of control, and positive attitudes. Another important component of knowledge is understanding how to navigate the healthcare system and when to seek care (Crowley et al., 2019:11-12; Sawin, 2017:172).

Social facilitation and resource utilisation in the context of ALWH concerns adolescents' confidence and participation in the decisions around their care. It also refers to communication with the people involved in their care and being able to identify and utilise sources of support (Crowley et al., 2019:12; Ryan & Sawin, 2009:226).

Coping and self-regulation refer to an array of processes used to change health behaviour, including coping with and managing stigma and self-regulating disclosure and negative emotions. The adolescents have to master goal setting and monitor their own progress – taking responsibility for their condition. ALWH must also formulate action plans to overcome barriers in collaborating with healthcare workers and practice self-care to improve their health; in turn, improving their quality of life (Crowley et al., 2019:12-13; Ryan & Sawin, 2009:226).



*VL Viral load; CD4 Cluster of differentiation 4

Figure 2.1: Self-management processes applied to ALWH (Ryan & Sawin, 2009; Crowley et., 2019)

2.4.2 Self-management tasks

SM processes have been applied to formulate SM tasks and activities that ALWH should complete, specifically related to transitioning to adult care. These tasks have been classified under the three domains in Table 2.1. It is recommended that ALWH

achieve these tasks before they transition to adult care, as it may function as an indication of transition readiness (Duffy, Bergman & Sharer, 2014).

Table 2.1: Specific self-management tasks (Crowley et al., 2019; Duffy, Bergman & Sharer, 2014)

| Knowledge (including biomedical management and beliefs) | Social facilitation, participation and resource utilisation | Coping and self-regulation |
|--|--|--|
| <ul style="list-style-type: none"> • Independently gives a medical history • Knowledge of HIV, CD4, VL • Knows treatment regimen, dosages and frequency – what to do if a dose is missed and in case of side-effects • Discusses pros and cons of contraceptive options • Explains the meaning of the HIV diagnosis for pregnancy • Faith and hope for future • Confident in taking care of oneself | <ul style="list-style-type: none"> • Interacts with healthcare providers; asks questions • Knows who and when to call in a healthcare emergency • Knows where to seek help in the community • Attends peer support groups • Involved at school and in the community | <ul style="list-style-type: none"> • Identifies emotions and has a person to speak to about emotions • Explains reasons for disclosure and disclosure methods • Describes stigma & effects • Makes healthy diet and exercise decisions • Abstains from drugs/alcohol abuse • Attends clinic appointments/fills prescriptions independently • Demonstrates adherence to treatment without having to be reminded, and shows commitment to treatment schedules • Has positive coping strategies |

Sattoe et al. (2015:705) also explain that young people with chronic conditions should undertake specific tasks in working with their family, community and healthcare

workers in order to accomplish SM. These tasks include medical management, role management, and emotion management.

Medical management refers to condition-specific tasks; for example, knowledge of HIV, Cluster of differentiation 4 (CD4) and viral load (VL), as well as understanding the treatment regimen (dose and frequency; what to do when a dose is missed) and an action plan when they experience side-effects (Crowley et al., 2019:E14-E15; Sattoe et al., 2015:707).

Role management involves tasks related to social participation; for example, interaction with healthcare providers, understanding where to seek help in the community, and attendance of peer support groups, to name a few (Crowley et al., 2019:E16-E17; Sattoe et al., 2015:707).

Emotion management (or identity management) includes tasks related to a person's feelings. These include the development of a positive body image, faith and hope for the future, confidence in taking care of oneself, and stress management (Crowley et al., 2019:E11-E13).

2.4.3 Self-management needs

ALWH have numerous complicated SM needs, including adherence to lifelong medication regimes and stigma (Crowley et al., 2019:E7; Duffy, Bergman & Sharer, 2014:6; Mutumba et al., 2019:1). A study conducted in the Eastern Cape identified specific SM needs among ALWH (Adams & Crowley, 2021:8). In that study, the researchers identified a lack of knowledge about HIV and sexual and reproductive health. Some of the participants mentioned they were persuaded to not use condoms during intercourse. A further lack of knowledge could be attributed to participants being afraid or embarrassed to talk to their caregivers or healthcare workers about HIV or sex. They felt more at ease searching for the information they needed on the internet.

Recommendations by Adams and Crowley (2021:6-8) were, firstly, the implementation of strategies to increase HIV and sexual health knowledge, positive feelings and self-esteem, and the use of information-communication technology (ICT) platforms.

Secondly, they advocated for the implementation of strategies to improve self-regulation skills. Thirdly, they encouraged the provision of adolescent-friendly services (dedicated areas and time), training healthcare workers in adolescent care and SM support, and increasing family and peer support.

In Zambia, Denison and colleagues similarly identified a lack of SM amongst ALWH. They particularly focused on adherence, which can be viewed as an SM behaviour or outcome of SM processes (Denison, Banda, Dennis, Packer, Nyambe, Stalter, Mwansa, Katayamoyo & McCarraher, 2015:4). Although their study primarily focused on adherence, the identified SM needs were in the domains of social facilitation, knowledge and beliefs. Under the domain of social facilitation, family members reminded adolescents to take their ART, and clinic youth support groups served as an opportunity to make friends with people who share similar experiences. Under the domain of knowledge and beliefs, adolescents had a need to live longer and healthier lives. Many participants said they initiated ART after extended periods of infirmity (Denison et al., 2015:4).

In a study conducted in Uganda by Mutumba et al. (2019:3) amongst ALWH, caregivers and healthcare workers, general needs relating to SM were identified. Looking at adolescent HIV self-care, the pivotal needs identified were social facilitation, which includes counselling and guidance (specifically on ART adherence), knowledge (prevention of HIV/STI transmission), and self-regulation (to handle HIV stigma and goal setting or future planning). A need for open communication with the adolescent was also mentioned by healthcare workers as well as the adolescents; communication falls under the domain of social facilitation. The ALWH were only made aware of their status at a later stage (lack of communication), which contributed to scepticism, ultimately resulting in non-adherence (Mutumba et al., 2019:3).

Another need identified was sexuality education, under the domain of knowledge and beliefs. This should be commenced at an early stage so that ALHW are prepared with the appropriate skills and knowledge to prevent HIV transmission. The ALHW expressed a need for providers to be people living with HIV as they would be able to relate to them (Mutumba et al., 2019:3-4). Moreover, caregivers were identified as important role models for the adolescents because their views and actions directly

impacted the adolescents' SM behaviour. Lastly, caregivers and healthcare workers expressed the need to assist ALWH in planning for the future by providing them with career counselling and assisting them in attaining appropriate life skills (Mutumba et al., 2019:5).

The toolkit for ALWH's transition of care and other services (Duffy, Bergmann & Sharer, 2014:101) has several suggestions for health and community care workers on how adolescent needs can be supported:

- Assessment of psychosocial development to evaluate their ability to take charge of their own health;
- Mental health support for adolescents who may suffer from a mental health condition (e.g. anxiety or depression);
- Counselling services for loss or grief for adolescents who may have lost a family member, as well as support and guidance during the disclosure process; and
- Education about sexual and reproductive health, risks surrounding drug and alcohol abuse, and positive living, health education and goal setting.

2.5 SELF-MANAGEMENT PROGRAMMES/INTERVENTIONS FOR ALWH

As part of the intervention development process, a systematic review of SM interventions for ALWH was conducted (Crowley & Rohwer, 2021:1). In the review, an SM intervention was defined as any educational strategy encouraging individuals to manage their disease. For the review, interventions had to have an educational component that addressed one or more SM domains, namely knowledge and beliefs, self-regulation, and social facilitation (Crowley & Rohwer, 2021:2). The review included randomised controlled trials (RCTs), cluster RCTs, non-randomised controlled trials (non-RCTs), and controlled before-after (CBA) studies.

The findings were used to inform the development of an intervention and provide an overview of available interventions for ALWH internationally and in the African and South African context. This section provides a brief overview of the type of interventions, delivery format, setting, duration, and facilitators.

2.5.1 Type of interventions (methods and strategies)

SM interventions for ALWH vary from group education to individual counselling or a combination of the two, and the use of peer groups (Crowley & Rohwer, 2021:1-29). The systematic review included studies on adolescents aged 10–19 years (definition of the World Health Organisation) and studies on young people aged 10–24 years to include any youth that might not fall into the 10–19 years age group.

With individual counselling, for example, an RCT by Belzer, Naar-King, Olsen, Sarr, Thornton, Kahana, Gaur and Clark (2014:1-16) used cell phone support to assist with medication adherence. Daily phone conversations with healthcare providers (from Monday to Friday) took place over 24 weeks, and for 24 weeks post-intervention to compare controls. Conversations revolved around self-care and medication adherence. The SM domains covered were self-regulation and social facilitation. The results of this trial demonstrated an increase in adherence and virologic control.

Another example of an individual approach is the Positive Strategies to Enhance Problem-Solving Skills (STEPS) intervention (Mimiaga, Bogart, Thurston, Santostefano, Closson, Skeer, Biello & Safren, 2019:21-24), which used a combination of five individual counselling sessions and daily text message reminders. During these counselling sessions, the counsellor and adolescent discussed HIV care and treatment problems, together worked on solutions and a plan, and established how to implement the plan. The SM domains addressed in that study were social facilitation, and knowledge and beliefs. The study demonstrated an increase in ART adherence compared to standard care.

With group counselling, an RCT in Rwanda, by Donenberg, Cohen, Ingabire, Fabri, Emerson, Kendall, Remera, Manzi and Nsanzimana (2019:S289-S298), used peer-led (indigenous youth leaders) trauma cognitive behavioural therapy (CBT) to provide and address psychosocial health education, relaxation training, cognitive restructuring, adherence barriers, and caregiver psychological education. The intervention comprised six 2-hour sessions over two months on a Sunday, and a booster session after a 12-month assessment. Three SM domains were addressed in their study, namely social facilitation, knowledge and beliefs, and self-regulation.

In a combined individual and family intervention, Letourneau, Ellis, Naar-King, Chapman, Cunningham and Fowler (2013:1-24) used multisystemic therapy, which is home and community-based therapy that addresses numerous components of troubled youth behaviour. Trained therapists were used, and the techniques included CBT, parent training, behavioural family systems therapy, and communication skills training.

Another intervention in KwaZulu-Natal involving the family (Bhana, Mellins, Petersen, Alicea, Myeza, Holst, Abrams, John, Chhagan, Nestadt, Leu & McKay, 2014:1-17) was called the VUKA Family Programme, delivered by a healthcare worker. The intervention consisted of six sessions delivered over three months (2 Saturdays a month). The quantitative analysis reported improvement in ART adherence, greater knowledge, and improved communication between the child and caregiver, especially around sensitive topics.

Evidence on the efficacy of SM interventions in general when compared to standard care is currently very ambiguous. Interventions should be adapted to the individual and should be culturally and socially relevant (Crowley & Rohwer, 2021:3-4; Mutumba et al., 2019:1). Some family involvement seems to be appropriate and needed. However, there is no clear evidence whether group interventions versus individual interventions, or a combination, are better.

2.5.2 Delivery format and duration

Delivery can be in the form of face-to-face/ICT, gaming, telephone/text messaging or applications (Crowley & Rohwer, 2021:1-29). Face-to-face sessions in a study by Bhana et al. (2014:4) included six sessions over a three-month period (2 Saturdays a month) with the aim of communicating crucial information and promote discussion and problem-solving within families.

In the cell phone support study by Belzer et al. (2014:5), individual telephone calls were made by a trained individual lasting between 3-5 min once or twice a day for 24 weeks. The aim was to provide YLWH with a reliable, accessible, and understanding

relationship to help find solutions for their barriers in adherence, together with assistance and advice.

Another interesting study by Whiteley, Brown, Mena, Craker and Arnold (2018:25) utilised an ART-related iPhone game (called BattleViro) that was made available for 14 weeks. A medication monitoring device was also employed to empower youth to promote adherence by enhancing information, motivation, and behavioural skills.

Crowley and Rohwer's (2021:24-25) systematic review did not identify any delivery method (e.g., face-to-face vs ICT) to be more effective or deliver better outcomes than the other. The studies that utilised cell phone support, SMS reminders and ICT were most often conducted in the USA and not in low-resource high HIV burden settings such as Africa (Crowley & Rowher, 2021:25). Therefore, there is little evidence of ICT-based SM interventions available in the African context. Various durations in interventions were also observed, from brief sessions over eight weeks to longer sessions that stretched over eight months; however, few studies were available on long-term follow-up outcomes (Crowley & Rohwer, 2021:11-14).

2.5.3 Setting

Intervention research was conducted in various countries (Crowley & Rohwer, 2021:1-29). Of the 14 studies used in the systematic review, nine were conducted in the USA, four in Africa, and one in Thailand. All the studies took place in urban communities.

Group interventions typically take place at the health facility or community arranged setting. Individual counselling was conducted at the health facility or via a telephone call. Most studies did not provide any rationale for choosing a particular setting. This might be a limitation because participants should be involved in selecting the type of setting they prefer and in which they feel most comfortable (Crowley & Rohwer, 2021:1-29).

2.5.4 Facilitators

Facilitators ranged from trained adherence counsellors, healthcare workers, peers (indigenous youth leaders), therapists, and facilitators using ICT to promote the interventions. Four interventions in the African context (the Vuka Family Programme, Sauti Ya Vijana, Peer-led Trauma-Informed CBT, and Stepping Stones) mainly used lay healthcare workers and peers to deliver the interventions, as well as group education and counselling (Bhana et al., 2014:1-17; Dow, Mmbaga Gallis, Turner, Gandhi, Cunningham & O'Donnell, 2020:1-13; Donenberg et al., 2019:S289-S298; Holden, Gordon-Deseagu, Gordon, Chiziza, Kiwia, Magesa, Manyama & Welbourn, 2019:124-137).

In another systematic review of the literature on SM interventions and discussions of their potential relevance for people living with HIV in sub-Saharan Africa, the researchers highlighted that trained professional healthcare workers led most SM interventions. This will not be feasible in low-income countries such as Africa, suggesting that more research needs to focus on interventions that utilise lay healthcare workers and peers as the delivery agents (Aantjies, Ramerman & Bunders, 2014:198; Crowley & Rohwer, 2021:26).

A recent systematic review on SM interventions for adults living with HIV claim interventions to improve SM varied across studies. However, promising outcomes were achieved in most studies through interventions comprising a combination of skills training, phone counselling, counselling with symptom management manuals, and technology-assisted interventions (Areri, Marshall & Harvey, 2020:1-22). SM generally requires a combination of strategies and methods.

2.6 SUMMARY

More meticulous research on SM interventions for ALWH is needed in Africa to achieve the global targets and assist this continent with its high HIV morbidity and mortality rates amongst adolescents. There is a need for culturally relevant interventions that will cater to the individual, especially ALWH, who have unique needs, living with a highly stigmatised condition, in order for them to thrive and live their best life. Further

research may assist them in attaining a healthy future, which is worth exploring. In Chapter 3, the research methodology employed in this study is discussed in more detail.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

Chapter 2 provided an overview of relevant information on ALWH and their SM needs. A summary of the SM methods and strategies used in interventions focusing on ALWH was also presented. In this chapter, the research methodology is discussed in more detail.

A research methodology guides the way the study is structured and the investigation is conducted by the researcher to gather and analyse information to answer the research question (Polit & Beck, 2017:11).

3.2 AIM AND OBJECTIVES

The research aim was to explore the views of experts and key stakeholders as part of the development of a SM intervention for ALWH in a South African context, to refine the intervention.

The objectives were:

1. To explore if the objectives and outcomes of the intervention are relevant and clearly defined.
2. To determine if the theoretical methods and practical strategies of the intervention are relevant and feasible.
3. To establish if the format, setting, programme duration, and leaders/facilitators of the intervention are relevant and feasible.
4. To explore if the intervention contents are clearly described and relevant.

3.3 RESEARCH DESIGN

A research design is a framework or plan of the methods used to conduct the research (collecting and analysing data) to answer the research question (Akhtar, 2016:68).

3.3.1 Qualitative research

Qualitative research is a comprehensive process and aims to understand the entire topic under discussion. Researchers are intensely involved during the complete process from data collection to ongoing analysis of the data (Polit & Beck, 2017:463). Qualitative research depends on linguistic words instead of numerical data and meaning-based data analysis methods instead of statistical methods. Another important attribute of qualitative research is open-ended questioning where great emphasis is placed on the understanding of the experiences of the participants and developments during the data collection and analysis (Creswell, Ebersöhn, Eloff, Ferreira, Ivankova, Jansen, Nieuwenhuis, Pietersen & Clark, 2019:59).

3.3.2 Exploratory-descriptive qualitative research

The researcher followed a qualitative exploratory-descriptive approach. According to Grove, Gray and Burns (2015:76-78), this is the most appropriate research design for obtaining information needed to develop a programme or intervention for a specific group of people.

The exploratory-descriptive approach is used when researchers explore a new topic. For example, in this study, the researcher explored experts' and key stakeholders' views as part of the development of an SM intervention for ALWH. With an exploratory-descriptive approach, research findings provide the necessary information to further develop and refine the developed intervention (Gray, Grove & Sutherland, 2017:29).

As part of the exploratory-descriptive design, the researcher chose to use an expert panel and key stakeholders to obtain feedback on the development intervention. The expert panel could provide feedback on the overall programme, particularly the objectives, outcomes and theoretical methods, whereas the stakeholders could

provide feedback on aspects of implementation such as the format, facilitators, duration and setting.

3.3.3 Expert panel

Expert panels are used in clinical and health services research to achieve consensus on a specific topic. These panels hold advantages such as to include experts from other countries which in turn reflects the diversity of opinion in fields like HIV and SM (Khodyakov, Hempel, Rubenstein, Shekelle, Foy, Salen-Schatz, O'Neill, Danz & Dalal, 2011:1-7). During the development of an intervention, consultation with experts may play a pivotal role in the content area of the problem or with the target population especially when many questions are not answered by the research literature or descriptive studies (Polit & Beck, 2017:610).

According to Polit and Beck (2017:610) consulting experts in the content area or with the target population is crucial in intervention development. They are used to review preliminary interventions to corroborate their utility and provide suggestions for strengthening them. Procedures for reviewing the content of interventions are less formalized than for instrument development.

3.3.4 Focus groups

Focus groups is a good method for individuals to express their attitudes, perceptions, beliefs and opinions regarding a certain health topic in a secure environment and also encourages discussion and for individuals to change their opinion. The focus group setting is also ideal for obtaining rich data by direct contact with the individuals where group dynamics can also be observed. This allows the researcher to gather sufficient knowledge and a broad understanding of the topic being explored (Then, Rankin & Ali, 2014:16-11). Since this is an intervention, the researcher required a wide range of opinions from the stakeholders, to elicit ideas from one another as well as building on those ideas.

3.3.5 Researcher's position and bracketing

The researcher is a Master of Nursing student in a larger project. She was not known to the participants, nor part of the development process of the intervention. The researcher focused on exploring the views of the experts and stakeholders.

3.4 STUDY SETTING

To ensure that the intervention is contextually relevant yet internationally aligned, local and international researchers and academics involved in adolescent or SM science research were consulted as experts to review the intervention. The SM intervention is being developed for the public health sector, since this is where most adolescents in South Africa receive care (Zanoni et al., 2018:958). The key stakeholders interviewed in the public sector were the ALWH or YLWH, as they are the target group for the intervention, and healthcare workers and representatives from NGOs delivering adolescent-specific services. These key stakeholders were recruited from clinics and NGOs that provide adolescent HIV health services in the Cape Metropole of the Western Cape, the setting chosen for this study. Initially, the researcher wanted to include urban and rural areas to ensure the intervention would be contextually relevant for both settings. However, due to the COVID-19 pandemic and various embargos on research, the researcher was not granted approval from the Western Cape Department of Health for data collection in the rural area (Worcester). As a result, she could not conduct research in a rural setting as planned.

Together with the community gatekeepers, the researcher decided to recruit adolescent participants from Crossroads Community Health Centre. This health centre is situated in an informal settlement and serves approximately 36 043 people (StatsSA, 2020). The anti-retro viral (ARV) clinic at Crossroads serves approximately 250 ALWH, aged 10–19 years, in the teen adherence clubs. The teen adherence clubs are also attended by YLWH from a wider local area than what community health centres typically serve, since the centre is one of only a few providing paediatric ARV services (Wilson, 2021).

3.5 POPULATION AND SAMPLING

The population is the total group of individuals that meet specified criteria to be included in the study (Grove et al., 2015:46). In this study, the population consisted of two groups, namely experts (expert panel) and key stakeholders (focus groups).

3.5.1 Population

3.5.1.1 Expert panel

Experts (researchers and academics) in adolescent health care, HIV management, SM, and intervention mapping were consulted. Local researchers and academics were consulted due to their experience with the local context, and international experts were included due to the limited research on SM in Africa. These experts assessed the intervention's content validity and provided valuable feedback on the proposed programme's objectives, methods, and strategies. They also provided advice on the implementation plan and content based on their experience.

3.5.1.2 Focus groups

The key stakeholder groups included adolescents/youth (aged 15–24), healthcare workers and NGO representatives. Adolescents 15–19 are the target group for the intervention, and young people aged 20–24 may be used as peer facilitators. The researcher decided to include youth because they would be able to provide insight into their SM needs and context-appropriate strategies to teach SM skills. They will ultimately also function as peer facilitators in the intervention's rollout.

The second group consisted of healthcare workers and NGO representatives with experience in providing care to YLWH/ALWH. These healthcare workers and NGO representatives were included to tap their expertise about the methods and strategies that will be used in the intervention. In addition, they provided valuable insights about the feasibility of the proposed intervention's duration, setting, format, facilitators, and content.

3.5.2 Sampling and sample size

3.5.2.1 Expert panel

The researcher used purposive sampling to sample experts. According to Polit and Beck (2017:337), an expert panel of 8–12 members with a good amalgamation of roles and disciplines is advised for an initial review, and 3–5 members for a subsequent review of content validity. Polit and Beck (2017:337) also advise that it might be beneficial to include experts from various countries and regions if the content is intended for wider use, which is the case for this SM intervention. For this study, the sample included nine experts, consisting of academics (national and international) and researchers in the field of adolescence, HIV, and SM. The researcher used consensus methods to obtain experts' feedback.

Experts were purposively selected based on their clinical and research expertise in the field of adolescent HIV management, SM, adolescents' transition of care, and intervention mapping. Fourteen experts were identified through a literature search and the networks of the research team or based on referrals/recommendations from other experts. The expert panel's demographic details are provided in Chapter 4.

3.5.2.2 Focus groups

After receiving feedback from the experts, the researcher consulted local stakeholders. The stakeholders included a purposive sample of ALWH or youth (aged 15–24), healthcare workers and NGO representatives with experience working with adolescents. Stakeholders were recruited from the Cape Metropole of the Western Cape, and four focus groups were conducted over three months. The focus groups consisted of four to seven members. According to Gray, Grove and Sutherland (2017:263), for a focus group to be adequate, the group should contain 4–12 participants.

Purposive sampling was employed based on the researcher and her supervisor's judgement of experts and key stakeholders experienced and knowledgeable about adolescent HIV SM. According to Gray, Grove and Sutherland (2017:345), purposive sampling takes place when the researcher intentionally selects participants who are

rich in information about the specific topic under study to participate in the research. Participants' views were valuable in designing and refining an SM intervention for ALWH (Fernandez et al., 2019: 1). Therefore, the researcher used purposive sampling to ensure maximum variability and representation of adolescents for which the intervention is being developed (ages 15–19), youth (ages 20–24) who may be peer facilitators, and different genders.

The first and second focus groups consisted of seven healthcare workers: four in the first group and three in the second group. The second and fourth focus groups consisted of 11 adolescents ranging from 15 to 24 years: four in the first focus group and seven in the second. After conducting the fourth focus group, no new themes emerged.

3.5.3 Inclusion criteria

Expert panel:

- Researchers and academics with experience in adolescent HIV care/management or SM, as well as transition in care and intervention mapping.

Stakeholders:

- Adolescents/youth aged 15–24 who have been attending HIV services at the selected public clinic.
- Healthcare workers (doctors, nurses, lay counsellors, psychiatrists, occupational therapists, social workers) with experience in HIV care and management.
- Community board members or caregivers of ALWH with experience in adolescent healthcare services.
- NGO representatives focused on providing services for ALWH.

There were no specific exclusion criteria.

3.6 RECRUITMENT

3.6.1 Expert panel

A questionnaire containing information about the intervention, the background of the intervention, the target population, objectives, methods, strategies, implementation and content (Appendix A) was sent to the experts via email. One of the most important requirements for developing the SM intervention for ALWH was appropriate knowledge and competence among participants (Brady, 2015:3), hence the specific selection of the experts.

The researcher intended to gain consensus and measure judgements among a panel of experts (Keeney, Hasson & McKenna, 2000:195; Gray, Grove & Sutherland, 2017:417-418; Polit & Beck, 2017:244). The experts were recruited via email and asked whether they were interested in taking part in the research study. If they were not available, the researcher then asked for a referral to someone with similar expertise.

A total of 14 experts were contacted via email requesting their input in refining the intervention on the 7th of April 2020. Ten experts responded, and only one declined to take part due to the COVID-19 workload. Feedback on the intervention was received from nine experts by the end of April 2020. A feedback session via Zoom was arranged for the 28th of August 2020 to present the changes that were made to the intervention. The meeting was attended by eight of the nine initial participants.

3.6.2 Focus groups

After incorporating the experts' opinions in the intervention, the refined intervention was presented to the key stakeholders to gain insight into their views and opinions. This took place through focus group discussions in the Cape Metropole of the Western Cape.

According to Gray, Grove and Sutherland (2017:263), focus groups help acquire participants' opinions on a specific topic of interest in a setting that is unrestricted and

friendly. Literature suggests that a focus group should consist of 4–12 participants (Gray, Grove & Sutherland, 2017:263).

Two community gatekeepers recruited key stakeholders for the focus groups. The gatekeepers were health professionals who work in the public sector and have direct contact with the ALWH, as well as the nurses, doctors, counsellors and community board members in the Cape Metropole of the Western Cape.

The researcher had a meeting with the two community gatekeepers via Microsoft (MS) Teams and provided them with the purpose of the study and the inclusion criteria. They then made suggestions of who should be recruited as stakeholders. Following this, the community gatekeepers contacted potential participants and provided the researcher with the details of those interested in participating. The researcher also recruited adolescents at Crossroads Community Health Centre by informing them about the study and obtaining the contact details of interested adolescents. The researcher tried to ensure a mix of health professionals of different categories, as well as ALWH of varying ages and genders. However, this was challenging, as not all the invited participants attended the focus groups.

Of the 13 recruited healthcare workers, seven attended the focus groups; six could not attend. One caregiver was recruited but did not attend on the day of the focus group. Of the 24 ALWH recruited, 11 attended the focus groups. The demographic details of the focus group participants are presented in Chapter 4.

3.6.3 Data collection tools

For the expert panel, a questionnaire was compiled (Appendix 6) that comprised a brief description explaining that they will assess the content validity of the newly developed SM intervention for ALWH in a South African context, as well as provide valuable feedback on the intervention. The questionnaire contained a logic model of the problem, followed by an explanation of the process that would take place after they provided their feedback.

The experts were expected to provide basic biographical information such as their gender, age, qualification, and primary area of expertise. Firstly, the questionnaire provided information on the objectives and outcomes of the intervention, where the experts were then expected to rate the clarity and relevancy.

Secondly, information was provided on the intervention's methods and practical strategies, containing the following components: 1) Believing and knowing; 2) Goals and facilitation; 3) Participation; 4) Biomedical management; 5) Coping and self-regulation. The experts were asked once again to rate the clarity and relevancy of each component. Thirdly, the experts were asked to provide feedback on the programme's duration, format, setting, leadership/facilitators and content. In each section, open-ended questions were posed to ask participants to provide qualitative feedback.

During the focus group discussions with key stakeholders, a semi-structured interview guide was used. The participants received a brief overview of the intervention using a PowerPoint presentation. Moreover, the adolescent workbook and facilitator guide that were developed based on the experts' feedback were also presented to the participants. The interview guide was drawn up in English and consisted of open-ended questions, followed by probing questions. The questions were formulated in accordance with the research objectives. For example, 'Please reflect and tell us what you think about the objectives of the self-management intervention'. This was followed by probes such as: 'Are the objectives relevant to your context?'

An example of the interview guide is provided in Appendix 7.

3.7 PILOT TEST AND INTERVIEW

3.7.1 Expert panel

The expert questionnaire was piloted with one expert to ensure that the instructions in the questionnaire were clear. Minor revisions to the questionnaire were made based on the expert's feedback. A rating to indicate the importance of each component was added in case some components needed to be removed. Since the expert provided valuable feedback and only minor revisions were made to the questionnaire, their data were included in the main study.

3.7.2 Focus groups

The interview guide was piloted with one stakeholder. The pilot interview was conducted on MS Teams as per the participant's preference on the 23rd of February 2021 from 17:00 to 18:00. The participant was a registered nurse in the rural area of Worcester, with experience working with people living with HIV and YLWH.

The workbook and facilitator guide were sent to the participant in PDF format before the interview. A summary of the SM intervention was also presented to the participant at the start of the interview. The researcher's supervisor was present during the pilot interview, and the purpose of this interview was to see whether the format of presenting the intervention was clear and to test the interview guide.

Minor changes were made to the wording of the interview guide as the participant stated the first question was not clear enough. The participant suggested that a PowerPoint presentation would be valuable before the start of each focus group and could facilitate discussion by providing examples on the screen as each section is being discussed. Data from the pilot stakeholder interview were not included in the main study.

3.8 DATA COLLECTION

Data collection is the generation of large amounts of data and information in a precise and systematic manner, relevant to the study's specific objectives and research purpose (Grove, Gray & Burns, 2015:63; Sutton & Austin, 2015:227).

3.8.1 Expert panel

The researcher included national and international experts in the panel because, according to Keeney, Hasson and McKenna (2000:195), one of the strengths of an expert panel is the inclusion of experts across various geographic locations and expertise. The purpose was for the researcher (assisted by the study supervisor) to present the developed intervention to experts for content validation. Due to the experts' busy schedules, the researcher emailed the proposed intervention and questionnaire

to the participants on the 7th of April 2020. They were asked to rate each intervention component's clarity and relevancy and provide qualitative comments. Descriptions and definitions of key concepts were provided so they could evaluate whether the intervention components would address the programme's objectives.

The experts assessed the clarity and relevance of each of the components on a scale of 1 through 4. They also provided qualitative comments. Key issues that were addressed in the evaluation included whether the outcomes are relevant, the objectives clear, the methods and strategies appropriate to reach the objectives, and whether the programme duration, format, setting and leadership/facilitators are feasible.

The intervention was revised based on the criteria described in the data analysis section (Section 3.10). Another round of review was not required, but the researcher provided feedback on the intervention's revisions over MS Teams, which took place on the 28th of August 2020 and lasted 78 minutes. Permission was obtained from the participants to record the session. The feedback session allowed for more comments. Prior to the MS Teams meeting, an email was sent with a summary of comments of what was changed and a provisional outline of the intervention content. The feedback session was transcribed by the researcher for further analysis.

3.8.2 Focus groups

The researcher contacted the participants who agreed to take part via WhatsApp to provide more information about the study and screen for the eligibility criteria. The participants volunteered their information to the researcher and community gatekeeper. The researcher ensured a balanced representation of the key stakeholders and adolescents in terms of age and gender.

For participants younger than 18, the researcher obtained the contact details of their parents/guardians and asked them to sign the parental/guardian informed consent form if they were comfortable with their adolescent participating. The researcher telephonically arranged a suitable venue, date and time for the focus group

discussions. The two venues that were used were the Beautiful Gate NGO and the Cross Roads Community Health Centre.

On the day of the focus groups, the participants received a hard copy of the suggested intervention, objectives, outcomes and methods prior to the focus group discussion. They also received a hard copy of the draft adolescent workbook and the facilitator guide. They were asked to sign informed consent before data collection commenced. The researcher, assisted by the study supervisor, guided these discussions and asked the participants to provide their views on each component according to the objectives. A semi-structured interview guide (Appendix C) was used to focus on the objectives throughout the discussions.

The focus groups were conducted in English and audio-recorded, using a voice recorder as well as a mobile recording application. The researcher and supervisor are fluent in English and Afrikaans, and an isiXhosa speaking counselor's services were used during the adolescent focus groups. This was to ensure that participants could speak the language they felt most comfortable in and that the information they provided would truly portray their views.

The focus groups took place in a private and comfortable setting that was convenient for the participants; minimal disruption took place for effective audio recording. The focus groups lasted between 60 and 120 minutes to ensure adequate data collection with a break in between if needed. Refreshments were provided.

The researcher made use of a moderator (the study supervisor) during the focus group interviews. The moderator guided the discussion amongst the participants and aimed at collecting rich qualitative data regarding the perceptions, attitudes and experiences of the participants (Creswell et al., 2019: 111). The moderator also managed the voice-recording device and paid close attention to non-verbal cues. Field notes were taken of the participants' contributions/non-verbal cues and any additional observed information.

An eminent characteristic of focus groups are that oral data is combined with observation as a data-gathering technique (Creswell et al., 2019: 112). The moderator

also assisted in managing any possible power imbalances that might have arisen between healthcare workers and community members, and among different ages and genders in the adolescent focus groups. Unfortunately, it was not possible to conduct separate focus groups for each of these sub-groups due to time constraints.

The researcher and moderator ensured that all the participants had an equal opportunity to voice their views and opinions. Close attention was paid to data saturation during the interview process, which is the point during interviews where no new data emerge from additional data collection (Grove, Gray & Burns, 2015:274).

3.9 RIGOUR

The study's rigour depends on the extent to which the findings are dependable, confirmable, credible, and transferable (Grove, Gray & Burns, 2015:68). The researcher aimed to meet these four criteria of trustworthiness to ensure the study is rigorous and of high quality (Grove, Gray & Burns, 2015:392).

3.9.1 Credibility

Credibility is the extent to which the findings and results of the study truthfully reflect the views of the participants (Grove, Gray & Burns, 2015:392). For the expert review, data collection and analysis continued until consensus was reached. The revised intervention was taken back to the key stakeholders to confirm whether they agreed that the feedback was adequately interpreted and applied.

The researcher allowed enough time for the focus group discussions to ensure substantial data collection. Coding was also used to translate the verbal data into categories (Polit & Hungler, 1993:40). To ensure the credibility of the study, the data were also co-coded.

3.9.2 Transferability

Transferability means that the study's findings are transferable or applicable in different settings with similar participants (Grove, Gray & Burns, 2015:392). In this study, it was

the researcher's responsibility to provide adequate descriptive data so that the reader could evaluate the relevancy of the data to other contexts (Polit & Beck, 2017:560). To support transferability in this study, the researcher provided rich and detailed explanations of the context, location, and participants being studied. Moreover, inclusion criteria were applied when participants were recruited. Purposive sampling was employed in selecting participants, and the researcher was transparent in a comprehensive report about the study's trustworthiness and the data's analysis.

3.9.3 Dependability

For this study, the researcher documented all the steps taken and decisions made during the research process, also known as the audit trail (Grove, Gray & Burns, 2015:392). All email communication between the expert participants was saved on the researcher's personal computer under a folder named 'expert panel'. The researcher and supervisor verified transcripts from the audio recordings.

The researcher took notes of all activities and decisions during the study, which also insured dependability; this is called a process log. Peer debriefing with a colleague also occurred. Both aforementioned activities form part of an audit trail, which increases the study's dependability (Connely & Dehaemers, 2016:435).

3.9.4 Confirmability

Confirmability is the extent to which findings are consistent, and other researchers can trace and review the documentation process. It entails an audit trail, as mentioned above, and considerations of whether the researcher's findings and conclusions are logical and objective (Grove, Gray & Burns, 2015:392).

The researcher and supervisor regularly reflected on their own possible biases towards the intervention. During the expert feedback session and focus groups, participants were encouraged to provide contrary opinions, and these were carefully captured and presented in Chapter 4.

Power imbalances were managed during the adolescent focus groups, firstly, by not combining the stakeholders and the adolescents in one focus group, and secondly, using an interpreter known to the adolescents who did not have a vested interest in the intervention.

Confirmability was ensured using methodological memos of the process log, which formed part of the audit trail. Detailed notes were taken during the research process of all the researcher's decisions and data analysis as the study progressed. The notes were reviewed by a colleague and discussed in a peer-debriefing session. This process prevented bias by receiving another person's perspective on the research (Connelly & Dehaemers, 2016:435).

3.10 DATA ANALYSIS

Data analysis is the systematic organisation and amalgamation of research data (Polit & Beck, 2017:725). In this study, different analysis methods were used to analyse the data from the expert panel and the focus groups.

3.10.1 Expert panel

After completing the questionnaire, the researcher established the measure of agreement between individual experts' responses by using the CVI for items (I-CVI) as described by Polit and Beck (2017:311). In order to establish content validity, a panel of content experts rated each component in terms of its relevance to the intervention. Ratings were on a four-point ordinal scale, thereby avoiding a neutral midpoint. The scale was from 1=not relevant, through 4=highly relevant. I-CVI is computed as the number of experts giving a rating of either three or four, divided by the number of experts. An I-CVI higher than 0.78 is recommended when six or more experts are used. Items with low ratings should be deleted or revised.

All the components had a relevancy rating of 0.8 and above after the first round. According to Polit and Beck (2017:311), this process should continue until each item/statement has an I-CVI of 0.78 or more. The level of agreement is therefore set at a minimum of 0.8 or 80% for each component (Polit & Beck, 2017:311); the results

are presented in more detail in Chapter 4. Although the relevancy was high, qualitative comments were considered, and revisions were made accordingly.

In addition to rating item relevancy, experts rated component clarity from 1=very unclear to 4=very clear. A clarity score was calculated, and all components with clarity of less than 0.8 were revised. Seven components had a clarity rating below 0.8. The participants' comments were considered, and the components were revised accordingly. The clarity rating results are also presented in Chapter 4.

The experts' open-ended comments were analysed thematically according to the intervention components. The comments were used to revise the intervention components further, and notes were made to explore these in the stakeholder focus groups. A summary of the changes made was sent via email to the experts, and a brief presentation was provided via MS Teams. Additional comments were analysed thematically and further incorporated (see Chapter 4).

3.10.2 Focus groups

During the focus group discussions, data analysis took place throughout the process of data collection. To maintain a close link with the data being analysed, the researcher read, reread, and analysed the data over a period. The researcher transcribed the focus groups, and data were analysed manually.

All voice recordings were saved in marked folders, using numbers to ensure the participants' anonymity. Transcriptions were numbered, matching that of the voice recording. All the voice recordings and transcripts were saved on the researcher's personal computer and an external hard drive as a backup.

Thematic analysis was performed on the transcribed data. According to the seminal work of Braun and Clarke (2006:77-101), thematic analysis is a method that identifies, analyses, organises, describes and reports on themes found within data. Thematic analysis is a continual process consisting of six phases as described by the original work from Braun and Clarke (2006:77-101), moving back and forward, developing over time.

3.10.2.1 Phase one: Familiarising yourself with your data

Data were collected by the researcher during the focus groups using voice recordings. The researcher transcribed the voice recordings to written form and became immersed in the data and familiar with the content during this process. A verbatim account of the recordings was given. Field notes were also utilised not to lose any non-verbal cues and information that might be valuable to the outcome of the intervention.

3.10.2.2 Phase two: Generating initial codes

The researcher was familiar with the data after phase one. In phase two, the researcher completed the coding according to the objectives and based on each question.

Table 3.1: Example of initial code generation

| Researcher | Participant | Code |
|---|---|------------------------------|
| <p>What do you think of the components and objectives?</p> <p>Will we be able to achieve the components and objectives?</p> | <p>You mentioned something before on managing stigma, emotions, coping and self-regulation – that is perfect. If they are educated, they will be well equipped... It is good to improve skills to manage stigma and those things. It will help. This is placed well, these programme components and objectives.</p> | <p>Equipping Adolescents</p> |

3.10.2.3 Phase three: Searching for themes

This phase started after all the data were coded and the researcher identified themes across the data set; the researcher then sorted the codes into different themes, which were broader. Themes for each of the objectives were identified. Overarching themes were identified according to the objectives, with sub-themes under each of those overarching themes.

Table 3.2: Example of a theme and sub-themes

| Code | Sub-Theme | Theme |
|-----------------------|--|---|
| Equipping Adolescents | Benefits of encompassing components and objectives | Programme content, format, and practical strategies |

3.10.2.4 Phase four: Reviewing themes

During this process, the researcher reviewed and refined the themes. The researcher re-analysed the coded data for each theme to see whether there was a logical pattern. She then created a table with themes, sub-themes and codes, which was reviewed to see whether it was an accurate representation or whether any overlap could be identified.

3.10.2.5 Phase five: Defining and naming themes

The final themes and sub-themes were named after the overlap was removed and are presented in Chapter 4.

3.10.2.6 Phase six: Producing the report

The researcher ensured that all the meaning units/codes were discussed under each sub-theme and supported with verbatim quotes. A summary of the findings is presented in Chapter 4.

3.11 ETHICAL CONSIDERATIONS

As explained in Chapter 1, before conducting the study, approval was obtained from the HREC of Stellenbosch University as well as the Department of Health (DoH) to access adolescents and healthcare workers through the gatekeepers in the Cape Metropole of the Western Cape. Ethical principles were applied, as discussed in more detail in the following sections.

3.11.1 Right to self-determination

The experts and key stakeholders signed informed consent prior to participating in the study (Appendix 4 and 5). The participants were treated with respect and made aware that participation was voluntary and that they could withdraw from the study at any time. The signed consent was deemed valid once the participant demonstrated an understanding of the information provided to them.

The adolescents selected as participants were aged 15–19 years and already seen as mature; there was no separate assent form for this age group. Participants also ensured that their guardians signed the parental consent forms prior to the focus group. The researcher ensured that the language used in the consent was appropriate and on their age level – Grade 8.

3.11.2 Right to confidentiality and anonymity

The participants' privacy was taken into account for the entire duration of data collection and analysis, as well as the reporting of the findings. Participants' right to privacy entails the freedom they possess to control the time, amount, and general conditions under which they are willing to share their private information (Grove, Gray & Burns, 2015:105). Confidentiality was maintained throughout the data collection process.

The participants' personal data and information shared during the sessions were audio-recorded and then saved into password-protected folders on the researcher's personal computer. These audio recordings were destroyed after transcription. Transcripts contained no personal identifiers, and all data were backed up on the iCloud. All written consent forms are stored in a locked cupboard in the Department of Nursing and Midwifery at the Stellenbosch University, Tygerberg Campus.

Prior to the commencement of the focus group, the researcher asked the participants to agree verbally not to share any personal information or data discussed during the focus groups. A summary of the collected data and the final developed intervention will be communicated back to the participants.

3.11.3 Right to protection from discomfort and harm

Participants were not able to directly benefit from taking part in this study. The study's findings will be used to contribute to the development and further refinement of the SM intervention for ALWH, which may positively affect the health outcomes of ALWH.

Moreover, taking part in this study might have caused some inconvenience. Participants made use of their personal time to travel to the venue, as well as the time spent during the session. The participants were reimbursed for their travel costs to and from the venues, and refreshments were provided. Ultimately, there were no direct/immediate risks involved in taking part in this study as the expert panel and focus groups were non-experimental studies.

A referral system was in place in the event of a participant becoming or showing any symptoms of distress. This was, however, not needed.

3.11.3.1 COVID-19 specific measures

The researcher followed the latest guidelines and communication relating to the COVID-19 protocol prior to data collection (Health Research Ethics Communique 1: Research in the time of the COVID-19 Outbreak; Health Research Ethics Committee, Stellenbosch University, 2020). The researcher also considered the advice from the clinic/NGO where the focus groups were held. Participants wore protective face masks, practiced hand hygiene, coughing and sneezing etiquette, and followed social distancing guidelines as stipulated in the Government Gazette of 17 August 2020 (Department of Co-operative Governance, 2020:3-15).

There was a possibility that the face masks might have affected sound quality. Therefore, the settings of the Voice memo app on iOS were changed from 'compressed' to 'lossless' to improve the sound quality. The participants were also asked to speak in a loud and clear voice.

The researcher monitored the team and participants' temperature at the start of each focus group. Surfaces were cleaned/sanitised before the commencement of the focus

groups. Participants were also spaced approximately one meter apart, and windows were opened to ensure good ventilation in the room (WHO, 2020).

Thorough record-keeping took place on the day of the focus groups. The researcher, supervisor, translator and participants completed a register with the date, time and temperature of each person, as well as their contact details (mobile number, email and address where they live). The register also reflects whether any of the participants showed COVID-19 symptoms or whether they had been in contact with anyone who may have been infected with COVID-19.

The record was attained for one month after data collection (WHO, 2020) to help the DoH trace people who may have been exposed to COVID-19 if one or more of the participants became ill shortly after the focus group. None of the participants had symptoms or were exposed to COVID-19 to the researcher's knowledge.

Face masks and hand sanitiser were made available to each participant in the focus groups. This was included in the research budget, and refreshments were purchased and provided in pre-packed form. The participants were encouraged to practice hand hygiene throughout the focus group.

If one of the participants or researchers had become infected around the time of the focus groups, that person would have gone into isolation for 14 days. This measure was in place but not needed.

3.12 SUMMARY

This chapter provided a comprehensive description of the research methods employed with the expert panel and stakeholder focus groups. The researcher discussed both phases separately to clearly communicate the steps that were followed.

In this study, the researcher applied a qualitative exploratory-descriptive approach. Purposive sampling was employed for the expert panel and stakeholders of the focus groups. Firstly, input was received from the expert panel on the intervention. After incorporating the experts' input, the intervention was revised and presented to the

stakeholders during focus groups to gain insight into their views and opinions. A pilot test and interview were conducted for both phases, and minor changes were made to the data collection tools prior to data collection.

The following chapter focuses on the findings obtained from the expert panel and focus groups.

CHAPTER 4

FINDINGS

4.1 INTRODUCTION

In the previous chapter, the research methodology was discussed, and the findings of the study are presented in this chapter. The first part of the chapter includes all the findings from the electronic feedback and MS Teams session with the expert panel. The second part of the chapter presents the focus group findings.

4.2 EXPERT PANEL

4.2.1 Biographical data of experts

Experts' biographical data (Table 4.1) were considered, as this provided an overview of their area of expertise. The participants were both male and female and aged between 36 and 63 years. Their primary areas of expertise were research in healthcare transition, HIV adolescent management, adolescent and young adult oncology nursing and SM, adolescent psychiatry, and SM. The experts' years of experience in their area of expertise ranged from eight to 20 years. There was a combination of international and local experts.

Table 4.1: Summary: Biographical data of experts

| Gender | Age | Qualifications | Country currently working in | Primary Area of Expertise |
|--------|-----|----------------|------------------------------|--|
| Male | 51 | PhD, RN | Belgium | Research in healthcare transition |
| Female | 48 | MChB | South Africa | Family Medicine, with a focus on HIV, TB, NCD |
| Female | 63 | PhD, RN | United States | Adolescent and Young Adult Oncology, Oncology Nursing; Self-management |

| Gender | Age | Qualifications | Country currently working in | Primary Area of Expertise |
|--------|-----|--|---|--|
| Female | 52 | MChB | South Africa | Paediatrics, HIV, Adolescent Psychiatry, Self-management: HIV |
| Female | 38 | MChB | South Africa | Family medicine - with a particular interest in paediatric and adolescent HIV Care |
| Female | 42 | Master of Science in Nursing, Master of Science in Public Health | United States (mostly working in African countries) | HIV and Nursing |
| Female | 41 | PhD Psychology | Northern Ireland | Sexual and Reproductive Health Research (Health Promotion Programme Design and Evaluation) |
| Male | 36 | PhD | South Africa | Socio-behavioural science applied to health interventions for young people |
| Female | 48 | PhD | United States (mostly working in African countries) | Transition, social support, mental health-social worker |

4.2.2 Results of expert feedback

4.2.2.1 Content clarity and validity indexes

Experts were asked to rate the clarity and relevance of the programme outcomes, objectives of the intervention, methods and practical strategies, and the programme duration, format, setting and leaders/facilitators. The item clarity and relevancy are depicted in Table 4.2. In addition, experts' qualitative feedback is provided under *4.2.1.2 Qualitative feedback and revisions*. Additional input received during the

electronic feedback meeting was analysed and grouped according to the programme components and is included as well.

The item relevancy for all the components had a CVI rating of more than 0.8, indicating that the programme outcomes, objectives, methods and practical strategies, programme delivery (e.g., the duration, format, setting and leaders/facilitators) were valid.

Item clarity ratings ranged from 0.4 to 1.0. Components with low clarity ratings included the secondary outcomes; the objectives of the 'participation' component; the methods and strategies for the 'believing and knowing' component; the methods and strategies for the 'participation' component; and the programme duration, timing and format. These components were revised based on the qualitative feedback to improve clarity.

Table 4.2: Results of expert feedback

| ITEM | Clarity | Relevancy |
|--|---------|-----------|
| Programme outcomes | | |
| Primary outcome: Improved self-management processes and behaviours | 0.9 | 0.8 |
| Secondary outcome: The provision of adolescent-friendly/tailored services/improved experiences of adolescents attending services | 0.5 | 0.9 |
| Secondary outcome: Increased family and peer support/perception of adolescent of family/peer support | 0.6 | 0.8 |
| Objectives of the intervention: | | |
| Believing and knowing | 0.8 | 0.9 |
| Goals and facilitation | 0.8 | 0.9 |
| Participation | 0.4 | 1.0 |
| HIV biomedical management | 0.9 | 1.0 |
| Coping and self-regulation | 0.9 | 1.0 |
| Adolescent HIV self-management intervention: methods and practical strategies | | |
| Component: Believing and knowing | 0.6 | 1.0 |
| Component: Goals and facilitation | 0.8 | 1.0 |

| ITEM | Clarity | Relevancy |
|--|---------|-----------|
| Component: Participation | 0.5 | 1.0 |
| Component: Biomedical management | 0.8 | 1.0 |
| Component: Coping and self-regulation | 0.8 | 0.9 |
| Adolescent HIV self-management intervention: Programme duration, format, setting and leaders/facilitators | | |
| Programme duration and timing | 0.6 | 0.9 |
| Programme format | 0.6 | 1.0 |
| Programme leaders/facilitators | 1.0 | 0.9 |
| Setting | 1.0 | 1.0 |
| Adolescent HIV self-management intervention: programme content and materials | 0.9 | 0.9 |

4.2.2.2 Qualitative feedback and revisions

Qualitative feedback included experts' responses to open-ended questions in the questionnaire and discussions during the feedback session. This section summarises the feedback and revisions made based on the feedback (Refer to Appendix 8 for a summary of the revisions in table format).

Regarding the **programme's primary outcomes**, the experts commented that the outcome 'self-management' should be more clearly operationalised, and the meaning of 'processes' should be clarified. Two experts mentioned that biological outcomes such as CD4, VL or health-related quality of life and acceptability should rather be considered as primary outcomes since it is important that the intervention improves young people's well-being. Subsequently, revisions to the primary outcomes included dividing the primary outcomes into programme performance outcomes, as well as behaviour and health outcomes. Behaviour (adherence and risk behaviours) and health outcomes (VL, CD4) were added as primary objectives.

Similarly, with the **secondary outcomes**, there was a need to operationalise the terms 'adolescent-friendly' and 'support'. Experts commented that it is important to consider what the adolescent views as support (perceived support), and the concept of 'support' could be broadened to include healthcare worker, family, peer, and community

support. One of the experts recommended that the types of support could be separated, while another commented that it is unclear if the programme is hospital-based or primary care based. Following the experts' feedback, the secondary outcomes were divided into programme performance objectives, as well as behaviour and health outcomes. The one secondary outcome was changed from 'adolescent-friendly services' to 'adolescent satisfaction with services', as the focus of the intervention is not specifically on the improvement of adolescent-friendly services. Increased family and peer support were specified as being perceived support. Healthcare worker and community support were added. Behaviour (improved clinical attendance/retention) and health outcomes (Health Related Quality of Life [HRQOL], mental health) were also included as secondary outcomes.

With the **programme objectives** under **believing and knowing**, the experts emphasised that the outcomes should focus on improving all aspects of the adolescents' health, including substance use, women's health, and men's health, to name a few. The separation of certain concepts was needed, for example, beliefs, faith, attitudes, and feelings of control because they commented that these attributes are distinct. Also, experts recommended adding certain phrases like "knowing when to seek care". Another suggestion was to use a theoretical model to clarify complex concepts.

Revisions included the objectives being separated and changed to:

- Increase adolescents' knowledge about their health.
- Increase adolescents' knowledge about their illness and the importance of ART.
- Increase knowledge about how to navigate the healthcare system.
- Increase knowledge about when to seek care.
- Increase positive beliefs.
- Increase positive attitudes.
- Increase feelings of control (self-efficacy and confidence) to self-manage.

Under the objectives for **goals and facilitation/support**, suggestions were made by the experts to improve communication, particularly negotiating for something – like

ART that ran out and a refill that is needed at the clinic – and how to handle themselves with regards to an argumentative healthcare worker. Realities such as the risk of failing to meet goals and the role of being socially disempowered to reach goals needed to be considered, as well as how to manage such failure and disappointment.

The objectives under goals and facilitation were changed to:

- Increase internal- and external motivation for SM by setting individual health and life goals.
- Increase confidence in meeting goals.
- Communicate goals to others to garner appropriate support and revise when support is lacking.
- Improve communication skills with family, healthcare workers and peers.
- Improve skills to identify resources and supports.
- Increase the adolescents' awareness of social support from family, healthcare workers, peers, and friends to take care of one's health.

Regarding the objectives for the **participation** component, the comments included a change “*to increase activities aimed at general self-care*” and for the adolescent to be involved as much as they desire, since some adolescents may not desire involvement. Barriers to participation, such as language barriers or a lack of capacity/empowerment, were also highlighted. Confidence to participate in healthcare decisions and social contexts was separated out and differentiated from participation behaviours.

The objectives were changed to:

- Improve confidence in being actively involved in healthcare decision-making as much as the adolescent desires, and consequently, their participation in decision-making.
- Improve confidence in being actively involved socially as much as the adolescent desires, and consequently, their social participation.
- Increase activities aimed at general self-care and proactively take steps to enhance one's own general health status for improved long-term health outcomes.

Under the objectives for **HIV biomedical management**, the experts suggested adding aspects of medication management, for example, not necessarily only knowing the names of the ARVs but including how to take ARVs and the side-effects. One expert commented that this component should include general health outcomes. However, since this component particularly focuses on chronic disease management, objectives for general health knowledge/behaviours were added under the components 'Beliefs and Knowledge' and 'Participation'. Lastly, experts suggested that an objective for collaboration among healthcare workers as a support team for the adolescents' management of HIV is added.

The objectives were changed to:

- Improve knowledge of and motivation to understand whether one is doing well on treatment or not.
- Gain knowledge and understanding of biomedical outcomes, such as VL and knowledge of the names of ARVs.
- Be able to self-monitor taking of treatment, side-effects, and VL.
- Collaborate with healthcare workers as a support team to manage HIV.
- Identify risks/barriers for not taking treatment and develop action plans to manage barriers to adherence.

Lastly, in terms of the objectives for the **coping and self-regulation** component, the experts identified that the health needs and concerns might be too HIV specific because the adolescents may have other needs as well. One expert suggested adding emotional self-regulation and information on where and how to seek help.

The objectives were changed to:

- Improve coping skills to manage HIV stigma.
- Improve ability to manage emotions.
- Improve decision-making skills about disclosure.
- Identify possible risks/barriers to SM of HIV and health and develop strategies to overcome barriers.

- Develop strategies to integrate taking treatment into one's daily routine.
- Understand where and how to seek help.

Programme methods and practical strategies are divided into five components and discussed separately. Based on the experts' feedback, the strategies were aligned to and based on specific intervention mapping approaches (Kok, 2014:156-170). For example, the following strategies were included: belief selection; modelling; technical knowledge; discussions; individual coaching sessions/motivational interviewing; goal setting and action plans; journaling; mobilising social support networks; relationship building; interaction with healthcare worker/caregiver; peer education; skills training; self-monitoring; providing contingent rewards; problem-solving; and planning coping responses.

Under the first component, **believing and knowing**, the experts' comments related to the following aspects: the peer supporter/leader/healthcare worker assisting in groups or clinical support should stay the same throughout so that a relationship of trust can be built. Moreover, the language barrier and learning difficulties of these adolescents should be considered. With the second and third components (**goals and facilitation** and **participation**), several comments highlighted that it is important to consider peer facilitators and adolescent-friendly clinics with specially trained providers and facilitators who are able to communicate effectively. The experts once again reiterated under the **biomedical management** component that it is important not only to focus on HIV-related information but to see the adolescents as a "whole-person" and not just HIV positive. Strategies should thus be more clinically focused, such as adherence monitoring via smart boxes, pill counts and laboratory monitoring. Referring to the component **coping and self-regulation**, the experts requested more clarity and details on the group leader/facilitator, how they will be equipped, confidentiality issues and assurance on the continuity of care.

Based on the feedback, the following parameters for effectiveness were identified:

- Peer support leaders should speak the same language as adolescents, be trained and remain the same so trust can be built.

- Establish adolescents' literacy/reading/writing ability and the languages in which they would prefer to receive information.
- Each adolescent should be assigned a healthcare worker/counsellor trained in coaching to ensure a trusting relationship is established, promoting the ability to freely communicate in their language of choice.
- Goals should be within the adolescent's skill level.
- Willingness among social/family support networks to reach out; availability of networks that can provide appropriate support and linkage agents.
- Providing contingent rewards, for example, praising, encouraging, or providing material rewards explicitly linked to the achievement of specified behaviours.
- Technical knowledge and self-monitoring must be specific, for example, CD4 count, VL, side-effects and how to manage these, names of ARVs, and times of taking the ARVs.

Lastly, the experts commented on the **programme's duration, format, setting and leaders/facilitators**. The experts verbalised that it is important to know what the adolescents think to obtain their view on what would suit them best because every community is very different, and flexibility would be needed. They also highlighted that an incentive for adolescents would be appropriate once they completed their workbook/homework, and that the intervention should include a hybrid approach (smartphone and paper-based) to see which one works best. Specifically considering the setting, the experts narrated that it is important to keep confidentiality and access to transport in mind, as well as a large enough space to accommodate everyone comfortably, with few interruptions and the provisions of snacks.

The parameters for effectiveness were identified as follows:

- Negotiate timing, duration, and time of year with adolescents, as well as transport costs.
- Consider incentives for completing the activities.
- Consider using a hybrid approach, both paper-based and smartphones, to see what is most suitable.
- Consider who will be responsible at a higher level to support peer facilitators.

- Consider a team care approach.
- Careful selection and training of facilitators.
- Discuss the appropriateness of same or mixed-gender peer-group sessions with stakeholders.
- Large enough space to accommodate everyone with few interruptions, and snacks should be provided at groups sessions.

During the feedback session over MS Teams with the nine experts, more suggestions were made. One expert suggested the use of interactive activities and face-to-face rather than virtual meetings when working with adolescents. Fewer worksheets and less writing, and more interaction and discussion were recommended. It was also mentioned that an incentive at the end of the week would help encourage adolescents.

Another expert suggested the researcher facilitates individual motivational interviewing earlier, making that an integral part of the design:

“This might be helpful in keeping the adolescents engaged throughout the entire period. I would see a key aspect of that being a positive mentorship relationship that could occur via WhatsApp/Technology throughout the week.”

Stigma was also raised as an issue, and discussions ensued about whether it would be more appropriate to arrange the intervention sessions elsewhere, away from the clinic situated in the participants' community, because it is a specific group for young people living with HIV. In addition to the meeting place, one of the experts was concerned about the sessions taking place weekly, since adolescents might see these sessions as 'clinic time' and then *“get tired of them and don't come back to fetch their ARVs.”*

Lastly, a suggestion was made to have an empowerment/strengths approach and not a deficit approach *“for every young person receiving this intervention package, making it clear that they are being intervened for and they are given things to help cope with these special pressures that the world is putting on them.”*

4.3 FOCUS GROUPS

The second part of the study involved the focus groups. These findings are presented in the following section, according to themes and sub-themes identified during the data analysis. Participants' verbatim quotations are provided to validate the researcher's interpretation.

4.3.1 Section A: Biographical data

Four focus groups were conducted in the Cape Metropole of the Western Cape, with a total of 19 participants. The participants' demographic details are presented in Table 4.3.

Table 4.3: Demographic details of focus group participants

| Focus group | Description of participants | Ages |
|----------------------------|---|----------------|
| Group 1 (4 members) | 1 doctor, 1 counsellor/social worker, 1 assistant social worker, 1 counsellor | 29 to 52 years |
| Group 2 (4 members) | 2 boys; 2 girls | 16 to 23 years |
| Group 3 (4 members) | 2 doctors, 1 counsellor, 1 assistant social worker | 35 to 55 years |
| Group 4 (7 members) | 2 boys; 5 girls | 15 to 19 years |

4.3.2 Section B: Themes emerging from the data analysis

The researcher identified three major themes during the data analysis process, which included input from the stakeholders who would be utilising the SM intervention. Table 4.4 displays the major themes and sub-themes that were identified.

Table 4.4: Themes and sub-themes

| Themes | Sub-themes |
|--|---|
| 4.3.2.1 Programme aim and outcomes | <ul style="list-style-type: none"> ○ Possible benefits of programme outcomes ○ Importance of considering the context |
| 4.3.2.2 Programme content, format, and practical strategies | <ul style="list-style-type: none"> ○ Benefits of having broad (encompassing) components and objectives ○ Workbook preferences and criteria for effectiveness ○ App preferences and criteria for effectiveness ○ Peer groups' preferences and criteria for effectiveness ○ Individual counselling/coaching preferences and criteria for effectiveness |
| 4.3.2.3 Programme facilitators, duration and setting | <ul style="list-style-type: none"> ○ Criteria for the effectiveness of using peer facilitators ○ Communication and language preferences ○ Human resources ○ Timing and duration ○ Selection of participants ○ Criteria for effectiveness for setting |

4.3.2.1 Theme one: Programme aim and outcomes

This theme had two sub-themes that emanated from it, namely: possible benefits from programme outcomes; and the importance of considering the context.

The **possible benefits of the programme outcomes** shared by the stakeholders during the focus groups included the importance of the focus on mental health, acceptance of their HIV status, improving confidence, the inclusion of all adolescents, and repetition and emphasis on what the adolescents previously learned.

Participants drew attention to the broader focus on ALWH's well-being by emphasising the importance of quality of life and mental/psychological health as outcomes. They

mentioned how this is interconnected with adolescents accepting their HIV status and their identity formation.

“Regarding quality of life and mental health it is very important, and I like it as an outcome, and it is achievable. I think it will also impact on their sense of accepting their status and themselves.” (Participant 1, female, focus group 1)

The intervention may especially assist and equip adolescents who are withdrawn and do not get support at home, as it is goal-driven and may give adolescents a sense of purpose. Adolescent participants added that the intervention would provide them with confidence, as some do not feel comfortable and confident to openly talk about their HIV status, even in the presence of their peers who are also living with HIV.

“Because you think that you are the only one who’s only positive even though we know we are attending one thing [peer group]. That it’s just not easy to say it in front of the others.” (Translator, female, focus group 4)

The intervention was seen as complementary to what is offered at the healthcare facility, and healthcare workers commented that they would feel supported. They mentioned collaboration would be promoted, and adolescents would benefit from the programme if the information provided at the clinic is repeated in other contexts.

“It would be nice to know that you’ve gone through this with every teenager and that there are none that have missed out.” (Participant 4, female, focus group 1)

Although they had the desire for all adolescents to have access to such a programme, they were unsure how it would be practically implemented with limited resources.

“We have approximately 200 teens coming into this age group, how will you make this programme run?” (Participant 4, female, focus group 1)

The **importance of considering adolescents’ context** was emphasised. The contexts that were highlighted included the individual context (target age group,

identity, individual barriers), family context (family involvement/lack of support), the community (addressing stigma, cultural practices, discrimination, schools, friends), and healthcare services, which include the multidisciplinary team.

The individual context included the adolescent's identity of who they are and the barriers they face daily. The stakeholders emphasised that knowledge on how to manage stigma, disclosure, their emotions, and acceptance of their status is needed for these adolescents to cope in society.

“These people need to be equipped to be able to cope around those societies. So, it's got a lot of barriers around them, and I really think there is a need for them to be equipped more.” (Participant 4, female, focus group 3)

Some of the adolescents and healthcare workers commented that the intervention should start before the age of 15 as the ALWH need to learn these skills before they start to experience challenges.

“When they reach 15 or something like that, I think that is where they start not coping. I'm not sure whether they are not coping, or it is just them reaching that stage, their mind is all over the place.” (Translator, female, focus group 2)

When the discussion turned to family support, stakeholders stressed the importance of family involvement and support (or the lack thereof) in the lives of adolescents. Family plays an essential role in the life of African youth since their decisions are influenced by their family. Therefore, issues such as stigma and non-disclosure affect the whole family.

“I think family plays an important role in the life of African youth, even when they are much older; their decisions are influenced by their family, so by involving the family the individual is also more empowered.” (Participant 1, female, focus group 1)

“For me, when I grew up I already had TB, I was very sick, I was drinking ‘pillies’ on a regular basis. So when my sister told me, I don't know where I was, but

when she told me you had HIV, I was like What?! I've been drinking 'pillies' the whole time." (Participant 1, female, focus group 2)

Some parents living with HIV do not take their own treatment and, in turn, their children default on treatment as well. One of the stakeholders emphasised the benefit of facilitating parent/caregiver-adolescent communication about sensitive matters that are not typically discussed in the culture. For example, some adolescents may not know who their parents are, and open discussions may facilitate identity formation. Involving the family in the programme and providing them with knowledge and skills will therefore empower the individual and family.

"You will find that the parent is not taking medication and too making the children default their treatment. Which when you probe more to try and find out you get that it's about disclosure, it's about stigma around them." (Participant 4, female, focus group 3)

Under community involvement, the stakeholders made it clear that stigma and discrimination against people living with HIV are still a reality for many in the community. The negative way people in the community talk about people living with HIV in front of these adolescents discourages them from sharing their status. The adolescents realise they would be discriminated against, so they choose not to disclose their status, making them more vulnerable and unable to cope. It would thus be valuable to include the community and schools in this intervention programme and educate them on HIV.

"What I've noticed is that our community has a big impact in discouraging them. For example, the friends – they will have a topic they are chatting about e.g., people living with HIV and then there is a particular teenager who is HIV positive and then they will be criticising people living with HIV. And this affects them because they hear this, that people are discrimination against them." (Participant 3, female, focus group 1)

In the discussion on the role of healthcare services, one of the healthcare workers stated that the clinic staff could not cope on their own and needed as much support

and collaboration from other people and organisations as possible by working together as a multidisciplinary team.

“We need as much support and collaboration as possible. We all have that same heart for our teenagers.” (Participant 4, female, focus group 1)

4.3.2.2 Theme two: Programme content, format, and practical strategies

The benefits identified by the stakeholders in **having encompassing components and objectives** included a range of topics and information to assist adolescents in navigating the health system (especially if they move to another clinic/province). They also emphasised teaching them coping strategies, equipping them with skills, and helping them with disclosure and acceptance of their status. Adolescent participants commented that it is important to include information about healthy living, sexual conduct, alcohol, and drug use. Healthcare workers also mentioned awareness should be raised about cultural beliefs, important coping skills, career guidance and where to access help.

Participants had mixed feedback about the activity **workbook**. For example, the healthcare workers generally preferred a smaller book format, whereas adolescents preferred a larger format that makes it easier for them to write: *“... I can write on it then, if I can fit my entry inside.”* Other advantages of the workbook included that it is easy to carry, does not pose a risk to theft (as is the case with mobile devices), and is easy to access. Some of the disadvantages were that it might be a challenge to remember to bring the workbook to the sessions, or adolescents may lose the workbook. The wordiness of the workbook was another possible challenge. Adolescents’ reading and writing abilities must be kept in mind as not all of them are on the same level of education; they may not be able to read and write on a Grade 8 level.

Confidentiality was another concern because people might be able to see the book or get hold of it and read some of the private entries made by the adolescent. However, some adolescents mentioned that privacy would not be a problem for them as their family members are aware of their status. One healthcare worker stressed that, in her experience, adolescents do not engage well with workbooks:

“We have the disclosure books. Often, I will mention it. We will look at it that day, we discussed it but then they never go back.” (Participant 1, female, focus group 3)

The stakeholders made suggestions to improve the workbook’s effectiveness, including adapting the content and language to be less complicated and presented in more manageable portions. Stories and scenarios can be used that are relevant for ALWH. Also, brighter colours in the illustrations and even word ‘bubbles’ for extra writing and creativity were recommended.

“Some of them are not very strong with writing. Drawing or something like that or filling in bubbles. That kind of thing.” (Participant 2, female, focus group 3)

Although the smartphone application is not developed yet, participants provided feedback on the possible translation of activities on an application. Feedback on the utilisation of the **smartphone application** varied. The advantages were that most adolescents have smartphones, and they would be receiving notifications and reminders that could engage them more. The language used in the application should be simplified and easier to use for adolescents who find reading challenging, and accompanying voice narrations were mentioned. The use of videos and recordings made by adolescents could also increase engagement and interactivity:

“It will be good if they get notifications, the app can have a reminder to remind them to do an activity and to guide them as well. So, there is a step-by-step notification or something like that, or pop-ups.” (Participant 1, female, focus group 3)

The disadvantages highlighted were that some adolescents might have limited access to phones, and they need to use the phone of a caregiver/parent or family member. Some parents do not allow adolescents to have phones:

“For some other kids the phone is not going to work because parents don’t allow children to have phones because they think they will do something wrong with

the phone, so they will search some things that are wrong, or they won't be given one." (Participant 2, female, focus group 2)

It is also unsafe in the communities to walk around with a smartphone. Phones get lost or stolen, and the battery or data might run out. Some adolescents commented that they use their phones for other things: "*my phone is always busy*". These are all factors to consider. For the smartphone application to be effective, adolescents should also be able to use the application offline.

In general, adolescent participants appeared to prefer the workbook, but also commented that everyone should have an opportunity to choose between the options.

"I think they are brilliant methods. I think it is nice to have a workbook, and if you have a workbook, you can probably use them both. Phones do get lost, they get stolen, batteries die, data run out. I like the idea of using them both." (Participant 4, female, focus group 1)

Responses to the **peer groups** were very favourable. The advantages that were emphasised were the transfer of knowledge between peers, and that they will be learning from each other, helping to build confidence amongst each other. The adolescents will feel comfortable amongst peers who are going through similar experiences daily. Many adolescents had been exposed to peer groups and reported positive experiences.

"This group thing where you could ask questions and post things on the wall talking about this: if you drink your 'pillies' regularly, then this is going to happen, you will feel good, and you'll be okay. They boost your confidence and that helped a lot." (Participant 1, female, focus group 2)

For the peer groups to be effective, groups should include fun activities to keep the participants engaged. Adolescents should also be able to engage in their home language with their peers to express themselves better. A suggestion was made to potentially separate the groups according to gender for certain topics, such as sex education or male circumcision. Lastly, peer-group facilitators should receive training,

complete the programme, and set goals themselves so that they understand the programme.

“When you use peers, you would actually have to take the peers through that, the process of setting goals. They are then able to at least know the basics.”
(Participant 4, female, focus group 1)

“I don’t think we need to separate them, but like you say it may depend on the activity in the workbook. There are things that are specific to boys then we can do that, but we shouldn’t separate them.” (Participant 3, female, focus group 1)

Feedback on **individual counselling and coaching** was largely positive. The participants expressed that it was an acceptable method and required for this programme because counselling and coaching will provide a platform for privacy, individual planning and setting of goals, and empower individuals. Certain adolescents are not open to discussing their challenges in the group, necessitating an individual approach. An important aspect to remember that one healthcare worker highlighted was that the counsellor/coach needs to focus more on facilitating decision-making and goal setting, rather than telling the adolescents what to do.

“I think that what is important with individual coaching sessions is just to try being more facilitator [sic], making sure that they are making the decisions – empowering them rather than being told.” (Participant 1, female, focus group 3)

As part of the intervention, one individual counselling session involves a family member or confidant; however, the one disadvantage highlighted was that family members might not have time to attend or be involved. The adolescent should also give consent whether their family may be involved or not. Adolescent participants generally expressed they were comfortable with the individual sessions and to involve a family member:

“If I have someone on my side that I can come to and ask ‘my goal is this, this, and that, how do I easily go ...’ and you know. For a family member ... (big sigh) ...it can be anyone, its fine.” (Participant 1, female, focus group 2)

For counselling and coaching to be effective, adolescents need to feel comfortable enough to share; they need to trust the counsellor or coach. Some adolescents mentioned that they may not feel comfortable sharing their goals with another person because of fear of witchcraft. Such individual aspects must be considered depending on the context.

“In our culture it is hard. Because if you tell someone that you want to pass [school] maybe that person will be so jealous and do something...maybe witchcraft.” (Participant 1, female, focus group 4)

Stakeholders also highlighted there might be a need to continue counselling after the programme ended, or adolescents may need to be referred for more specialised care as some may have complex challenges.

“I’m just thinking of those, somebody struggling with drug addiction – I’ve heard some sell their HIV medication or they mix it with other drugs. So if you identify that problem it will be a slow progress because you refer someone to a specific facility and sometimes they never come back.” (Participant 1, female, focus group 1)

4.3.2.3 Theme three: Programme facilitators, duration and setting

The criteria related to the effectiveness of using **peer facilitators** focused on the willingness of older adolescents who are chosen to be peer facilitators to engage with the younger peers (confidentiality). Peer facilitators should also be comfortable sharing their own experiences and disclosing their status. There were mixed responses when some of the older adolescents were asked if they would be willing to be peer facilitators:

“Probably not. I don’t feel comfortable, because I’ve not reached that level yet.”
(Participant 4, male, focus group 2)

“I’m fine with that. I’ve been drinking ‘pillies’ and known I had HIV for a long time. I am comfortable talking about it.” (Participant 1, female, focus group 2)

The peer facilitators must be role models and should complete the programme themselves and undergo training. They could also be selected from existing peer mentors if such exist at the facility. The peer facilitators' gender should be kept in mind when selection takes place to have both male and female peer facilitators available when the groups are separated for specific topics. Moreover, peer facilitators and coaches should be able to speak the same language as the adolescent participants.

“Also dealt with people who have really been broken because of certain peers who are not sufficiently trained or have not been taught about confidentiality. They have taken information around...I know in this community, I know, information goes.” (Participant 1, female, focus group 1)

“I’m just thinking in terms of facilitators, it would be beneficial to have male and female. Depending on whether you are splitting the groups.” (Participant 4, female, focus group 1)

The peer facilitators should receive specific training on confidentiality and communication skills. Supervision should also be provided to peer facilitators, as well as debriefing after the sessions. Debriefing should be done by a psychologist, if available, as it works in other settings. One participant commented that untrained facilitators could be harmful.

“Also dealt with people who have really been broken because of certain peers who are not sufficiently trained or have not been taught about confidentiality.” (Participant 1, female, focus group 1)

The stakeholders discussed **communication and language preferences** in relation to the language to be used in the workbook and smartphone application. Some adolescents stated that it is very long to read isiXhosa, and they preferred simplified language or English. Communication skills training will also be needed to manage conversations in peer groups.

“Our own language is very difficult. English is better.” (Participant 1, female, focus group 2)

“I didn’t even do Xhosa at school, so I don’t know how to read Xhosa.”

(Participant 2, female, focus group 2)

During the discussion on **human resources**, important topics were highlighted by the stakeholders, which included that the programme is time consuming when human resources are being considered. This specifically referred to the three individual counselling sessions of approximately one hour per session. Some additional resources would be needed as it is not feasible to involve counsellors from clinics. Referral systems will also need to be in place and follow-ups should be facilitated for specific needs and complicated cases.

“I think you can see from today how stretched the staffed are. Uhm I don’t think in terms of feasibility to have someone here to do it, even at Grootte Schuur with NGO involvement and support. Try and get some NGO support.”

(Participant 2, female, focus group 3)

In terms of the **timing and duration** of the programme, most stakeholders agreed that either a counselling or peer-group session once a week for 12 weeks is acceptable, and that Friday afternoons are more convenient than Saturday mornings. Important matters to consider were special considerations during exam times and holidays; provision should be made for exam times and holidays to be excluded. When a camp-style programme was suggested, the points to consider were that confidentiality would be improved but that the time might be too short for reflection if the camp were to take place over 4 to 5 days.

“There is some duties to do at home [on a Saturday]. It is better to manage our time. On Friday afternoon we would come from school.”

(Participant 2, female, focus group 2)

When the **selection of participants** was discussed, the stakeholders highlighted that parental consent would be needed, and that all the sessions for adolescents should be voluntary. It was also stated that Grade 12 learners should not participate due to their high workload during the final year of school.

“Not during Matric, because they often have extra lessons on Saturdays and on Fridays. So not in Grade 12.” (Participant 4, female, focus group 1)

The adolescents voiced their opinions regarding the **criteria for effectiveness for the setting**. They emphasised the importance of the programme venue being away from the clinic in a neutral space. They wanted a change in environment away from their communities where stigma plays a significant role in their daily lives. For the adolescents, access and transport to the venue were not an issue as they stated they receive transport money from their parents to attend clinic appointments and programmes elsewhere in the community. Most stakeholders emphasised that incentives for attending the programme would be good, but not monetary, as that will create a negative motivation. It was also mentioned that refreshments should be served that are healthy and substantial. The stakeholders were in favour of a certificate ceremony when the ALWH had completed the programme. Lastly, one stakeholder verbalised that it would be important to consider COVID-19 regulations.

“Far away from home. Because I don’t want people in my community to know my status. It will be best when it is not close to where I stay. I am most comfortable with people that I don’t know. Even the clinic is fine, just as long it is away from home.” (Participant 1, female, focus group 2)

“Our parents have already started to give us money to come to the clinic. So, we can just continue...” (Participant 1, female, focus group 2)

4.4 SUMMARY

In this chapter, the researcher conveyed the findings of the study based on the feedback received from the experts. Moreover, three themes were identified during the analysis of the stakeholder focus group data. In the next chapter, the researcher discusses the study’s findings according to the research objectives and in relation to current literature. The dissemination, conclusion and proposed recommendations are also provided.

CHAPTER 5

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In the previous chapters, the background to the study, aim and objectives were provided, as well as a comprehensive literature review on ALWH and SM. The research methodology was then unpacked in detail, and the study's findings were presented. This final chapter contains the findings of the study compared with the latest literature.

5.2 DISCUSSION

The aim of the research was to explore the views of experts and key stakeholders as part of the development of an SM intervention for ALWH in a South African context, to refine the intervention. The findings were derived from the feedback from nine national and international experts and four focus groups in the Cape Metropole of the Western Cape, that included 19 stakeholders. The views of the experts and stakeholders are discussed, and the findings are presented under each objective.

5.2.1 Objective 1: To explore if the objectives and outcomes of the intervention are relevant and clearly defined

The experts rated the programme's objectives and outcomes based on their relevancy and clarity. Item **relevancy** for the objectives and outcomes was greater than 0.8, indicating the objectives and outcomes are valid. Item **clarity** ratings ranged from 0.4–0.9, indicating low clarity ratings, and certain objectives and outcomes were revised to improve clarity.

The feedback provided by the experts emphasised that the **primary outcomes** should focus on improving adolescents' well-being, and the objectives in the components should not only be focused on HIV. This was confirmed in the stakeholder focus groups that highlighted the importance of encompassing objectives that address various issues such as stigma, disclosure, and identity formation. Previous studies amongst

ALWH have also identified a range of SM needs, such as accountability in managing their condition, compliance to lifelong treatment, improved knowledge about HIV and reproductive health, to name a few (Adams & Crowley, 2021:8; Mutumba et al., 2019:1; Slogrove & Sohn, 2018:2).

Many SM interventions focus on specific outcomes, such as health-related quality of life, viral suppression, and mental health (Crowley & Rohwer, 2021:2). The systematic review by Crowley and Rohwer (2021:8-10) identified two studies that utilised health-related quality of life as an outcome, 10 studies used VL, and seven studies used mental health as an outcome. Other outcomes included in these SM programmes were health risk behaviour, such as sexual behaviour and drug use; social support; self-care abilities, including binge drinking, alcohol and illicit drug and alcohol use; confidence; and adherence. In a review of key interventions for scale, UNICEF (2021:7) identified the key outcomes being retention, VL, adherence, and ALWH well-being (including knowledge, sexual health and mental health).

Regarding the secondary outcomes, experts confirmed perceived support as one of the important outcomes of the intervention. This was supported by the feedback from the stakeholders mentioning the importance of the family and community context. Family, community, and healthcare support have been found to improve adherence and SM amongst youth living with a chronic illness (Sattoe et al., 2015:705).

Although family support appears central to SM, a recent systematic review identified only one intervention that involved the family and measured family support as an outcome (Crowley & Rohwer, 2021:29). Some participants also suggested involving the community. Another recent systematic review of mental health interventions for ALWH similarly suggested that family and community interventions may be important to foster adolescent-parent communication and address societal issues such as stigma (Bhana, Abas, Kelly, Van Pinxteren, Mudekunya & Pantelic, 2020:1-15).

The objectives in the intervention cover a range of SM domains, including believing and knowing; participation; goals and facilitation; biomedical management; and coping and self-regulation. Both experts and key stakeholders found this to be an advantage of the programme, which may equip and empower adolescents with a range of skills,

especially after learning and completing various SM tasks. These will promote their knowledge (including biomedical management and beliefs), social facilitation and resource utilisation, as well as coping and self-regulation.

In most SM interventions, knowledge is condition-specific; for example, understanding the treatment regimen and CD4 counts and VLs. However, based on the feedback from stakeholders, this intervention promotes expanded knowledge of general health with a broader scope than only HIV information and skills. Social facilitation also includes interactions with healthcare providers, knowing which questions to ask and where to seek help when needed, as well as attending peer support groups. Coping and self-regulation include learning positive coping strategies, identifying emotions, stigma, and the effects thereof, and speaking about these aspects (Crowley et al., 2019:11-12; Duffy, Bergman & Sharer, 2014:6).

5.2.2 Objective 2: To determine if the theoretical methods and practical strategies of the intervention are relevant and feasible

The experts rated the intervention's theoretical methods and practical strategies based on relevancy and clarity. The item relevancy was between 0.9 and 1.0, indicating the methods and strategies are relevant. The item clarity ratings ranged between 0.4 and 0.9, indicating low clarity ratings for some of the components, which were revised accordingly.

The components of the intervention were developed based on the IFSMT (Ryan & Sawin, 2009) and the steps outlined in the IM approach (Kok, 2014:156-170). The three main strategies include a **workbook with individual activities, peer groups, and individual counselling/coaching**. Based on the experts' feedback, the methods and practical strategies were further refined and linked to specific behaviour change strategies (Kok, 2014:156-170). These include strategies such as modelling, technical knowledge, discussions, goal setting, action plans, and journaling, to name a few, which have been shown to be effective (Kok, 2014:156-170).

SM interventions typically use a combination of **strategies** (Crowley & Rohwer, 2021:11-15); for example, either individual counselling, group counselling, family

interventions or a combination of two of these. The present intervention is a combination of all three strategies. Although it is not clear which strategy is most effective, a combination of strategies appears to work (Bal et al., 2016:1293-1309; Sattoe et al., 2015:704-715). This may be due to the variability between ALWH and their preferences. In a systematic review of SM interventions for adults living with HIV, the researchers emphasised that the complicated nature of HIV SM demands more than one or a combination of strategies to improve SM among people living with HIV requiring ART (Aneri, Marshall & Harvey, 2020:12).

The effectiveness of an intervention may also depend on the context. In the present study, the experts and key stakeholders highlighted contextual factors at various levels. These included the individuals' identity or barriers they are facing in terms of family support (including the structure and functioning of the family), their community (e.g., the culture, stigma, friends, or discrimination), and lastly, the multidisciplinary healthcare team. The IM approach followed during the larger study recommended that experts and key stakeholders be consulted to verify that the intervention is methodologically sound, contextually relevant, and feasible. Obtaining their opinions and adapting the strategies accordingly will likely lead to a positive and effective SM intervention (Fernandez et al., 2019:1-8).

All three of the main strategies, namely individual activities (in a workbook/app form), peer groups, and individual counselling, appeared to be feasible from the key stakeholders' point of view. However, they were concerned about the resource implications of individual counselling sessions.

Peer support mainly consists of adolescents who are of a similar age providing psychosocial support, information, knowledge, and a bond with other peers who face similar issues. Peer support might positively influence adolescents' retention in care, coping with stigma, disclosing their HIV status to others, and treatment adherence (UNICEF, 2021:8). Peer-based group interventions have been identified as an evidence-driven model for scale-up (UNICEF, 2021:2). According to a paper that examined peer support for young people living with HIV in sub-Saharan Africa, there are many ways in which peer support may be provided, ranging from individual to group support, community- or facility-based, and in-person or virtual support (Mark, Hrapcak,

Ameyan, Lovich, Ronan, Schmitz & Hatane, 2019:3). In the present study, behaviour change methods employed in the peer groups included modelling, belief selection, peer education, discussions to raise consciousness, and relationship building, amongst others.

The stakeholders were in favour of the peer groups as this method provides a platform for role modelling, interactive activities, and the sharing of knowledge. Some criteria for peer group effectiveness identified in this study emphasised that the adolescents should be able to communicate in their home language or language in which they feel most comfortable. Another important criterion was that older adolescents must volunteer or want to be peer facilitators and be comfortable enough to share their HIV status, knowledge, and own experiences.

During the focus groups, the stakeholders expressed that individual counselling and coaching were needed for an individualised approach. It would also provide a platform for privacy where adolescents can communicate their goals and future planning. Some individuals prefer not to share such private information in a group, but rather in a one-on-one approach. An example of an individualised approach is the WHO participants' manual for the integrated management of adolescent and adult illness (IMAI) *One-day Orientation on Adolescents Living with HIV*. It recommends the 5 "A's" approach comprising factors like assess, advise, agree, assist, and arrange. This approach serves as a template for healthcare workers specifically working with matters that are distinct for ALWH (WHO, 2010:73-74). The approach plays a vital part in chronic care and is different from traditional counselling and focuses on improving motivation.

Another example of a successful individualised approach is the Healthy Choices intervention that has been used in the US and Thailand. It consists of four motivational interviewing sessions that resulted in a decrease in sexually risky behaviour and improved HIV disclosure to partners (Rongkavilit, Naar-King, Wang, Panthong, Bunupuradah, Parsons, Phonphithak, Koken, Saengcharnchai & Phanuphak, 2013:1-9).

5.2.3 Objective 3: To establish if the format, setting, programme duration, and leaders/facilitators of the intervention are relevant and feasible

The intervention format or delivery format refers to face-to-face, cell phone or ICT-based. In this study, the intervention format is mostly face-to-face (counselling and peer groups), with the workbook activities either being completed at home in adolescents' own time or via a smartphone application. Experts mentioned that face-to-face contact would be more appropriate in the South African context, but engagement could be enhanced by ICT.

With regards to the **workbook**, the key stakeholders had conflicting feedback, especially regarding the size of the workbook. The adolescents preferred a larger book to have more space for writing and making notes, and the healthcare workers wanted a smaller version, mainly for confidentiality reasons. The criteria for effectiveness included simplifying the language and content of the workbook and adding brighter colours.

None of the interventions in a recently conducted systematic review had a workbook specifically for adolescents (Crowley & Rowher, 2021:1-29). Moreover, many resources in the South African context are written for healthcare workers working with adolescents. For example, the Wits RHI adolescent toolkit for healthcare workers in the South African context focuses on assisting healthcare workers who are working with ALWH (Fick et al., 2015).

As mentioned in Chapter 1, the Toolkit for the Transition of Care and other Services for ALWH was developed with the support of PEPFAR and USAID. This toolkit focuses on supporting ALWH and their families in developing SM skills and resilience during their transition to adult care. It was implemented in Kenya, and certain aspects of the toolkit were researched and implemented in Zambia (Gage, Do & Grant, 2017:190; Sharer, 2019).

With regards to the **smartphone application**, feedback varied between the stakeholders. Many adolescents have smartphones, but some must use their caregiver's phones. The main concern was the safety of the adolescents walking

around in communities where phones get lost or stolen. Some positive remarks were that the adolescents would be receiving notifications and reminders, engaging them more in the programme. In general, the adolescents preferred the workbook, but said people should be able to decide whether they want to use the workbook or smartphone application.

A systematic review by Crowley and Rohwer (2021:11-15) showed no published technology-enhanced SM interventions in the African setting. Technology-enhanced SM interventions have potential but with some limitations in terms of access to Wi-Fi or data and access to smartphones. A systematic review by Zhang and Li (2017:81) also looked at ICT for HIV SM; they found ICT platforms had limited geographic scope and were mainly based in English-speaking countries like Australia or the US.

Responses related to intervention **peer groups** were mostly positive. Peers will be able to learn from each other, transferring knowledge amongst themselves. This is an effective strategy used in many interventions (Donenberg et al., 2019:S289-S298; Dow, Mmbaga, Turner, Gallis, Tabb, Cunningham & O'Donnell, 2018:12-20; Hosek, Harper, Lemos, Burke-Miller, Lee, Friendman & Martinez, 2018:2650-2661). The strategy would be a more viable and affordable way to deliver the intervention, specifically in low-resource settings with high HIV burdens.

The feedback on **individual counselling and coaching** reflected the benefit of providing a private platform for adolescents to share thoughts and ideas that they normally feel uncomfortable sharing in a group; for example, future planning and setting of goals. Many interventions successfully used individual counselling (Crowley & Rohwer, 2021:11-15; Dow et al., 2018:13; Mimiaga et al., 2019:21-24).

In terms of the **setting**, responses mainly emphasised that the programme must be presented away from the adolescents' communities and the clinic due to privacy and stigma challenges. In a study in the Eastern Cape on multiple forms of discrimination and internalised stigma among ALWH, poor retention in HIV care was reported. This could have been attributed to multiple forms of discrimination, including healthcare settings and internalised stigma (Pantelic, Casale, Cluver, Toska & Moshabela, 2020:1-8).

Additional parameters to promote the effectiveness of the setting included incentives; these were suggested to encourage the adolescents to attend the programme. However, incentives should not be in the form of money, which could be a misleading reason to attend the programme. All the stakeholders were in favour of a certificate ceremony once the adolescents complete the programme, as well as healthy and substantial refreshments being served since adolescents will likely be attending the programme after school.

The **timing and duration** of the programme elicited similar suggestions among key stakeholders. Their preferred time was a Friday afternoon after school, instead of a Saturday morning, once a week over 12 weeks. Considerations had to be kept in mind that Grade 12 learners should be excluded due to their busy schedule. Winter holidays might be too cold and rainy, and people often go away with their families during the summer holiday.

When considering the duration of other SM interventions, the longest intervention is the Stepping Stones intervention (Holden et al., 2019:124-137), consisting of two parts (30 sessions) over eight months. Another intervention called the VUKA Family Programme consists of six sessions over a three-month period (2 Saturdays a month). Based on the timing and duration of other SM interventions, this intervention is thus not too short or too long to ensure completion.

In the present study, both experts and key stakeholders agreed on using older peers as peer facilitators and healthcare workers as counsellors. The **peer leaders/facilitators** must be role models to the adolescents, should complete the same programme, and receive additional training, for example, on confidentiality and communication skills. The peer facilitators should speak the same language as the adolescents. Moreover, both male and female facilitators should be selected so groups can be separated when gender-sensitive topics are discussed.

Additional important considerations include a trusting relationship with the counsellor/coach for the adolescent to be able to share their personal information. Moreover, adolescents should be guided and facilitated rather than being told what to do. Counselling might also have to continue after the programme, as some adolescents

may face complicated challenges. One last important consideration mentioned is that three individual counselling sessions of 60 minutes each will require extra human resource support. The clinical facilities will not be able to provide those counsellors as they hardly have enough support at the facilities on a normal day.

In countries with more resources, interventions make use of psychologists or degree-trained staff, which may not be feasible in an African- or South African setting. Therefore, for many interventions, peer leaders and lay counsellors are trained, which may be more sustainable in low-income countries. In an African setting, lay-people are thus used due to a lack of human- and other resources. Moreover, in a peer-led trauma-informed CBT intervention by Donenberg et al. (2018:S289-S298), promising results were found in terms of feasibility and sustainability. However, when using peers and lay counsellors, oversight will have to be provided.

5.2.4 Objective 4: To explore if the intervention contents are clearly described and relevant

The experts rated the clarity and relevancy of the programme content and materials at 0.9, indicating the content and materials to be valid. The stakeholders also emphasised the benefits of the programme's content, referring to the range of topics and detailed information that may help the ALWH handle the healthcare system. They approved of other topics and extra information, such as career advice, healthy living, alcohol, and drug use, so that the content not only covers HIV-related matters.

SM interventions typically either focus on HIV-specific content (Jeffries, Ross, Matoff-Stepp, Thomson, Harris, Uhrig & Cheever, 2016:UCARE4LIFE: Mobile Texting to Improve HIV Care Continuum Outcomes for Minority Youth) or relational or psychological functioning (Dow et al., 2018:1-13). Few interventions are comprehensive in covering all the SM domains.

Key stakeholders made suggestions that should be considered during the review and editing of the workbook. Some issues that were pointed out included the aesthetics of the workbook. Illustrations and colours in the workbook were not bright enough to capture adolescents' interest, and it was recommended to add more space to enable

additional writing in the form of journaling or word ‘bubbles’ to complete. The language should be edited to a more readable or conversational style; some ‘slang’ could be added to get the adolescents to engage with the content.

These recommendations relate to adolescent-friendly approaches as recommended in other literature (Gage et al., 2017:7-8; Southern African HIV Clinicians Society, 2017:36-40). ‘Adolescent-friendly’ entails adolescents’ engagement in programme design and implementation; improved access to services; affordable or free services; schools, youth clubs and youth-friendly institutions working together; information accessible in alternative ways; training for staff delivering adolescent-friendly services; privacy and confidentiality; and peer counselling on overall risk reduction (Gage et al., 2017:7-8).

5.3 LIMITATIONS OF THE STUDY

Due to the COVID-19 pandemic, the researcher could not complete the focus groups in 2020 due to a countrywide lockdown and restrictions. Permission to conduct focus groups in a rural area was also not permitted also due to COVID-19 regulations causing limited geographical input. This meant the study was limited to the metro and only one facility. Access to participants was thus challenging due to a lack of response and geographical access. Some participants who were recruited did not attend due to transport problems or illness. The researcher could not include all groups of stakeholders, for example, caregivers who were not available.

There was not enough time in the focus groups to discuss the programme/intervention content in detail. Although the contents were broadly discussed, the individual workbook activities, peer-group discussion topics, and counselling session contents were not evaluated in detail by the stakeholders; this precluded more detailed feedback on the contents. There was also insufficient time for a follow-up session with the stakeholders to provide feedback on the revisions made to the intervention.

5.4 CONCLUSIONS

The researcher obtained experts' and key stakeholders' feedback on the intervention as set out in the initial aim. The objectives were reached in that the relevancy and clarity of the various components were established. Further, some preliminary data on possible feasibility and criteria for effectiveness were identified.

5.5 RECOMMENDATIONS

The following recommendations are based on the study's findings. Further development and refinement of the components and training guide will take place. A pilot study will be conducted to obtain data on the feasibility and assist in formulating the implementation guidelines.

5.5.1 Recommendation 1: Further development of the intervention's components

The researcher recommends further development of the intervention components. For example, the workbook is currently being adapted to consider the feedback from the experts and stakeholders; the smartphone application is also being developed to transfer the workbook activities onto an application. A support guide for caregivers on their role as part of the one coaching/individual counselling session will have to be developed. The researcher did not get detailed feedback on the various workbook contents, so further developmental work will be conducted on the facilitator guide and workbook. Experts in coaching will be consulted to obtain their input.

5.5.2 Recommendation 2: Development of training guides

Before pilot testing can commence, training guides for coaches and peer facilitators should be developed. These should include some of the criteria for effectiveness already identified in this study's context, as well as based on a further literature review.

5.5.3 Recommendation 3: Piloting and development of implementation guidelines

This study followed the IM approach, which includes the following steps: Step 1 - needs assessment; Step 2 - matrices; Step 3 - theory-based methods and practical strategies, Step 4 - programme; Step 5 - adoption and implementation plan; Step 6 - evaluation plan (Detaille et al., 2010:3). The researcher completed Step 4, which entailed the consultation with intended participants and implementers, a review, and the development of programme materials. Further refinement is recommended. Steps 5 and 6 are to follow, which include the programme implementation plan and evaluation plan development.

The programme components need to be piloted with a control group to see whether it is feasible and whether there is a change in the study's primary and secondary outcomes. Measuring instruments should be identified that could measure the primary and secondary outcomes. An investigation should also be conducted into the programme's feasibility; for example, related to the issue of resources constraints identified during the focus groups and, whether possible, which NGOs could be involved in the pilot and larger-scale rollout of the intervention, should it be found to be effective. An implementation guide should also be written.

5.6 DISSEMINATION

The researcher aims to write an article to be published in a peer-reviewed journal based on the research findings. The workbook for adolescents was revised based on the experts' feedback and was then presented to the stakeholders during the focus groups. The preliminary findings of this study were discussed at the 2021 International Workshop on HIV and Adolescence conference in poster form. There is also a plan to implement the pilot in the same study context so that the participants may ultimately benefit.

5.7 CONCLUSION

An HIV SM intervention has been developed for ALWH facing numerous challenges. Feedback was obtained from experts and key stakeholders to make the intervention contextually appropriate and feasible. More interventions are needed to improve this growing vulnerable population group's health outcomes and quality of life.

Progress in ALWH's health outcomes and the development of interventions are lagging. Interventions and programmes showing promising results in supporting ALWH should be placed at the forefront for development, particularly focusing on reaching the UNICEF 95-95-95 global targets.

This intervention might be a solution to ALWH in South Africa and the African context to support and guide them and healthcare workers in reaching their targets in care. Adolescents deserve to live their best life and thrive.

REFERENCES

- Aantjes, C.J., Ramerman, L. & Bunders, J.F.G. 2014. A systematic review of the literature on self-management interventions and discussion of their potential relevance for people living with HIV in sub-Saharan Africa. *Patient Education and Counselling*, 95, 185-200.
- Adams, A.L. 2019. Exploring the self-management needs of adolescent living with HIV in the Nelson Mandela Bay area of the Eastern Cape. Master Thesis. University of Stellenbosch, Cape Town.
- Adams, L. & Crowley, T. 2021. Adolescent human immunodeficiency virus self-management: Needs of adolescents in the Eastern Cape. *African Journal of Primary Health Care & Family Medicine*, 13(1), 1-9.
- Akhtar, M.I. 2016. Research Design. *Research in Social Science: Interdisciplinary Perspectives*. [Online] Available at: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2862445 [Accessed 16 February 2022].
- Anderson, K., Muloiwa, R. & Davies, M. 2020. Long-term outcomes in perinatally HIV-infected adolescents and young adults on antiretroviral therapy: a review of South African and global literature. *African Journal of AIDS Research*, 19(1), 1-12.
- Areri, H.A., Marshall, A. & Harvey, G. 2020. Interventions to improve self-management of adults living with HIV on Antiretroviral Therapy: A systematic review. *PLoS ONE*, 15(5), 1-22.
- Armstrong, A., Nagata, J.M., Vicari, M., Irvine, C., Cluver, L., Sohn, A.H., Ferguson, J., Caswell, M.A., Njenga, L.W., Oliveras, C., Ross, D., Puthanakit, T., Baggaley, R. & Penazzato, M. 2018. A Global Research Agenda for Adolescents Living With HIV. *Acquir Immune Defic Syndr*, 78(Supplement 1), S16-S21.
- Bal, M.I., Sattoe, J.N.T., Roelofs, P.D.D.M., Bal, R., van Staa, A. & Miedema, H.S. 2016. Exploring effectiveness and effective components of self-management interventions for young people with chronic physical conditions: A systematic review. *Patient Education and Counseling*, 99(2016), 1293-1309.
- Bandura, A. 2005. Adolescent development from an agentic perspective. *Self-efficacy Beliefs of Adolescents*, 1, 1-44.

- Barlow, J., Wright, C., Sheasby, J., Turner, A. & Hainsworth, J. 2002. Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48(2002), 177-187.
- Belzer, M.E., Naar-King, S., Olson, J., Sarr, M., Thornton, S., Kahana, S.Y., Gaur, A.H. & Clark, L.F. 2014. The Use of Cell Phone Support for Non-adherent HIV-Infected Youth and Young Adults: An Initial Randomized and Controlled Intervention Trial. *National Institute of Health*, 18(4), 686-696.
- Bernardin, K.L., Toews, D.N., Restall, G.J.B. & Vuongphan, L. 2013. Self-management interventions for people living with human immunodeficiency virus: A scoping review. *Canadian Journal of Occupational Therapy*, 80(5), 314-327.
- Bhana, A., Abas, M.A., Kelly, J., Van Pinxteren, M., Mudékunye, L.A. & Pantelic, M. 2020. Mental health interventions for adolescents living with HIV or affected by HIV in low- and middle-income countries: systematic review. *BJPsych Open*, 6(e104), 1-15.
- Bhana, A., Mellins, C.A., Petersen, I., Alicea, S., Myeza, N., Holst, H., Abrams, E., John, S., Chhagan, M., Nestadt, D.F., Leu, C. & McKay, M. 2014. The Vuka Family Program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. *AIDS Care*, 26(1), 1-17.
- Brady, S.R. 2015. Using and adapting the Delphi Method for Use in Qualitative Research. *International Journal of Qualitative Methods*. [Online] Available at: <http://web.b.ebscohost.com.ez.sun.ac.za/ehost/pdfviewer/pdfviewer?vid=1&sid=bb30527a-2302-49d5-8054-7a12d5ef2ac9%40sessionmgr103> [Accessed 28 October 2019].
- Braun, V. & Clarke, V. 2006. Qualitative Research in Psychology. *Using Thematic Analysis in Psychology*, 3, 77-101.
- Chairs, Health Research Ethics Committees (HREC); Undergraduate Research Ethics Committee (UREC), Head of the Health Research Ethics Office (HREO). 2020. Stellenbosch University, Faculty of Medicine and Health Sciences HREC COMMUNIQUE 1: *Ethical Research Conduct in the Time of the COVID-19 Outbreak*. [Online] Available at: <https://www.sun.ac.za/english/faculty/healthsciences/rdsd/covid-19-latest-updates> [Accessed 9 September 2020].

- Cincinnati Children's Hospital. 2007. *Evidence-Based Care Guideline: Chronic Care: Self-management*. Cincinnati Children's Hospital Medical Center. Available at: www.cincinnatichildrens.org/svc/alpha/h/health-policy/ev-based/chronic-care.htm [Accessed 3 March 2019].
- Connelly, L.M. & Dehaemers, R.J. 2016. Trustworthiness in Qualitative Research. *Medsurg Nursing*, 25(6), 435-436.
- Côté, J., Godin, G., Ramirez-Garcia, P., Rouleau, G., Bourbonnais, A., Gueheneuc, Y.G., Tremblay, C. & Otis, J. 2015. Virtual Intervention to Support Self-Management of Antiretroviral Therapy Among People Living With HIV. *Journal of Medical Internet Research*, 17(1), 1-12.
- Creswell, J.W., Ebersöhn, L., Eloff, I., Ferreira, R., Ivankova, N.V., Jansen, J.D., Nieuwenhuis, J., Pietersen, V.L. & Plano Clark, V.L. 2019. *First Steps in Research*. Van Schaik Publishers. Hatfield, Pretoria.
- Crowley, T. 2018. The Development of an instrument to measure adolescent HIV self-management in the Western Cape, South Africa. PhD thesis Stellenbosch University, Cape Town.
- Crowley, T. & Rohwer, A. 2021. Self-management interventions of adolescents living with HIV: a systematic review. *BMC Infectious Diseases*. [Online] Available at: <https://bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-021-06072-0> [Accessed 8 July 2021].
- Crowley, T., Van der Merwe, A., Kidd, M. & Skinner, D. 2019. Measuring Adolescent HIV Self-management: An Instrument Development Study. *AIDS and Behaviour*. [Online] Available at: <https://doi.org/10.1007/s10461-019-02490-z> [Accessed 21 July 2019].
- Dahourou, D.L., Gautier-Lafaye, C., Teasdale, C.A., Renner, L., Yotebieng, M. & Desmonde, S. 2017. Transition from paediatric to adult care of adolescents living with HIV in sub-Saharan Africa: challenges, youth-friendly models, and outcomes. *Journal of the International AIDS Society*, 20(S3), 1-9.
- Denison, J.A., Banda, H., Dennis, A.C., Packer, C., Nyambe, N., Stalter, R.M., Mwansa, J.K., Katayamoyo, P. & McCarragher, D.R. 2015. "The sky is the limit": adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers. *Journal of the International AIDS Society*, 18(19358), 1-6.

- Department of Co-Operative Governance No. 891 (South Africa). 2020. Disaster Management Act, 2002 (Act no. 57 of 2002). Government Gazette, 436203: 3-15, 17 Augustus. [Online] Available at: https://www.gov.za/sites/default/files/gcis_document/202008/43620gon891s_0.pdf [Accessed 9 September 2020].
- Detaille, S.I., Van der Gulden, J.W.J., Engels, J.A., Heerkens, Y.F. & Van Dijk, F.J.H. 2010. Using intervention mapping (IM) to develop a self-management programme for employees with a chronic disease in the Netherlands. *BMC Public Health*, 10(353), 1-12.
- Dick, B. & Ferguson, B.J. 2015. Health for the World's Adolescents: A Second Chance in the Second Decade. *Journal of Adolescent Health*, 56, 3-6.
- Donenberg, G.R., Cohen, M.H., Ingabire, C., Fabri, M., Emerson, E., Kendall, A.D., Remera, E., Manzi O. & Nsanzimana, S. 2019. Applying the Exploration Preparation Implementation Sustainment (EPIS) Framework to the Kigali Imbereheza Project for Rwandan Adolescents Living With HIV. *J Acquir Immune Defic Syndr*, 82(3), S289-S298.
- Dow, D.E., Mmbaga, B.T., Turner, E.L., Gallis, J.A., Tabb, Z.J., Cunningham, C.K. & O'Donnell, K.E. 2018. Building resilience: a mental health intervention for Tanzanian youth living with HIV. *AIDS Care, Psychological and Socio-medical Aspects of AIDS/HIV*, 30(54), 12-20.
- Dow, D.E., Mmbaga, B.T., Gallis, J.A., Turner, E.L., Gandhi, M., Cunningham, C.K. & O'Donnell, K.E. 2020. A group-based mental health intervention for young people living with HIV in Tanzania: results of a pilot individually randomized group treatment trial. *BMC Public Health*, 20(1358), 1-13.
- Duffy, M.H., Bergmann, H. & Sharer, M. 2014. Toolkit for Transition of Care and Other Services for Adolescents Living with HIV. Arlington, VA: USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1.
- Fernandez, M.E., Robert, A.C., Markham, C.M. & Kok, G. 2019. Intervention Mapping: Theory- and Evidence-Based Health Promotion Program Planning: Perspective and Examples. *Frontiers in Public Health*, 7(209), 1-8.
- Fick, C., Fairlie, L., Moultrie, H., Woollett, N., Pahad, K., Thomson, K. & Pleaner, M. 2015. *Working with adolescents living with HIV: A handbook for healthcare providers*. Johannesburg: Wits RHI and Southern African HIV Clinicians Society.

- Gage, A.J., Do, M. & Grant, D. 2017. *Best Practices for Adolescent- and Youth-Friendly HIV Services*. A Compendium of Selected Projects in PEPFAR- Supported Countries. Edited by A. J. Gage and D. Grant. MEASURE Evaluation, University of North Carolina at Chapel Hill.
- Grady, P.A. & Gough, L.L. 2014. Self-Management: A Comprehensive Approach to Management of Chronic Conditions. *Framing Health Matters*, 104(8), e25-e31.
- Gray, J.R., Grove, S.K. & Sutherland, S. 2017. *The Practice of Nursing Research. Appraisal, Synthesis, and Generation of Evidence*. Eight Edition. St. Louis, Elsevier Publishers.
- Grove, S.K., Gray, J.R. & Burns, N. 2015. *Understanding Nursing Research. Building an Evidence-Based practice*. Sixth Edition. St Louis, Saunders Elsevier Publishers.
- Holden, S., Gordon-Deseagu, V.L.Z., Gordon, G., Chiziza, N., Kiwia, P., Magesa, D., Manyama, W. & Welbourn, A. 2019. Building resilience to adverse childhood experiences: An assessment of the effects of the Stepping Stones with Children training programme on Tanzanian children affected by HIV and their caregivers. *Health Educational Journal*, 78(2), 124-137.
- Hosek, S.G., Harper, G.W, Lemos, D., Burke-Miller, J., Lee, S., Friedman, L. & Martinez, J. 2018. Project ACCEPT: Evaluation of a Group-Based Intervention to Improve Engagement in Care for Youth Newly Diagnosed with HIV. *AIDS and Behaviour*, 22, 2650-2661.
- Khodyakov, D., Hempel, S., Rubenstein, L., Shekelle, P., Foy, R., Salem-Schatz, S., O'Neill, S., Danz, M. & Dalal, S. 2011. Conducting Online Expert panels: a feasibility and experimental replicability study. *BMC Medical Research Methodology*, 11(174), 1-8.
- Jaworska, N. & MacQueen, G. 2015. Adolescence as a unique developmental period. *J Psychiatry Neurosci*, 40(5), 291-293.
- Jeffries, C., Ross, P.E., Matoff-Stepp, S., Thompson, R., Harris, J. Uhrig, J. & Cheever, L.W. 2016. Ucare4life: mobile texting to improve HIV care continuum outcomes for minority youth. [Online poster]. Available at: <https://www.croiconference.org/wp-content/uploads/sites/2/posters/2016/993.pdf> [Accessed 16 November 2021].

- Keeney, S., Hasson, F. & McKenna, H.P. 2000. A critical review of the Delphi technique as a research methodology for nursing. *International Journal of Nursing Studies*, 38(2001), 195-200.
- Kok, G. 2014. A practical guide to effective behaviour change. How to apply theory- and evidence-based behaviour change methods in an intervention. *The European Health Psychologist*, 16(15), 156-170.
- Letourneau, E.J., Ellis, D.A., Naar-King, S., Chapman, J.E., Cunningham, P.B. & Fowler, S. 2013. Multisystemic Therapy for Poorly Adherent Youth with HIV: Results from a Pilot Randomized Controlled Trial. *AIDS Care*, 25(4), 1-13.
- Lorig, K. 2015. Chronic Disease Self-Management Program: insights from the eye of the storm. *Frontiers in Public Health*, 2(253), 1-3.
- Mark, D., Hrapcak, S., Ameyan, W., Lovich, R., Ronan, A., Schmitz, K. & Hatane, L. 2019. Peer Support for Adolescents and Young People Living with HIV in sub-Saharan Africa: Emerging Insights and a Methodological Agenda. *Curr HIV/AIDS Rep*, 16(6), 467-474.
- Mimiaga, M.J., Bogart, L.M., Thurston, I.B., Santostefano, C.M., Closson, E.F., Skeer, M.R., Biello, K.B. & Safren, S.A. 2019. Positive Strategies to Enhance Problem-Solving Skills (STEPS): A Pilot Randomized, Controlled Trial of a Multicomponent, Technology-Enhanced, Customizable Antiretroviral Adherence Intervention for HIV-Infected Adolescents and Young Adults.
- Munyayi, F.K. & Van Wyk, B. 2020. The effects of Teen Clubs on retention in HIV care among adolescents in Windhoek, Namibia. *South African Journal of HIV Medicine*, 21(1), 1-9.
- Mutumba, M., Mugerwa, H., Mussiime, V., Gautam, A., Nakyambadde, H., Matama, C. & Stephenson, R. 2019. Perceptions of Strategies and Intervention Approaches for HIV Self-Management among Ugandan Adolescents: A Qualitative Study, *Journal of the International Association of Providers of AIDS Care*, 18, 1-8.
- Nasaba, R., Tindyebwa, D., Musiime, V., Iriso, R., Ingabire, R., Nansera, D., Etima-Kizito, M., Kasule, J. & Duffy, M. 2018. *Handbook on Counselling and Psychosocial Care for Children and Adolescents Living With and Affected by HIV in Africa*. [Online] Available at: www.anecca.org [Accessed 16 May 2020].
- Panel on Antiretroviral Guidelines for Adults and Adolescents. 2018. *Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents Living with HIV*. Department of Health and Human Services. [online] Available at:

<http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>. [Accessed 3 March 2019].

- Pantelic, M., Casale, M., Cluver, L., Toska, E. & Moshabela, M. 2020. Multiple forms of discrimination and internalized stigma compromise retention in HIV care among adolescents: findings from a South African cohort. *Journal from the International AIDS Society*, 23(e25488), 1-8.
- Parker, L., Maman, S., Pettifor, A., Chalachala, J.L., Edmonds, A., Golin, C.E., Moracco, K. & Behets, F. for the SYMPA Study Team. 2013. Feasibility analysis of and evidence-based positive prevention intervention for youth living with HIV/AIDS in Kinshasa, Democratic Republic of the Congo. *AIDS Educ Prev*, 25(2), 135-150. doi: 10.1521/aeap.2013.25.2.135.FEASIBILITY.
- Polit, D.F. & Beck, C.T. 2017. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 10th Edition. Wolters Kluwer, Philadelphia.
- Polit, D.F. & Hungler, B.P. 1993. *Nursing Research: Methods, Appraisal, and Utilisation*. 3rd Edition. J.B. Lippincott Company, Philadelphia.
- Rongkavilit, C., Naar-King, S., Wang, B., Panthong, A., Bunupuradah, T., Parsons, J.T., Phonphithak, S., Koken, J.A., Saengcharnchai, P. & Phanuphak, P. 2013. Motivational Interviewing Targeting Risk Behaviours for Youth Living with HIV in Thailand. *AIDS Behav*, 17(6), 2063-2074.
- Ryan, P. & Sawin, K. 2009. The Individual and Family Self-management Theory: Background on Perspectives on context, process and outcomes. *Nursing Outlook*, 57(4), 217-225.
- Sattoe, J.N.T., Bal, M.I., Roelofs, P.D.D.M., Bal, R., Miedema, H.S. & van Staa, A. 2015. Self-management interventions for young people with chronic conditions: A systematic overview. *Patient Education and Counselling*, 98, 704-715.
- Sawin, K.J. 2017. Definitions, frameworks and theoretical issues in self-management. *Journal of Paediatric Rehabilitation Medicine: An Interdisciplinary Approach*, 10, 169-176.
- Sharer, M. 2019. Personal Interview. 22 October, Tygerberg.
- Shaw, S. & Rivet Amico, K. 2016. Antiretroviral Therapy Adherence Enhancing Interventions for Adolescents and Young Adults 13-24 Years of Age: A Review of the Evidence Base. *J Acquir Immune Defic Syndr*, 72(4), 387-399.

- Sherr, L., Cluver, L.D., Toska, E. & He, E. 2018. Differing psychological vulnerabilities among behaviourally and perinatally HIV infected adolescents in South Africa – implications for targeted health service provision. *AIDS Care*, 30(S2), 92-101.
- Slogrove, A.L. & Sohn, A.H. 2018. The global epidemiology of adolescents living with HIV: Time for more granular data to improve adolescent health outcomes. *Cur Opin HIV AIDS*, 13(3), 170-178.
- Southern African HIV Clinicians Society. 2017. Guidelines for adherence to antiretroviral therapy in adolescents and young adults. Johannesburg, South Africa, 36-40.
- Statistics South Africa (StatsSA). 2020. *2020 Mid-year population estimates*. Media release. Pretoria: Statistics South Africa, 2020. [Online] Available at: <http://www.statssa.gov.za/?p=13453> [Accessed 24 July 2021].
- Sutton, J. & Austin, Z. 2015. Qualitative Research: Data Collection, Analysis, and Management. *CJHP*, 68(3), 226-231.
- Swendeman, D., Barbara L., Ingram, B.L. & Rotheram-Borusa, M.J. 2009. Common elements in self-management of HIV and other chronic illnesses: an integrative framework. *AIDS Care*, 21(10), 1321–1334.
- Then, K.L., Rankin, J.A. & Ali, H. 2014. Focus Group Research: What is it and how can it be used? *Canadian Journal of Cardiovascular Nursing*. 24(1), 16-22.
- UNAIDS. 2015. Update: *Active involvement of young people is key to ending the AIDS epidemic by 2030 – UNAIDS*. [Online] Available at: https://www.unaids.org/en/resources/presscentre/featurestories/2015/august/20150812_PACT [Accessed 15 June 2019].
- UNAIDS. 2015. *Fast Track: accelerating action to end the AIDS epidemic by 2030 – UNAIDS*. [Online] Available at: https://www.unaids.org/sites/default/files/media_asset/201506_JC2743_Understanding_FastTrack_en.pdf [Accessed 14 October 2021].
- UNAIDS. 2019. *Country Factsheet, South Africa*. [Online] Available at: <https://www.unaids.org/en/regionscountries/countries/southafrica> [Accessed 20 October 2020].
- UNAIDS. 2020. *90–90–90: good progress, but the world is off-track for hitting the 2020 targets*. [Online] Available at: https://www.unaids.org/en/resources/presscentre/featurestories/2020/september/20200921_90-90-90 [Accessed 14 October 2021].

- UNAIDS. 2021. *Confronting inequalities: Lessons from pandemic responses from 40 years of AIDS*. [Online] Available at: <https://reliefweb.int/report/world/2021-unaids-global-aids-update-confronting-inequalities-lessons-pandemic-responses-40> [Accessed 25 October 2021].
- UNAIDS. 2021. *Fact Sheet 2021*. [Online] Available at: https://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf [Accessed 24 July 2021].
- UNICEF. 2016. *UNICEF Publications: For Every Child, End AIDS: Seventh Stocktaking Report, 2016 – UNICEF*. [Online] Available at: https://www.unicef.org/publications/index_93427.html [Accessed 15 June 2019].
- UNICEF. 2019. Adolescent HIV prevention. [Online] Available at: <https://data.unicef.org/topic/hivaids/adolescents-young-people/> [Accessed 2 October 2021].
- UNICEF. 2021. *HIV and AIDS in adolescents: Turning the tide against AIDS will require more concentrated focus on adolescents and young people*. [Online] Available at <https://data.unicef.org/topic/adolescents/hiv-aids/> [Accessed 14 October 2021].
- UNICEF. 2021. HIV treatment, care, and support for adolescents living with HIV in Eastern and Southern Africa: A review of interventions for scale. [Online] Available at: <https://www.unicef.org/esa/reports/hiv-treatment-care-and-support-adolescents> [Accessed 15 November 2021].
- UN. 2008. Definition of Youth. *United Nations Youth*. [Online] Available at: <https://www.un.org/esa/socdev/documents/youth/fact-sheet/youth-definition.pdf> [Accessed 21 October 2020].
- Van Staa, A. 2012. 'On Your Own Feet: Adolescents with chronic conditions and their preferences and competencies for care', PhD thesis Erasmus University, Rotterdam.
- Viner, R.M., Ozer, E.M., Denny, S., Marmot, M., Resnick, M., Fatusi, A. & Currie, C. 2012. Adolescence and the social determinants of health. *The Lancet: Adolescent Health*, 379(9826), 1641-52.
- Whiteley, L., Brown, L.K, Mena, L., Craker, L. & Arnold, T. 2018. Enhancing health among youth living with HIV using an iPhone game. *AIDS Care*, 30(S4), 21-33.
- Wilson, L. 2021. Email. 5 July.

- World Health Organisation. 2010. Participant manual: IMAI one-day orientation on adolescents living with HIV. [Online] Available at: <https://apps.who.int/iris/handle/10665/44258> [Accessed 17 November 2021].
- World Health Organisation. 2019. Maternal, newborn, child and adolescent health. *HIV and Youth*. [Online] Available at: https://www.who.int/maternal_child_adolescent/topics/adolescence/hiv/en/ [Accessed 3 March 2019].
- World Health Organization pdf. 2020. *Getting your workplace ready for COVID-19*. [Online] Available at: <https://www.who.int/docs/default-source/coronaviruse/advice-for-workplace-clean-19-03-2020.pdf> [Accessed 9 September 2020].
- World Medical Association. 2013. *World medical association declaration of Helsinki. Ethical principles for medical research involving human subjects*. [Online]. Available at: [https://www.who.int/bulletin/archives/79\(4\)373.pdf](https://www.who.int/bulletin/archives/79(4)373.pdf) [Accessed 9 September 2019].
- Zanoni, B.C., Archary, M., Buchan, S., Katz, I.T. & Haberer, J.E. 2016. Systematic review and meta-analysis of the adolescent HIV continuum of care in South Africa: The Cresting Wave. *BMJ Global Health*, 1(e000004), 1-7.
- Zanoni, B.C., Sibaya, T., Cairns, C. & Haberer, J.E. 2018. Barrier to Retention in Care are [sic] Overcome by Adolescent-Friendly Service for Adolescents Living with HIV in South Africa: A Qualitative Analysis. *AIDS and Behaviour*, 23, 957-965.
- Zhang, Y. & Li, X. 2017. Uses of information and communication technologies in HIV self-management: A systematic review of global literature. *International Journal of Information Management*, 37, 75-83.
- Zungu, N., Naidoo, I., Hodes, R., North, A., Mabaso, M., Skinner, D., Gittings, L., Sewpaul, R., Takatshana, S., Jooste, S., Moyo, S., Ramlagan, S., Cloete A. & Toska, E. 2021. Adolescents living with HIV in South Africa. *Human Sciences Research Council*. Cape Town, South Africa.

APPENDICES

APPENDIX 1: ETHICAL APPROVAL FROM STELLENBOSCH UNIVERSITY



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approval Notice

New Application

25/03/2020

Project ID :13322

HREC Reference No: S20/01/011

Approval Notice New Application

Project Title: The development of a self-management intervention for adolescents living with HIV in a South African context: views of experts and key stakeholders

Dear Miss Petra De Lange

We refer to your response to modifications received on 18/03/2020. Please be advised that your submission was reviewed and **approved** by members of

the **Health Research Ethics Committee** via **expedited** review procedures on 25/03/2020. Please note the following information about your approved research protocol:

Protocol Approval Date: 25 March 2020

Protocol Expiry Date: 24 March 2021

Please remember to use your Project ID 13322 and Ethics Reference Number S20/01/011 on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: [Links Application Form Direct Link](#) and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC

website <https://applyethics.sun.ac.za/ProjectView/Index/13322>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely, Mrs. Melody Shana Coordinator HREC1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number: IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

APPENDIX 2: ETHICS PROGRESS REPORT FROM STELLENBOSCH UNIVERSITY



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

31/03/2021

Project ID: 13322

Ethics Reference No: S20/01/011

Approval Letter Progress Report

Project Title: The development of a self-management intervention for adolescents living with HIV in a South African context: views of experts and key stakeholders

Dear Miss Petra De Lange

We refer to your request for an extension/annual renewal of ethics approval dated 08/03/2021.

The Health Research Ethics Committee reviewed and approved the annual progress report through an expedited review process. The approval of this project is extended for a further year.

Approval date: 25 March 2021

Expiry date: 24 March 2022

Kindly be reminded to submit progress reports two (2) months before expiry date.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please remember to use your Project Id 13322 and ethics reference number S20/01/011 on any documents or correspondence with the HREC concerning your research protocol.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica. Yours sincerely,

Mrs. Ashleen Fortuin
Health Research Ethics Committee 1 (HREC1)

National Health Research Ethics Council (NHREC) Registration Number: REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number: IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

APPENDIX 3: PERMISSION OBTAINED FROM WESTERN CAPE DEPARTMENT OF HEALTH

REFERENCE: WC_202008_019 ENQUIRIES: ****

**Francie van Zijl Drive Tygerberg
7505
Cape Town**

South Africa

For attention: Mrs Frances de Lange

STRATEGY & HEALTH SUPPORT

Health.Research@westerncape.gov.za tel: +27 21 483 0866; fax: +27 21 483 6058 5th Floor, Norton Rose House,, 8 Riebeeck Street, Cape Town, 8001 www.capegateway.gov.za)

Re: The development of a self-management intervention for adolescents living wit

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

Crossroads CDC ** 021 386 1119**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR ****

DIRECTOR: HEALTH IMPACT ASSESSMENT DATE: 06/12/2020

CC

APPENDIX 4: CONSENT FORMS**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

| | |
|--|--|
| TITLE OF RESEARCH PROJECT: | |
| The development of a self-management intervention for adolescents living with HIV in a South African context: views of experts and key stakeholders | |
| DETAILS OF PRINCIPAL INVESTIGATOR (PI): | |
| Mrs Frances de Lange-Cloete | Ethics reference number: |
| Full postal address: 38 Kronenbosch, Rochester Road, West Beach, 7441 | PI Contact number: 076 237 9980 |

We would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary**, and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University**. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

1. What is this research study all about?

- The research study will be conducted in the Western Cape of South Africa. The study participants will consist out of two groups. The one group will be 6-8 experts (researchers and academics) in adolescent health care, HIV management, self-management, and intervention mapping.
- The second group namely, the key stakeholders will be divided in two and consist of 6 participants and will include health care workers and NGO representatives with experience in providing care to adolescents living with HIV. Secondly the adolescents living with HIV (aged 15-18 years).

- The researcher wishes to gain valuable insight and information on the feedback you provide regarding the newly developed self-management intervention for adolescents living with HIV, so that we may use this information to further refine this intervention for implementation.
- Firstly we would like feedback from the experts by means of a questionnaire. After reaching consensus between the experts, the intervention will be modified/refined. This version of the intervention will then be presented to the focus groups for further input and feedback.

2. Why do we invite you to participate?

- We have selected you as either one of the experts in the study (academic or researcher) or as one of the key stakeholders because of your knowledge.

3. What will your responsibilities be?

- If you are one of the experts taking part in this study, you will be expected to answer a questionnaire, which may require more than one round of feedback. Your feedback will then be used to further refine the intervention. The refined intervention and feedback will be given back to you until consensus is reached.
- If you are a stakeholder, you will be participating in a focus group discussion that will be arranged at a convenient time. You will be asked to complete a register with your contact details and your temperature will be taken and recorded on the same register. The register will be kept for one month to assist the department of health to trace people that might have been exposed to COVID-19. As the research team we will provide you with disposable face masks, hand sanitiser and all surfaces will be cleaned with alcohol surface cleaner. Social distancing will be followed, where each of the participants will be seated at least 1m apart and windows will be opened for good ventilation of the room. The focus groups are anticipated to last between 40 to 90 minutes to ensure adequate data collection with a break in between. Refreshments will be provided in prepacked form. Focus groups will be audio-recorded. There will be a follow up focus group to provide you with feedback and the refined intervention. To provide honest feedback.

4. Will you benefit from taking part in this research?

- Participants will not directly benefit from taking part in this research study. The study findings will be used to contribute to the development and further refinement of the self-management intervention for ALHIV, which will have a positive effect on the health outcomes of adolescents living with HIV. The intervention will then be piloted in another study to test if the intervention is working.

5. Are there any risks involved in your taking part in this research?

- Taking part in this study may be of inconvenience. You will make use of your personal time to travel to the specific venue, as well as the time spent during the sessions. You will be reimbursed for your traveling costs to and from the venues and refreshments will be provided. There are no direct/immediate risks involved by taking part in this study.

6. If you do not agree to take part, what alternatives do you have?

- As the participant, you are under no obligation to take part in the study. You may also decide to leave the study if you do not feel you want to take part any longer. There will be no consequences for leaving the study at all.

7. Who will have access to your information?

- Your personal data and information shared during the sessions will be audio recorded and then saved into password-protected folders on the researcher’s personal computer.
- Prior to the commencement of the focus group, the researcher will ask all the participants to agree verbally not to share any personal information or data discussed during the focus groups.

8. How will you receive feedback from the study?

- You will receive feedback on the information you provided to the researchers in the form of your own feedback on the intervention. A summary of the data collected as well as the final developed intervention will be communicated back you.

9. Will you be paid to take part in this study and are there any costs involved?

- Focus group participants will be provided with refreshments during the sessions. Travel costs will be reimbursed if needed.

10. Is there anything else that you should know or do?

- You can phone Mrs Frances de Lange-Cloete at 076 237 9980 if you have any further queries or encounter any problems.
- You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that your study researcher has not explained to you, or if you have a complaint.
- You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I agree to take part in a research study entitled ‘The development of a self-management intervention for adolescents living with HIV in a South African context: views of experts and key stakeholders’

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary**, and I have not been pressurised to take part.
- I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.

Signed at (*place*) on (*date*) 2020.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document in a simple and clear manner to
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she completely understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2020.

.....
Signature of investigator

.....
Signature of witness

APPENDIX 5: LEGAL GUARDIAN/PARENT PARTICIPATION CONSENT FORM

LEGAL GUARDIAN/PARENT PARTICIPANT CONSENT FORM

| | |
|--|--|
| TITLE OF RESEARCH PROJECT: | |
| The development of a self-management intervention for adolescents living with HIV in a South African context: views of experts and key stakeholders | |
| DETAILS OF PRINCIPAL INVESTIGATOR (PI): | |
| Mrs Frances de Lange-Cloete | Ethics reference number: |
| Full postal address: 38 Kronenbosch, Rochester Road, West Beach, 7441 | PI Contact number: 076 237 9980 |

We would like to invite your child to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your child's participation is **entirely voluntary** and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you or your child negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you and your child are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to let your child take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University**. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

- The research study will be conducted in the Western Cape of South Africa. The study participants will consist out of two groups. The one group will be 6-8 experts (researchers and academics) in adolescent health care, HIV management, self-management, and intervention mapping.
- The second group namely, the key stakeholders will be divided in two and consist of 6 participants and will include health care workers and NGO representatives with experience in providing care to adolescents living with HIV. Secondly the adolescents living with HIV (aged 15-18 years).

- The researcher wishes to gain valuable insight and information on the feedback your child provide regarding the newly developed self-management intervention for adolescents living with HIV, so that we may use this information to further refine this intervention for implementation.
- Firstly, we would like feedback from the experts by means of a questionnaire. After reaching consensus between the experts, the intervention will be modified/refined. This version of the intervention will then be presented to the focus groups for further input and feedback.

Why do we invite your child to participate?

- We have selected your child as one of the key stakeholders because of their knowledge.

What will your child's responsibilities be?

- Your child will be participating in a focus group discussion that will be arranged at a convenient time. The focus groups are anticipated to last between 40 to 90 minutes to ensure adequate data collection with a break in between. Refreshments will be provided. Focus groups will be audio-recorded. There will be a follow up focus group to provide you with feedback and the refined intervention. To provide honest feedback.

Will you or your child benefit from taking part in this research?

- Participants will not directly benefit from taking part in this research study. The study findings will be used to contribute to the development and further refinement of the self-management intervention for ALHIV, which will have a positive effect on the health outcomes of adolescents living with HIV. The intervention will then be piloted in another study to test if the intervention is working.

Are there any risks involved in your child taking part in this research?

- Taking part in this study may be of inconvenience. You and your child will make use of your personal time to travel to the specific venue, as well as the time spent during the sessions. You will be reimbursed for your traveling costs to and from the venues and refreshments will be provided. There are no direct/immediate risks involved by taking part in this study.

If you do not agree to let your child, take part, what alternatives do you have?

- As the participant, your child is under no obligation to take part in the study. Your child may also decide to leave the study if they do not feel they want to take part any longer. There will be no consequences for leaving the study at all.

Who will have access to your child's information?

- Your child's personal data and information shared during the sessions will be audio recorded and then saved into password-protected folders on the researcher's personal computer.
- Prior to the commencement of the focus group, the researcher will ask all the participants to agree verbally not to share any personal information or data discussed during the focus groups.

How will your child receive feedback from the study?

- Your child will receive feedback on the information they provided to the researchers in the form of their own feedback on the intervention. A summary of the data collected as well as the final developed intervention will be communicated back your child.

Will you/your child be paid to take part in this study and are there any costs involved?

- Focus group participants will be provided with refreshments during the sessions. Travel costs will be reimbursed if needed.

Is there anything else that you should know or do?

- You can phone Mrs Frances de Lange-Cloete at 076 237 9980 if you have any further queries or encounter any problems.
- You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that your study researcher has not explained to you, or if you have a complaint.
- You will receive a copy of this information and consent form for you to keep safe.

Declaration by legal guardian/parent

By signing below, I agree to let my child take part in a research study entitled 'The development of a self-management intervention for adolescents living with HIV in a South African context: views of experts and key stakeholders'.

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary**, and that my child have not been pressurised to take part.
- My child may choose to leave the study at any time and nothing bad will come of it – my child and I will not be penalised or prejudiced in any way.
- My child may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my child's best interests, or if my child do not follow the study plan that we have agreed on.

Signed at (*place*) on (*date*) 2020.

.....
Signature of legal guardian/parent

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document in a simple and clear manner to
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she completely understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2020.

.....
Signature of investigator

.....
Signature of witness

APPENDIX 6: EXPERT QUESTIONNAIRE

EXPERT QUESTIONNAIRE

Adolescent HIV self-management intervention

Review guidelines

Thank you for agreeing to participate as an expert to assess the content validity and provide feedback on a newly developed self-management intervention for adolescent HIV self-management in a South African context for older adolescents **aged 15 – 19 who are preparing for or are in the process of transitioning to adult care.**

You are one of ten academics and researchers from a range of disciplines who have been selected for this expert committee.

The current intervention has been developed using an Intervention Mapping (IM) approach. Intervention mapping (IM) uses a social ecological approach in which health is the function of individuals and their (social, physical, cultural) environments. It provides a framework for theory- and evidence-based health promotion program planning that involve community-based participatory research methods. The steps in the intervention mapping approach include: 1) Logic model of the problem; 2) Programme outcomes, objectives, and logic model of change; 3) Program design; 4) Program production; 5) Implementation plan; and 6) Evaluation (Fernandez et al., 2019).

We used data from a PhD study conducted in the Cape Metropole of the Western Cape on the development of an instrument to measure adolescent HIV self-management (Crowley *et al.*, 2019; Crowley, van der Merwe and Skinner, 2019) to inform the needs assessment and logic model of the problem (step 1, see Figure 1). The intervention will specifically focus on self-management processes identified in the South-African context (i.e., increasing adolescents' knowledge and beliefs, goals and facilitation, biomedical management and coping and self-regulation skills (Crowley, 2018)) as these are more amenable to change than contextual factors (Sawin, 2017). For the purpose of this study, we define self-management as *“the processes and behaviours adolescents engage in to take care of their chronic illness with the assistance of their caregivers, health workers, family, friends, peers and educators.”*

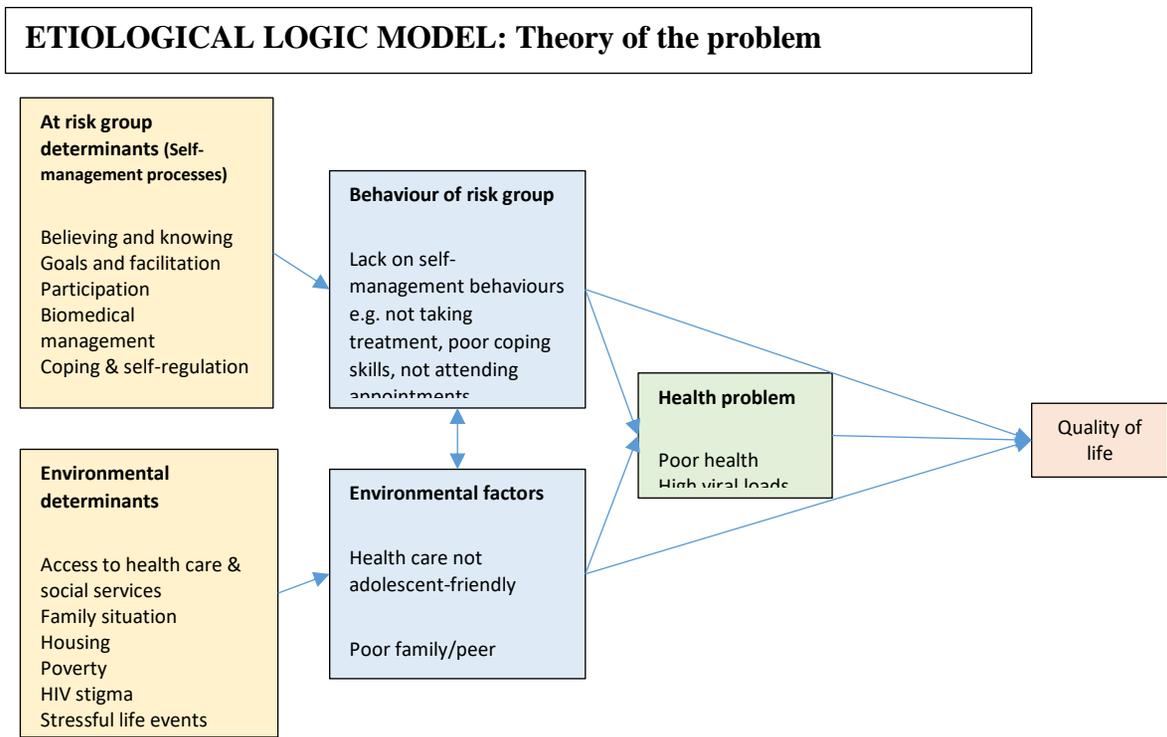


Figure 1: Logic model of the problem

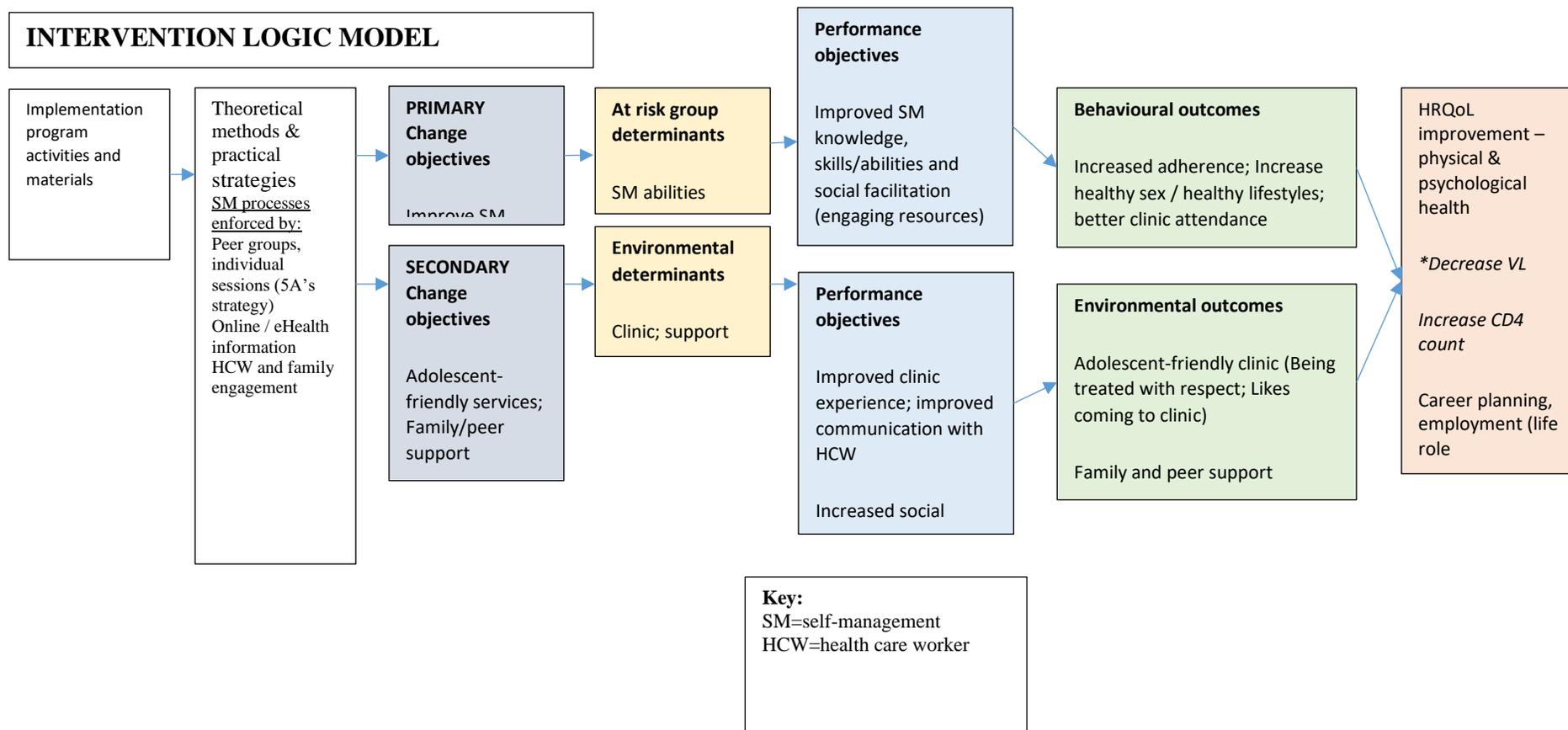


Figure 2: Intervention logic model

We would like your feedback on step 2 and 3 of the IM process, namely, the programme outcomes, objectives and logic model of change and the program design. Your feedback will be used to modify the abovementioned.

Following your feedback, we will also obtain feedback from two groups of key stakeholders (including health care workers, adolescents living with HIV aged 15-24, NGO representatives etc.), one in the Cape Metropole of the Western Cape and one in the Nelson Mandela Bay district of the Eastern Cape.

Your input and comments are highly valued. Once you have answered the questions, please send it back to me (fdelange@sun.ac.za). We will organise a follow-up meeting to discuss the feedback from all the experts should you be available.

Biographical information of expert

Kindly provide us with your personal details.

Sex: Choose an item.

Age: [Click here to enter text.](#)

Please list your qualifications: [Click here to enter text.](#)

Indicate your primary area of expertise e.g., Paediatrics, Nursing, HIV, Adolescent Psychiatry, Self-Management or other: [Click here to enter text.](#)

Indicate how many years you have been working in your primary area of expertise: [Click here to enter text.](#)

Adolescent HIV self-management intervention: Objectives and outcomes

Outcomes of the intervention

We have identified the following intervention outcomes:

- **Primary outcome: Improved self-management processes and behaviours**
- **Secondary outcome: The provision of adolescent-friendly/tailored services / improved experiences of adolescents of attending services.**
- **Secondary outcome: Increased family and peer support / perception of adolescent of family/peer support.**

The self-management was operationalised through an instrument development study and is depicted in Table 1. These self-management processes are considered to be the determinants of behaviour and the intervention is focused on addressing all 5 components of self-management.

Table 1 Self-management processes (Crowley, 2018)

| Component | Key attributes |
|-----------------------------------|---|
| Believing and knowing | Views or ideas about one's illness, the future and confidence to self-manage. Awareness and comprehension of how to navigate the healthcare system and the importance of treatment (ART). |
| Goals and facilitation | Internal- and external motivation for self-management by setting individual goals and obtain support from family, healthcare workers, peers and friends to take care of one's health. |
| Participation | Actively involved in own healthcare and socially. |
| HIV biomedical management | Knowledge of and motivation to understand whether one is doing well on treatment or not. This includes knowledge of one's viral load and names of ARV's. |
| Coping and self-regulation | Manage HIV stigma, make decisions about disclosure and integrate taking treatment into one's daily routine. |

The self-management behaviours of adolescents have been operationalised as:

- Increased adherence increased healthy sex / healthy lifestyles and better clinic attendance.
- The distal or health outcomes include health-related quality of life and viral suppression (see Figure 2).

With reference to the study outcomes, please select the applicable answer from the dropdown list:

- **Primary outcome: Improved self-management processes and behaviours**

Clarity: Relevancy:

COMMENTS – Please tell us if you think we should amend the outcome and why. You are welcome to make changes to the outcomes in track changes:

[Click here to enter text.](#)

- **Secondary outcome: The provision of adolescent-friendly/tailored services / improved experiences of adolescents of attending services.**

Clarity: Relevancy:

COMMENTS – Please tell us if you think we should amend the outcome and why. You are welcome to make changes to the outcomes in track changes:

- **Secondary outcome: Increased family and peer support / perception of adolescent of family/peer support.**

Clarity: Relevancy:

COMMENTS – Please tell us if you think we should amend the outcome and why. You are welcome to make changes to the outcomes in track changes:

[Click here to enter text.](#)

Objectives of the intervention

We would like to improve the adolescents' self-management by focusing on all the components of self-management. Below are a table of all the components and the objectives identified for each of the components.

| Component | Objectives |
|----------------------------------|---|
| 1. Believing and knowing | <p>To increase adolescents' knowledge about their illness.</p> <p>To gain a clear understanding of how to navigate the health care system and the importance of ART.</p> <p>To increase positive beliefs, faith, attitudes, and feelings of control (self-efficacy and confidence) to self-manage and the future.</p> |
| 2. Goals and facilitation | <p>To increase internal- and external motivation for self-management by setting individual health and life goals.</p> |

| Component | Objectives |
|--------------------------------------|---|
| | <p>To increase confidence in meeting goals.</p> <p>To improve communication skills with family, healthcare workers and peers.</p> <p>To improve skills to identify resources and supports.</p> <p>To increase the adolescents' perception of social support from family, healthcare workers, peers, and friends to take care of one's health.</p> |
| 3. Participation | <p>To improve confidence to be actively involved (including decision-making) in own healthcare and socially.</p> <p>To increase activities aimed at general self-care.</p> |
| 4. HIV biomedical management | <p>To improve knowledge of and motivation to understand whether one is doing well on treatment or not.</p> <p>To gain an understanding of biomedical outcomes such as viral load and names of ARV's.</p> <p>To identify risks/barriers for not taking treatment and develop action plans.</p> |
| 5. Coping and self-regulation | <p>Improve coping skills to manage HIV stigma.</p> <p>Improve decision-making skills about disclosure.</p> <p>Identifying possible risks/barriers to self-management and develop strategies to overcome barriers.</p> <p>Develop strategies to integrate taking treatment into one's daily routine.</p> |

With reference to the intervention objectives, please select the applicable answer from the dropdown list for each of the components:

1. Believing and knowing

Clarity of the objectives: Relevancy of the objectives:

How important do you think it is to include this component in the intervention?

COMMENTS – Please tell us if we should revise the objectives and which objectives we should revise. You may suggest revisions using track changes:

[Click here to enter text.](#)

2. Goals and facilitation

Clarity of the objectives: [Choose an item.](#) Relevancy of the objectives: [Choose an item.](#)

How important do you think it is to include this component in the intervention? [Choose an item.](#)

COMMENTS – Please tell us if we should revise the objectives and which objectives we should revise. You may suggest revisions using track changes:

[Click here to enter text.](#)

3. Participation

Clarity of the objectives: [Choose an item.](#) Relevancy of the objectives: [Choose an item.](#)

How important do you think it is to include this component in the intervention? [Choose an item.](#)

COMMENTS – Please tell us if we should revise the objectives and which objectives we should revise. You may suggest revisions using track changes:

[Click here to enter text.](#)

4. HIV biomedical management

Clarity of the objectives: [Choose an item.](#) Relevancy of the objectives: [Choose an item.](#)

How important do you think it is to include this component in the intervention? [Choose an item.](#)

COMMENTS – Please tell us if we should revise the objectives and which objectives we should revise. You may suggest revisions using track changes:

[Click here to enter text.](#)

5. Coping and self-regulation

Clarity of the objectives: [Choose an item.](#) Relevancy of the objectives: [Choose an item.](#)

How important do you think it is to include this component in the intervention? [Choose an item.](#)

COMMENTS – Please tell us if we should revise the objectives and which objectives we should revise. You may suggest revisions using track changes:

[Click here to enter text.](#)

Adolescent HIV self-management intervention: methods and practical strategies

We would like your feedback on the methods and practical strategies that we selected to achieve the outcomes of each of the self-management components.

The methods, practical strategies, programme structure and content are derived from known adolescent transition/self-management programmes (Parker *et al.*, 2013; Duffy, Bergmann and Sharer, 2014), adolescent toolkits (Fick *et al.*, 2015), adolescent curriculums (Strengthening High-Impact Interventions for AIDS-free Generation (AIDSFree) Project, 2017) and guidelines; Cincinnati Children’s Hospital, 2007), adult self-management programmes (Lorig, 2015), qualitative studies (Denison *et al.*, 2015; Adams, 2019; Mutumba *et al.*, 2019), a scoping review of components interventions to promote self-management in adults (Bernardin *et al.*, 2013) and a systematic review effective interventions to enhance self-management of ALHIV (*not yet published, still in process*).

You will find the references in the list of references at the end of this questionnaire. The methods and practical strategies are divided into the different components of self-management.

Component: Believing and knowing

| Method | Practical strategies |
|--|--|
| Knowing self | Awareness exercises, group discussions and journaling (on electronic smartphone application ¹ or in workbook) – adolescent learn to identify current beliefs about living with HIV, problems encountered in daily living and the future |
| Beliefs about myself and the future | |
| Modelling | Peer group leader shares beliefs Information in <i>smartphone application/workbook</i> |
| Information about HIV, treatment adherence, attending appointments, safe sex, general healthy living | Knowledge self-assessment (<i>smartphone application/workbook</i>) Group sessions Individual coaching sessions |

¹ The smartphone application will be designed if found to be the most suitable method

Please select the applicable answer from the dropdown list:

Clarity: Choose an item.

Relevancy: Choose an item.

COMMENTS OR SUGGESTIONS: [Click here to enter text.](#)

Component: Goals and facilitation

| Method | Practical strategies |
|--|---|
| Goal setting and action plans | <p>Long- and short-term goals and action plans formulated in the beginning (<i>smartphone application / workbook</i>)</p> <p>Identification of conflicting priorities (goal incongruence), barriers and solutions</p> <p>Goals and action plans evaluated at each of the 2 individual coaching sessions or after group sessions</p> |
| Modelling | <p>Positive influence by other peers and peer group leader</p> <p>Identification / journaling of social support network (<i>smartphone application/ workbook</i>)</p> |
| Relationship building – social influence/support | <p>Integrate social networking in goals and action plans</p> <p>Role play in groups, peer group interaction</p> <p>Interaction with HCWs at one group session</p> <p>Interaction with caregiver at one individual coaching session</p> |

Please select the applicable answer from the dropdown list:

Clarity: Choose an item.

Relevancy: Choose an item.

COMMENTS OR SUGGESTIONS: [Click here to enter text.](#)

Component: Participation

| Method | Practical strategies |
|---|---|
| Skill training with guided practice – communication | Identifying own responsibility in health care (<i>smartphone application / workbook</i>) |
| Modelling | Role plays during group sessions with feedback Positive influence by other peers / peer group leader |

Please select the applicable answer from the dropdown list:

Clarity:

Relevancy:

COMMENTS OR SUGGESTIONS:

Component: Biomedical management

| Method | Practical strategies |
|---|--|
| Information about CD4 count, VL, ARV's, side-effects, clinical monitoring | Information in <i>smartphone application / workbook</i> Recording of personal information in <i>smartphone application / workbook</i> |
| Skills building | Personalised feedback provided during individual coaching session Group discussion: Identifying risks/barriers for not taking treatment and solutions |

Please select the applicable answer from the dropdown list:

Clarity:

Relevancy:

COMMENTS OR SUGGESTIONS:

Component: Coping and self-regulation

| Method | Practical strategies |
|---|--|
| Identification of risk behaviours (risk perception) | Self-assessment of risk; journaling (<i>Smartphone application/Workbook</i>) Group and individual discussions |
| Problem-solving | Identification of problems and action plans (<i>Smartphone application/workbook</i>) |
| Coping strategies | Identification of current coping strategies (<i>Smartphone application/workbook</i>), group discussions, formulating ways of coping better |
| Disclosure | |
| Skills training | |

| | |
|-----------|---|
| Modelling | Disclosure journal (<i>Smartphone application/Workbook</i>) Guided practice/ role plays with feedback Examples provided by group leader |
|-----------|---|

Please select the applicable answer from the dropdown list:

Clarity:

Relevancy:

COMMENTS:

Adolescent HIV self-management intervention: Programme duration, format, setting and leaders/facilitators

In this section we would like to know more about your views on how we would like to present the programme. There are sections for the programme duration and timing, format, etc.

Programme duration and timing

| | |
|--------------------------|--|
| Duration of intervention | 12 weeks |
| Timing | Fridays after school OR Saturday mornings OR negotiated time with groups or individuals |

Please select the applicable answer from the dropdown list:

Appropriate:

Feasible:

COMMENTS OR SUGGESTIONS:

Programme format

| | |
|-----------------------------|--|
| Format for contact sessions | Total of 9 sessions: 7 small group sessions (90 minutes each): introduction + 5 sessions + closing Two individual coaching sessions (60 minutes each) |
|-----------------------------|--|

| | |
|--|---|
| Format for information sharing and 'homework' activities | Smartphone application – electronic application (yet to be developed if deemed most feasible) OR Paper-based workbook at adolescent can take home with them |
|--|---|

Please select the applicable answer from the dropdown list:

Appropriate: Choose an item.
item.

Feasible: Choose an

COMMENTS: [Click here to enter text.](#)

Programme leaders / facilitators

| | |
|--|---|
| 2 Peer facilitators (older ALHIV aged 18-24 who can function as role models) | To conduct peer group sessions Peer leaders will be trained to facilitate discussions, role play and model behaviour |
| Counsellors / health care workers (doctor or nurse) | To supervise peer group sessions To conduct individual coaching sessions using the 5A's approach or motivational interviewing Health care workers will be trained to facilitate the individual sessions |

Please select the applicable answer from the dropdown list:

Appropriate: Choose an item.
item.

Feasible: Choose an

COMMENTS: [Click here to enter text.](#)

Setting

| | |
|--------------|--|
| Setting | <p>The setting for the peer groups can be in the community or at the clinic – the group should decide on a convenient place, but should consider confidentiality and safety</p> <p>The setting of the individual sessions should be in the consultation room of the counsellor or health care worker</p> |
| Refreshments | Snacks should be provided at group sessions |

Please select the applicable answer from the dropdown list:

Appropriate:

Feasible:

COMMENTS:

Adolescent HIV self-management intervention: programme content

In this section, we present an outline of the intervention programme. We would like you to provide feedback on the programme content and suggested materials.

| Timing | Lesson topic / Type | Content | Materials to be used/adapted |
|--------|--|---|--|
| | | | Transition toolkit²; *SYMPA programme; Swaziland curriculum; Cincinnati guidelines |
| Week 1 | <p>Introduction to course and materials</p> <p>Workbook / Smartphone application: Believing and knowing</p> | <p>Course overview</p> <p>Pre-course self-assessments</p> | <p>Transition checklist</p> <p>Workbook / <i>Smartphone application</i></p> <p>Self-management pre-assessment documents</p> <p>Life context form</p> |

² The colours in the materials column refer to the various references. The references are found in the reference list at the end of the questionnaire.

| | | | |
|--------|--|--|--|
| Week 2 | Workbook / Smartphone application: Believing and knowing | Who am I (identify & self-esteem) and what do I believe about myself (acceptance, positive self-esteem, dreams for the future, career, other goals) My chronic illness - what do I know and what do I need to know more about (what is HIV, taking treatment, attending appointments, managing stress, nutrition) | Naïve sketch of who I am, my dreams, goals, beliefs, faith etc. Knowing self & others - JOHARI window Mental health symptom screener HIV knowledge self-assessment HIV and chronic illness worksheet HIV information Positive living tips Self-care guide Food for health nutrition tips |
| | Group session 1: Believing and knowing | How can I live a healthy life with HIV and how can others live healthy lives with me (sexuality, partners) | Group discussion Facilitator shares own experiences |
| Week 3 | Workbook / Smartphone application: Goals and facilitation | Who are the people I trust? Who are the people supporting me? Who are my role models and why? | Psychosocial development journal |
| Week 4 | Workbook / Smartphone application: Goals and facilitation | What makes me happy/relaxed/enjoy life? What are my long and short term goals and how can I attain them? | My positive living journal Guide to health and social resources |
| | Group session 2: Goals and facilitation | How can I increase my support system? How do I build strong trusting relationships? What are possible barriers for attaining goals and how can I overcome them? What resources are there in my community that can help me attain my goals? | Group discussion of experiences Facilitator shares own experiences |
| Week 5 | Individual coaching session: 5A's / motivational interview and action planning Workbook / Smartphone application: Participation | Identify goals, barriers, strategies to overcome barriers. What does it mean to participate in my own care? | Comprehensive transitioning checklist Guide on coaching/5A's Tips for adolescent motivational interviewing Readiness for change ruler |

| | | | |
|---------|---|---|--|
| | | | My personal action plan |
| Week 6 | Workbook / <i>Smartphone application</i> : Participation | How can I take responsibility for my own care? | Assertive communication using 'I' messages, active listening worksheet |
| | Group session 3: Participation <i>(HCW's working with adolescents to attend this session)</i> | What makes it difficult to communicate with health care workers? What does my ideal clinic look like? How am I treated and how do I want to be treated? | Discussion and role play of HCW and adolescent interactions Group activity: draw ideal clinic situation |
| Week 7 | Workbook / <i>Smartphone application</i> : Biomedical management | How do I know if I am doing well on treatment? Names of ARV's, when I should take them, side effects? How can I remember to take my ARV's by myself? | Document in workbook/ <i>Smartphone application</i> : current ARVs, frequency of taking them, VL, CD4 count Medication adherence diary Medication worksheet |
| Week 8 | Workbook / <i>Smartphone application</i> : Biomedical management | What if taking my ARV's interfere with my life? How can I plan to take my treatment when my routine changes | My clinical considerations journal |
| | Group session 4: Biomedical management | What if I feel like not taking my ARV's anymore? | Discussion and role play Group leader shares experience |
| Week 9 | Workbook / <i>Smartphone application</i> : Coping and self-regulation | What are my health risks and how do I overcome them? How do I cope with my illness and life? | Alcohol and substance abuse journal Sexual and reproductive health journal Personal stressors worksheet and strategies for handling stressors Identification of current coping strategies |
| Week 10 | Workbook / <i>Smartphone application</i> : Coping and self-regulation | How do I cope with stigma? Who have I disclosed to, who would I like to disclose to and how? | Stigma action plan Decision-making activity worksheet Emotional health journal Disclosure journal |

| | | | |
|---------|--|---|---|
| | | | Emotional health – normal feelings and danger signs |
| | Group session 5: Coping and self-regulation | How do I disclose my status? How do I handle being HIV positive in a relationship? | Discussion and role play Sharing of problem-solving strategies Disclosure discussion guide Sex and relationships discussion guide Group leader shares experience |
| Week 11 | Individual coaching session: future <i>(Caregiver or close friend/confidant to attend this session)</i> | Review previous action plan and determine way forward Discuss how caregiver/close friend/confidant can assist adolescent | Comprehensive transitioning checklist Guide on coaching/5A's Tips for adolescent motivational interviewing Readiness for change ruler My personal action plan Family / caregiver checklist |
| Week 12 | Closing session | Post-self-assessments | Same as for pre-assessment |

With reference to the content and materials, please select the applicable answer from the dropdown list:

Appropriate: Choose an item.
item.

Feasible: Choose an

COMMENTS OR SUGGESTIONS: [Click here to enter text.](#)

End of questionnaire

THANK YOU

References

Adams, A. L. (2019) *Exploring the self-management needs of adolescents living with HIV in the Nelson Mandela Bay area of the Eastern Cape*. Stellenbosch University. Available at: <https://scholar.sun.ac.za/handle/10019.1/106000>.

Bernardin, K. N. *et al.* (2013) 'Self-management interventions for people living with human immunodeficiency virus: A scoping review', *Canadian Journal of Occupational Therapy*, 80(5), pp. 314–327. doi: 10.1177/0008417413512792.

Cincinnati Children's Hospital (2007) *Evidence-Based Care Guideline: Chronic Care: Self-management*. Cincinnati Children's Hospital Medical Center. Available at: www.cincinnatichildrens.org/svc/alpha/h/health-policy/ev-based/chronic-care.htm.

Crowley, T. (2018) *The development of an instrument to measure adolescent HIV self-management in the context of the Western Cape, South Africa*. Stellenbosch University. Available at: <http://scholar.sun.ac.za/handle/10019.1/103521>.

Crowley, T. *et al.* (2019) 'Measuring Adolescent HIV Self-management : An Instrument Development Study', *AIDS and Behavior*, pp. 1–15. doi: <https://doi.org/10.1007/s10461-019-02490-z>.

Crowley, T., van der Merwe, A. and Skinner, D. (2019) 'Adolescent HIV Self-management: Lived experiences of adolescents, caregivers and health care workers in a South African context', *Journal of the Association of Nurses in AIDS Care*, 30(4), pp. e7–e19. doi: 10.1097/jnc.000000000000098.

Denison, J. A. *et al.* (2015) "'The sky is the limit'": adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers', *Journal of the International AIDS Society*, 18, pp. 1–6.

Duffy, M., Bergmann, H. and Sharer, M. (2014) *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*. Arlington, VA: USAID's AIDS support and Technical Assistance REsources, AIDSTAR-One, Task Order 1.

Fick, C. *et al.* (2015) *Working with adolescents living with HIV: A handbook for healthcare providers*. Johannesburg: Wits RHI and Southern African HIV Clinicians Society. Available at: http://www.wrhi.ac.za/uploads/files/ALHIV_12August2015-1.pdf.

Lorig, K. (2015) 'Chronic Disease Self-Management Program : Insights from the Eye of the Chronic Disease Self-Management Program : insights from the eye of the storm', *Frontiers in Public Health*, 2(June), pp. 1–3. doi: 10.3389/fpubh.2014.00253.

Mutumba, M. *et al.* (2019) 'Perceptions of Strategies and Intervention Approaches for HIV Self-Management among Ugandan Adolescents : A Qualitative Study', *Journal of the International AIDS Society*, 18, pp. 1–8. doi: 10.1177/2325958218823246.

Parker, L. *et al.* (2013) 'Feasibility analysis of and evidence-based positive prevention intervention for youth living with HIV/AIDS in Kinshasa, Democratic Republic of the Congo.', *AIDS Educ Prev*, 25(2), pp. 135–150. doi: 10.1521/aeap.2013.25.2.135.

Strengthening High-Impact Interventions for AIDS-free Generation (AIDSFree) Project

(2017) *Swaziland Integrated Teen Club Curriculum*. Arlington, VA: AIDSFree Project.

APPENDIX 7: INTERVIEW GUIDE**Stakeholder Interview guide
Section A**

Demographic information of participant (to be completed by the researcher prior to the start of the focus group):

| Participant number | Age | Qualification | Experience | Category (NGO, Youth Clinic, ALHIV, HCW) | Comments/field notes |
|---------------------------|------------|----------------------|-------------------|---|-----------------------------|
| 1 | | | | | |
| 2 | | | | | |
| 3 | | | | | |
| 4 | | | | | |
| 5 | | | | | |

Section B

Introduction of facilitators and participants.

(Frances) INTRODUCTION: Tell us a bit more about yourself and your involvement in the care of ALHIV. (Each participant to be given a chance to respond)

(Talitha) Presentation of intervention: The researcher will provide copies of the intervention details to the participants and explain all the components and expectations for the focus group discussion. The various intervention components will then be reviewed by the group.

Question 1: Please reflect and tell us what you think about the Outcomes of the self-management intervention.

Probes:

- Are the overall outcomes (e.g., improved self-management, satisfaction with services, feeling supported, better adherence etc.) relevant to your context?
- How can we revise the outcomes to make it more relevant?
- Are the outcomes achievable?

Question 2: Please reflect and tell us what you think about the Objectives of the self-management intervention.

Probes:

- Tell me what you think about the programme components – e.g., believing and knowing, goals and facilitation, participation, biomedical management, coping and self-regulation? Are they relevant to your context?
- Tell us what you think about the objectives for each of these components, for example, for the first component, one of the objectives is to increase positive beliefs. Are they relevant and achievable?
- Do you have any suggestions of how the researchers can revise the objectives so that it is clearer?

Question 3: Please reflect and tell us what you think of the methods of the self-management intervention.

Probes:

- Do you feel that a workbook with activities for knowing self, reflection, knowledge of illness and healthy living, identifying risks, monitoring of taking treatment etc. is relevant to your context? Or would a smart phone app work better?
- Why will a workbook/app work better in your context?
- What is your opinion on the individual coaching sessions using the 5A approach for identifying barriers and enablers, increasing motivation for change, setting goals and developing action plans?
- Will this work in your setting?
- What do you think about the peer group sessions for assisting with role modelling, peer support, role plays, discussions?
- Is this viable in your setting?
- How can the researchers improve any of these methods to make this more relevant to your context?
- Do you think the methods are clear enough?

Question 3: Please provide us with your view on the programme duration and timing.

Probes:

- Do you feel that the duration and timing of the programme of 12 weeks is appropriate and/or feasible? (Probes: shorter e.g., over weekend/holiday, time of year, camps or longer over few months, linked with other health care appointments, transport costs, acceptability of frequent (weekly) meetings)
- Do you have any suggestions to make the duration and timing more appropriate to your context and needs?

Question 4: What is your opinion on the format of the programme – the delivery there of?

Probes:

- Do you feel that the format of the programme is appropriate and/or feasible? (Probes: workbooks vs Smartphone, the contact sessions)
- Tell us your thoughts on the contact sessions – 9 in total (5 peer group sessions of 90 minutes each) and the 3 coaching sessions of 60 minutes each. Would this be acceptable in your context. You can also refer to the programme set out in the Facilitator Guide and Adolescent Workbook.
- Do you have any suggestions to make the format more appropriate to your context and needs?

Question 5: Regarding the facilitators in the programme:

- What is your take on the leaders and facilitators of the programme? (Probes: peers vs health care workers, availability, selection (how to), training, who will take responsibility, agreement/similar approach, team care approach)
- Do you have any suggestion/ns to make the leaders or facilitators more appropriate to your context and needs?
- Anything we should change here?

Question 6: Do you feel that the setting is appropriate?

(Probes: clinic vs community, confidentiality, space)

- Tell us more about what setting will be the most appropriate for the peer group sessions?
- Tell us more about what setting will be the most appropriate for the individual coaching sessions?
- Do you think refreshments or other incentives for participation should be provided? Why or why not?
- Do you have any suggestions to make the setting more appropriate to your context and needs?

Question 4: Please reflect and tell us more about programme content and suggested materials of the self-management intervention. Please have a look through the participant workbook and facilitator guide.

Probes:

- Do you feel the content is appropriate and/or feasible? (Probes: readability level of workbook, cultural appropriateness, activities, preference workbook or Smartphone application, incentives for participation)
- Do you have any suggestions to make the content more appropriate to your context and needs?
- Do you feel that the suggested materials are appropriate and/or feasible in your setting or context?
- Do you have any suggestions to make the materials more appropriate to your context and needs?

Please let us know whether you have any questions?

We thank you for taking part and making this a very enjoyable mor

APPENDIX 8: SUMMARY OF CHANGES BASED ON EXPERT FEEDBACK**Adolescent HIV self-management intervention**

The current intervention has been developed using an Intervention Mapping (IM) approach. Intervention mapping (IM) uses a social ecological approach in which health is the function of individuals and their (social, physical, cultural) environments. It provides a framework for theory- and evidence-based health promotion program planning that involve community-based participatory research methods. The steps in the intervention mapping approach include: 1) Logic model of the problem; 2) Programme outcomes, objectives, and logic model of change; 3) Program design; 4) Program production; 5) Implementation plan; and 6) Evaluation (Fernandez et al., 2019).

We used data from a PhD study conducted in the Cape Metropole of the Western Cape on the development of an instrument to measure adolescent HIV self-management (Crowley *et al.*, 2019; Crowley, van der Merwe and Skinner, 2019) to inform the needs assessment and logic model of the problem (step 1, see Figure 1). The intervention will specifically focus on self-management processes identified in the South-African context (i.e., increasing adolescents' knowledge and beliefs, goals and facilitation, biomedical management and coping and self-regulation skills (Crowley, 2018)) as these are more amenable to change than contextual factors (Sawin, 2017). For this study, we define self-management as *“the processes and behaviours adolescents engage in to take care of their chronic illness with the assistance of their caregivers, health workers, family, friends, peers and educators.”*

SMART intervention

Table with summary of comments and changes based on first round Expert Feedback.

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|---|---|--|---|---|
| 1 | Primary outcome: Improved self-management processes and behaviours | Operationalise outcomes, including self-management Clarify meaning of 'processes' Consider biological primary outcomes (CD4, VL, HRQOL, acceptability) Ultimately the intervention should make life better for young people | Primary outcomes divided into programme performance objectives, behaviour and health outcomes SM will be a programme performance objective and operationalised as measured by the AdolHIVSM-35 that measures the five SM components Behaviour (adherence & risk behaviours) and health outcomes (VL, CD4) added as primary objectives | <ul style="list-style-type: none"> • Primary outcomes: <ul style="list-style-type: none"> ○ Performance objectives: Improved adolescent HIV self-management as measured by the AdHIVSM-35. ○ Behavioural outcomes: Improved treatment adherence, less risky behaviours (sex and alcohol/drug use), ○ Health outcomes: Decrease in VL; increased CD4 |
| 2 | Secondary outcome: The provision of adolescent-friendly/tailored services/improved experiences of adolescents of attending services | Operationalise adolescent-friendly To specify primary care or hospital-based Not clear if the focus is on providing new services or improving services Not clear why this outcome is included if the target of the intervention is not environmental/contextual determinants Better to consider improved quality as ranked by the adolescent | Secondary outcomes divided into programme performance objectives, behaviour and health outcomes Outcome changed to 'adolescent satisfaction with services' as the focus of the intervention is not specifically on improvement of adolescent-friendly services. Increased family and peer support specified as being perceived support. HCW and community support added. The AdHIVSM-35 measures perceived family, peer, community and HCW support. | <ul style="list-style-type: none"> • Secondary outcomes: <ul style="list-style-type: none"> ○ Performance objectives: Improved satisfaction with services; Improved perceived support from HCW, family/peers and the community ○ Behaviour outcomes: Improved clinic attendance / retention ○ Health outcomes: Improved HRQOL (incl. mental health) |
| 3 | Secondary outcome: Increased family and peer support/perception of adolescent of family/peer support | All three aspects could be separate. Important to consider what the adolescent sees as support (may vary by culture) and what is the right amount of support. Consider including HCW support Consider broadening the concept of support (e.g. include family, peer and community support. Focus on perceived support / perception of support If support is not the target of the intervention, this should not be included as an outcome. | Behaviour (improved clinical attendance/retention) and health outcomes (HRQOL, mental health) added as secondary outcomes. | |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|---|--------------------------------|--|--|---|
| | <i>Objectives</i> | Summary of comments | Summary of revisions | Changed to: |
| 4 | Believing and knowing | <p>Need to include improving knowledge in all aspects of health (women/men health, substance use, TB, STI risks) Change 'understanding of how to navigate...' to 'knowledge about and/or skills to navigate' Separate knowledge about the importance of ART to be a separate objective. Separate beliefs, faith, attitudes and feelings of control (self-efficacy and confidence) to separate objectives because these attributes are distinct. Take faith out of the last statement as is ambiguous what it means. To increase positive beliefs, attitudes and confidence to self-manage is clearer and within the scope of the intervention Knowledge may be an irrelevant outcome whereas navigating the health care system and confidence and self-efficacy is very important Consider adding to the second part, knowing when to seek care. 'Believing and knowing' difficult to understand, suggested using theoretical models e.g. TOPB This component may not be important at all – if other elements are addressed, young people will seek information out. All learning theory/educationalists will tell us not to be concerned with content but rather with their participation, engagement, and rewarding these.</p> | <p>More general aspects of health and prevention will be included in the first objective. The theory used for this study is the Individual and Family Self-Management Theory (IFSMT), the concepts of 'knowledge and beliefs' are from that theory For now, this component was retained pending feedback from the other stakeholders Knowledge as the basis for many other determinants, such as risk perception, attitudes, and skills (Kok et al., 2016)</p> | <p><u>Objectives separated out and changed to:</u></p> <ul style="list-style-type: none"> • To increase adolescents' knowledge about their health. • To increase adolescents' knowledge about their illness and the importance of ART. • To increase knowledge about how to navigate the health care system. • To increase knowledge about when to seek care. • To increase positive beliefs. • To increase positive attitudes. • To increase feelings of control (self-efficacy and confidence) to self-manage. |
| 5 | Goals and facilitation/support | <p>Separate support from healthcare workers from family, friends, and peers. In the last statement would awareness be a better word the perception? I have encountered significant challenges with the idea of goal setting with my teenagers. Improving communication is really really important. Particularly knowing how to</p> | <p>The last objective was not separated out, although support from the various groups will be measured separately. Sexual decision-making not added as it is part of 'self-regulation'</p> | <p><u>Objectives changed to:</u></p> <ul style="list-style-type: none"> • To increase internal- and external motivation for self-management by setting individual health and life goals. • To increase confidence in meeting goals. |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|---|--------------------|--|--|--|
| | | <p>negotiate for something at the clinic (eg: when ART has run out and a refill is needed but it is not their appointment date yet) – to be able to say “I would like this” clearly and with confidence, but without arguing / being able to deal with a healthcare worker who is “argumentative/dismissive”.</p> <p>I wonder if there should be an addition of optimizing sexual decision making and ASRH</p> <p>Not clear what facilitation is or how this relates to some of the components e.g. communication and skills?</p> <p>Consider realities e.g. risk of failing to meet goals and the role of being socially disempowered to reach goals.</p> <p>Suggest at minimum also including an objective to manage ‘failure’/disappointment, and one on communicating goals in ways that garner appropriate support or facilitate revision when we realise that support is lacking.</p> <p>Consider merging 2 and 3, some type of self-leadership/efficacy, or empowerment heading? I am not sure, but goals facilitation and participation is not clear, perhaps all under head of “participation and self-ownership.</p> | <p>We will still consider revising the components, however, it is difficult as these are based on previous qualitative and quantitative research</p> | <ul style="list-style-type: none"> • To communicate goals to others to garner appropriate support and revise when support is lacking. • To improve communication skills with family, healthcare workers and peers. • To improve skills to identify resources and supports. • To increase the adolescents’ awareness of social support from family, healthcare workers, peers and friends to take care of one’s health. |
| 6 | Participation | <p>For many adolescents there is a language barrier (and not just whether Eng/Afr/Xhosa but generational issues; body language etc). Change to ‘To increase activities (by the adolescent, or the health system/community/family/FBOs & NGOs) aimed at general self-care’</p> <p>I think it is confidence to be involved as much as the adolescent desires. You might revise wording to ‘health care decision’ and ‘social activities’ and consider making these separate objectives.</p> <p>“Is the objective increased participation in one’s own health care (measure behaviours/activities)</p> | <p>Comments regarding language barriers / general issues as well as power differences and social inequality that may affect participation noted and to be considered in this intervention.</p> <p>Participation here specifically refers to the participation of the adolescent and not the health system/NGO’s etc.</p> | <p><u>Objectives changed to:</u></p> <ul style="list-style-type: none"> • To improve confidence to be actively involved in health care decision-making <i>as much as the adolescent desires</i>, and consequently their participation in decision-making. • To improve confidence to be actively involved socially <i>as much as the adolescent desires</i>, and consequently their social participation. |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|---|---------------------------|--|---|--|
| | | <p>or increased confidence to participate in one's own healthcare (measure confidence)? Or both?" My ideal patient is one who is self-motivated and thus participating in healthcare decisions and taking some responsibility for the outcome of those decisions. However I have a number of patients who really just want someone to tell them what to do, and are not interested in being part of the decision making process – and are achieving good adherence on ART. I think the relevance of this may depend on the personality and capacity of the teen. It may also vary between situations – e.g.: can't decide about ART, but is able to participate in decisions around sex" Participation in what – could you add an additional couple of words? Need to consider capacity to participate and the social processes driving health/social inequity.</p> | | <ul style="list-style-type: none"> • To increase activities aimed at general self-care and proactively taking steps to enhance one's own general health status for improved long term health outcomes. |
| 7 | HIV biomedical management | <p>This is an opportunity to not just address HIV, but the 'total' health of adolescents. Where is mention of prevention and health promotion activities - prevention of TB, unwanted pregnancies etc?" "Consider changing 'understanding' to knowledge. Should this also be about self-monitoring one's viral load? Should it be more than just knowing the names of ARVs and include knowing how to take, side effects, etc? Perhaps you should be more specific about what the action plans are about – such as action plans to manage problems, barriers, etc. Sometimes being able to remember the details are not linked with good adherence. I would suggest adding a point about proactively taking steps to enhance one's own general health status for improved long term health outcomes (e.g., nutrition, sleeping, etc.)</p> | <p>The previous quantitative and qualitative work identified biomedical management knowledge as separate from the general health and HIV knowledge. Comment regarding knowledge vs management considered and a management objective added. General health knowledge incorporated under component 1 and steps to enhance health added under participation.</p> | <p><u>Objectives changed to:</u></p> <ul style="list-style-type: none"> • To improve knowledge of and motivation to understand whether one is doing well on treatment or not. • To gain knowledge and understanding of biomedical outcomes such as viral load and knowledge of the names of ARVs. • To be able to self-monitor taking of treatment, side-effects, and viral load. • To collaborate with health care workers as a support team to manage HIV. |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|---|---------------------------------------|--|--|---|
| | | <p>This seems more like a knowledge component to me than management? It should be seen as a tool to empower them to make decisions rather than an imposition of a 'recipe' for how they 'should' manage their HIV." General comment: "To form a collaboration with their health workers as a support team for the young persons' management of HIV."</p> | | <ul style="list-style-type: none"> • To identify risks/barriers for not taking treatment and develop action plans to manage barriers to adherence. |
| 8 | Coping and self-regulation | <p>Very HIV-specific - adolescents may have other health needs/concerns - where and how will these be determined, addressed so that the adolescent can self-manage. I would also include something about emotional self-regulation. General comment: "To understand where and how to seek out help."</p> | <p>Difficult to include all possible needs of adolescents. We may use the individual coaching sessions to focus more on the individual needs/concerns.</p> | <p><u>Objectives changed to:</u></p> <ul style="list-style-type: none"> • Improve coping skills to manage HIV stigma. • Improve ability to manage emotions. • Improve decision-making skills about disclosure. • Identifying possible risks/barriers to self-management of HIV and health and develop strategies to overcome barriers. • Develop strategies to integrate taking treatment into one's daily routine. • To understand where and how to seek out help. |
| | <i>Adolescent HIV self-management</i> | Comments | <p>Revisions made:</p> <p>(See next table for objectives linked to strategies) Compared again with Taxonomy of behaviour change methods for IM</p> | Parameters for effectiveness identified: |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|---|--|---|---|--|
| | <i>intervention: methods and practical strategies</i> | | | |
| 9 | <p>Component: Believing and knowing</p> <p>Target determinants as per the AdolHIVSM-35</p> <ul style="list-style-type: none"> • <i>My faith helps me to stay positive about myself and my future.</i> • <i>I am confident I can take care of my health.</i> • <i>I can achieve as much as other people who don't have HIV.</i> • <i>I know the date of my next hospital or clinic appointment.</i> • <i>I know at what times I should take my ARVs.</i> • <i>I can get information about HIV.</i> • <i>I understand what will happen if I don't take my ARVs every day.</i> • <i>I understand why I am taking ARVs.</i> | <p>Continuity of care is sacred - the peer supporter/leader/HCW assisting in groups or clinical support, needs to stay the same so that trust can be built up. The benefit of this therapeutic relationship we see again and again.</p> <p>State that knowing self, awareness, beliefs, and modelling are all limited to HIV.</p> <p>To consider the language barrier and learning difficulties. A significant number of teens struggle to engage with writing/reading tasks.</p> <p>Further explanation, more details are needed to understand how effective these strategies will be.</p> <p>Overall, these methods are used with adolescent populations broadly and effectiveness varies. Practical strategies: Should be linked to the different strategies (applications) recommended by the IM approach? I'm not sure what an 'awareness exercise' is so it might be best to use more descriptive terms e.g. is it self-reflection or group work etc. Re group discussions: So I wasn't clear until now that it would be a group intervention! If peers are involved then you are in fact targeting an environmental (interpersonal) determinant. I think you would clarify this in your logic model. Re Peer group leader shares beliefs: "Will you train these peer group leaders? Re Individual coaching session: Who will provide the coaching? If a trained facilitator then you should note this.</p> | <p>Belief selection: (Using messages designed to strengthen positive beliefs, weaken negative beliefs, and introduce new beliefs) – Knowing self / beliefs about myself and the future - Self-reflection and journaling (on electronic smartphone application or in workbook) – adolescent learn to identify current beliefs about living with HIV, problems encountered in daily living and the future.</p> <p>Modelling: Peer group leader shares beliefs to reinforce positivity, optimism, future orientation, that they can achieve as much as a person without HIV, importance of health care visits and taking treatment.</p> <p>Technical knowledge: Information about HIV disease and symptoms, meds and side-effects, times of taking meds, reinfection risk, importance of taking treatment, attending appointments, safe sex, general healthy living, where to get more info. <i>Information in smartphone application/workbook. Knowledge self-assessment</i> (smartphone application/workbook)</p> <p>Discussion: Group sessions led by peer leader to discuss information and assess</p> | <p>Parameter: Requires investigation of the current attitudinal, normative and efficacy beliefs of the individual before choosing the beliefs on which to intervene.</p> <p>Parameters: Attention, remembrance, self-efficacy and skills, reinforcement of model; identification with model, coping model instead of mastery model. <u>Specific requirement in setting:</u> Peer support leader to be trained and to stay the same so trust can be built up, to speak same language as adolescents.</p> <p><u>Parameter for setting:</u> To establish the literacy/reading/writing ability of adolescents and the languages they would prefer to receive information in.</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|----|---|--|--|--|
| | | <p>These strategies can help to achieve the objective, but I don't believe they will lead to an outcome of better health or happiness. Also, what is the role of solidarity in these processes? Knowledge is about shared agreement between young people and adults significant in their lives.</p> | <p>general knowledge transferred through application/workbook and shared agreement of the content. To discuss where to go if they need more information.</p> <p>Individual coaching sessions /Motivational interviewing: HCW/lay health worker to reinforce self-efficacy and confidence that adolescent can take care of their health. Enquiring if they know why they take ART, the times, what to do if they miss a dose, attending appointments. To identify any other individual needs/challenges.</p> | <p>Parameter: Listening to the learner to ensure that the correct schemas are activated.</p> <p>Parameter: A supportive relationship between client and professional combined with the evocation of patient change talk. Professionals must recognize that MI involves collaboration not confrontation, evocation not education, autonomy rather than authority, and exploration instead of explanation.</p> <p><u>Specific requirements for setting:</u> Each adolescent to be assigned a HCW/counsellor trained in MI/Coaching to ensure building of a relationship, ensure ability to freely communicate in language of choice.</p> |
| 10 | <p>Component: Goals and facilitation</p> <p>Target determinants as per the AdolHIVSM-35</p> <ul style="list-style-type: none"> • <i>I feel confident that I can meet my health and life goals.</i> • <i>My family support me to live with HIV.</i> • <i>I aim to be successful (for example, finishing school,</i> | <p>Where is the link with existing community-based, faith-based organisations? How will family be involved; provided with skills to support the adolescent? What is the role of the teachers and school/dept of education?</p> <p>To be very clear, these strategies are all focused on HIV? Will you give examples of goals, action plans, etc?</p> <p>Some teenagers have gone through "long term goal setting" exercises (perhaps at school?) but there is a lot of disconnect with them. Will need to be handled with wisdom in order to be useful.</p> <p>Peer navigators and adolescent-friendly clinics with specially trained providers are an important avenue to consider.</p> | <p>Goal setting and action plans: Long and short term goals and action plans formulated in the beginning (smartphone application / workbook) Identification of conflicting priorities (goal incongruence), barriers and solutions</p> <p><i>Examples of goals –</i></p> <p>Health goals – e.g. to have optimal health, exercise etc. individually set and steps for getting there.</p> <p>Life goals – finishing school, education, enjoying life etc. and steps for getting there</p> <p>Prompting planning what the person will do, including a definition of goal-</p> | <p>Parameters: Commitment to the goal; goals that are difficult but available within the individual's skill level.</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|--|--|---|---|--|
| | <p><i>studying further or getting a job).</i></p> <ul style="list-style-type: none"> • <i>Doctors, nurses and counsellors at the clinic support me to live with HIV.</i> • <i>I aim to enjoy life, feel good and have fun.</i> • <i>Doing things I like (for example, listening to music, reading or playing sport) helps me to cope.</i> • <i>Other adolescents at the clinic (for example, in my support group or club) support me to live with HIV.</i> • <i>I aim to independent (taking care of myself).</i> | <p>RE Identification of conflicting priorities (goal incongruence), barriers and solutions: How will this be achieved? The kind of activity that will be used should be specified for all. Re Positive influence: "What will this look like? How will it be achieved? Re: Interaction with HCWs at one group session: You will involve HCWs but it's not clear what they will contribute or who they will be. Will they be the HCWs that the programme participants will interact with in real life? Re interaction with the caregiver: "Do you mean here a parent or primary carer? What will this interaction look like? What will it aim to achieve? Is it possible that their caregiver will not engage? Is it possible they do not know the YP has HIV?</p> <p>How much reinforcement of these will happen when they enter the 'real-world' contexts for practicing them? Suggest extending support for once the training is 'complete' and the young people start practicing these new skills, perhaps through long-term social support networks and mentorship.</p> <p>Consider merging with participation</p> | <p>directed behaviours that result in the target behaviour.</p> <p>Coaching / MI / Group sessions: Goals and action plans evaluated at each of the 2 individual coaching sessions or after group sessions. Exploring if goals are too easy/difficult, within skill level. Exploring any conflicting goals/priorities. Fostering confidence to meet goals.</p> <p>Modelling: Positive influence by other peers and peer group leader. Goal to foster peer relationships and friendships.</p> <p>Identification / journaling of social support network (smartphone application/ workbook)</p> <p>Mobilising social support/networks: Prompting communication about behaviour change in order to provide instrumental and emotional social support. Encouraging social networks to provide informational, emotional, appraisal, and instrumental support.</p> <p>Relationship building – social influence/support. Integrate social networking in goals and action plans Role play in groups, peer group interaction</p> <p>Interaction with HCWs at one group session. Goal to provide HCW with some insight into needs of adolescents.</p> | <p>Setting parameters: Peers / HCWs specifically trained.</p> <p>Parameters: Combines caring, trust, openness, and acceptance with support for behavioural change; positive support is available in the environment.</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|----|---|---|--|--|
| | | | <p>Interaction with caregiver (or confidant) at one individual coaching session. Goal to foster communication and support.</p> <p>Developing new social network linkages Availability of social network and potential support givers. Will often include information about others' approval, facilitation and persuasive communication.</p> <p>Use of HCW/peer education Mobilizing members of the target population to serve as boundary spanners, credible sources of information, and role models.</p> | <p>Parameters: Willingness of networks to reach out; availability of networks that can provide appropriate support and linkage agents</p> <p>Parameters: Natural helpers in community with opinion leader status and availability to volunteer for training.</p> |
| 11 | <p>Component: Participation Target determinants / change objectives as per the AdolHIVSM-35</p> <ul style="list-style-type: none"> <i>I take part in decisions about my health and treatment (for example, I tell the doctor or nurse what I think and we make decisions together).</i> <i>I tell the doctor or nurse when I miss a dose of my ARVs.</i> <i>I ask the doctor or nurse questions when there is anything that I don't understand.</i> <i>I would find help in my community if I needed it (for example, a social worker if I</i> | <p>Facilitators will need to be skilled in this type of training; consistent in their messaging; able to communicate effectively – not just a language issue, as mentioned above.</p> <p>Is this participation in health care? Above you also included participation in social activities. Is this participation or responsibility? You might consider variations in how much adolescents want to be involved in their health care – some want total control while others don't want much, which might be okay.</p> <p>Do you need to specifically include something here around activities aimed at general self-care as that is in your objectives. Also increasing participation socially.</p> <p>Participation is a really important component. I wonder if there are some additional activities that actual require inputs from the adolescent. Perhaps research other programs that have worked to motivate adolescents with non-monetary incentives.</p> | <p>Skill training with guided practice – communication - Identifying own responsibility and participation in health care and in social activities (smartphone application / workbook)</p> <p>Guided practice - Prompting individuals to rehearse and repeat the behaviour various times, discuss the experience, and provide feedback.</p> <p>Modelling - Role plays (with clear objectives and desired outcomes/skills which one would want the adolescent to learn) during group sessions with feedback. Positive influence by other peers / peer group leader. To role-play communicating with HCW – example of participation and one of not participating e.g. asking questions, making decisions together, telling/communicating sensitive</p> | <p>Parameters: Subskill demonstration, instruction, and enactment with Individual feedback; requires supervision by an experienced person; some environmental changes cannot be rehearsed. <u>Specific to context</u>: peer group leaders to be trained and skilled and consistent in messaging.</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|----|---|---|---|--|
| | <p><i>had problems at home or at school).</i></p> <ul style="list-style-type: none"> <i>I tell the doctor or nurse about private things (for example, If I am having sex or using drugs or alcohol).</i> <i>I tell the doctor or nurse how I am feeling (for example, when I feel sick, depressed or have side-effects because of my treatment).</i> <i>I do things to improve my health (for example, by exercising or eating healthy foods).</i> <i>I participate in activities at school or in my community.</i> <i>I have regular contact with friends (for example, at school or in my community).</i> <i>I attend clinic appointments on scheduled dates (for example, I use a calendar, phone or my clinic card to remind myself).</i> | <p>Re Role plays: Role plays about what? I'm not clear how this is linked to the previous objectives you listed in the table above. Particularly, how are the listed methods related to the 'To increase activities aimed at general self-care' element? It would be easier to navigate if you had the objectives, methods and strategies in one table and then it would be easier to see if all of the objectives are being targeted.</p> <p>This is key, the intervention has the potentiality to radically re-position young people's engagement in services as active health citizens. Therefore suggest investing more here.</p> <p>Consider merging with above.</p> | <p>information e.g. when missed ART/had sex without a condom/using drugs</p> <p>Discussions: To discuss scenarios of where to find help in the community and where to be involved.</p> <p>Providing contingent rewards: Praising, encouraging, or providing material rewards that are explicitly linked to the achievement of specified behaviours.</p> | <p>Parameters: Rewards need to be tailored to the individual, group or organization, to follow the behaviour in time, and to be seen as a consequence of the behaviour.</p> <p>Keeping record of appointments and providing 'rewards'/badges for attending appointments / participation in activities / practicing positive health behaviours.</p> |
| 12 | <p>Component: Biomedical management Target determinants / change objectives as per the AdoIHIVSM-35</p> | <p>I would not just focus on HIV-related information. Adolescents have asked to be seen as 'whole' people, and not just HIV+. Be specific about what HIV skills.</p> <p>Clarify - side effects of ARVs. Should this also include how to self-manage side effects of ARVs? What kind of skills are you building?</p> | <p>Technical knowledge – information about CD4 count, VL, ARVs, side-effects, clinical monitoring. Information in smartphone application / workbook</p> <p>Self-monitoring: Recording of personal information (CD4, VL, side-effects and how managed, names of ARVs, times of</p> | <p>Parameters: The monitoring must be of the specific behaviour (that is, not of a physiological state or health outcome).</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|----|---|---|--|---|
| | <ul style="list-style-type: none"> • <i>I know what my viral load should be.</i> • <i>I know what my viral load is.</i> • <i>I know the names of my ARVs.</i> • <i>I know what to do when I miss the time to take my ARVs.</i> | <p>I would recommend that the strategies in this are more clinically focused. Adherence monitoring via smart boxes, pill counts, OI monitoring, lab monitoring – having the adolescent report these to you and doing checks with their provider to ensure that adolescent is appropriately informed and managing appropriately.</p> <p>This looks good. Depends heavily on the content and functionality of the app.</p> <p>Consider adherence strategies/intervention here.</p> | <p>taking ARVs, adherence) in smartphone application / workbook</p> <p>Motivational interviewing/Coaching: Skills building - Personalised feedback about self-monitoring provided during individual coaching session</p> <p>Group discussion: Identifying risks/barriers for not taking treatment (adherence) and solutions</p> | <p>The data must be interpreted and used. The reward must be reinforcing to the individual.</p> |
| 13 | <p>Component: Coping and self-regulation Target determinants / change objectives as per the AdolHIVSM-35</p> <ul style="list-style-type: none"> • <i>I can cope with it if people say nasty or hurtful things about people living with HIV.</i> • <i>I decide by myself whom I want to tell about my HIV status.</i> • <i>I take my ARVs even when I don't want to (for example, when I feel depressed or am tired of taking them).</i> • <i>I plan how to take my ARVs when I am not at home (for example, when I am out with friends or on a school camp).</i> • <i>I would cope if I tell someone about my HIV status and that</i> | <p>As mentioned above, I am wondering who the Group Leader/facilitator will be; how they will be equipped to do this work; confidentiality issues addressed; continuity of care ensured.</p> <p>What kind of risk? What kind of problems? What kind of skills? Will you give some examples?</p> <p>Re Group and individual discussions: About what?</p> <p>Many of the young people who most need this intervention will face overwhelming obstacles to 'coping'. Is sufficient time spent engaging with that reality during the activities?</p> <p>For all above hard to tell without seeing more detail about the strategies.</p> | <p>Identification of risk behaviours / Risk perception. Self-assessment of risk; journaling (Smartphone application/Workbook) Risk behaviours – sexual activity, alcohol/drug use, missing treatment.</p> <p>Group and individual discussions for consciousness raising. Providing information, feedback, or confrontation about the causes, consequences, and alternatives for a problem or a problem behaviour.</p> <p>Problem solving - Identification of problems and action plans (Smartphone application/workbook) Specifically focused on barriers to taking treatment and planning treatment when not at home/going out etc. Managing negative emotions.</p> <p>Coping strategies - Identification of current coping strategies (Smartphone application/workbook), group</p> | <p>Parameters: Can use feedback and confrontation; however, raising awareness must be quickly followed by increase in problem-solving ability and (collective) self-efficacy.</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|----|--|---|--|---|
| | <i>person didn't accept it or ignored me.</i> | | <p>discussions, formulating ways of coping better</p> <p>Planning coping responses: Prompting participants to list potential barriers and ways to overcome these.</p> <p>Disclosure - Disclosure journal (Smartphone application/Workbook)</p> <p>Self-monitoring of behaviour: Prompting the person to keep a record of specified behaviour(s).</p> <p>Skills training - Guided practice/ role plays with feedback. Specifically focused on disclosing one's status – role playing disclosure, decisions and actual disclosure - positive and negative reactions.</p> <p>Modelling - Examples provided by group leader. Examples of coping, disclosure, overcoming adherence barriers.</p> | <p>Parameters: Identification of high-risk situations and practice of coping response. Specifically focused on coping with stigma</p> <p>Parameters: The monitoring must be of the specific behaviour (that is, not of a physiological state or health outcome). The data must be interpreted and used. The reward must be reinforcing to the individual.</p> |
| | <i>Adolescent HIV self-management intervention: Programme duration, format, setting and leaders/facilitators</i> | | | |
| 14 | Programme duration and timing | Knowing that adolescents want to be as normal as possible, and don't want to spend too much time on 'disease management', it could be | Duration of intervention: 12 weeks | Parameters for effectiveness: To negotiate timing with adolescents. Other options are holiday camps with |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|--|--------------------|--|--|--|
| | | <p>questioned if youngsters are motivated enough to spend Friday afternoons, or Saturday mornings. I think it will be important to negotiate with the patients on the most appropriate time for them.</p> <p>Option to answer 'unknown' is not given. I find this difficult to answer ... would need to know what adolescents think/suits them ...every community might be different, so flexibility is needed in the program to do this. Some adolescents like the idea of a 'holiday camp' – 3 days of focused information, followed up with weekly/2 weekly type of 'support group'</p> <p>The timing should be determined by the adolescent stakeholders – when they would be most likely to attend.</p> <p>Need to accommodate those at school and those who may be working. Transport costs/motivation to attend over extended time period may be issues.</p> <p>Unfortunately I think only the motivated individuals will commit to a weekly session which will bias your sample. Although I think this question would be best posed to ALHIV. Also consider adolescent clinics, adolescent corners, etc.</p> <p>I think the only way you'll know if it's feasible is if you pilot it. Is there any evidence to suggest that longer/shorter programmes are more effective? Could it all be delivered in one/two days if you thought that attendance for such a long period would be problematic.</p> <p>There is always a risk of 'sampling bias' in that the young people who are available after school</p> | <p>Timing: Fridays after school OR Saturday mornings OR negotiated time with groups or individuals</p> | <p>focused information followed by follow-up groups. Transport costs to be considered.</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|----|--------------------|---|---|--|
| | | <p>or on Saturday mornings will be significantly less vulnerable than others who are having to work or care for younger siblings etc.</p> <p>The linking to school timetables also reinforces an implicit association with this being about instructing young people to 'do better' rather than addressing the underlying drivers of their risk. How then does it interface with the existing Life Orientation programme? Also, 12 months (?weeks) is not long enough to introduce sustained change. This lends again to its apparent superficiality.</p> <p>Seems appropriate and feasible, but you know your context and kids best! Am doing a lot of work now w PM+ program (5 sessions) perhaps consider looking at that tool/info.</p> | | |
| 15 | Programme format | <p>I am concerned about the number of sessions. If 9 sessions of 90 minutes each are needed, I anticipate a large drop-out.</p> <p>As above, my response is 'unknown' – dependent on the adolescents. In the past, we have seen that it takes time, and continuity, to build trust ...</p> <p>Ask the adolescent stakeholders whether 60 or 90 minute sessions are appropriate. Will there be an incentive to complete the workbook/homework?</p> <p>What time of year would you aim to do this? Will need to be aware of exams and holidays (when teenagers usually don't attend clinic) Again, I think best posed to potential participants. Nine sessions sounds do-able though.</p> <p>Not sure how you deliver 9 sessions over 12 weeks?</p> | <p>Format for contact sessions: Total of 9 sessions: 7 small group sessions (90 minutes each): introduction + 5 sessions + closing</p> <p>Two individual coaching sessions (60 minutes each)</p> <p>Format for information sharing and 'homework' activities: Smartphone application – electronic application (yet to be developed if deemed most feasible) OR Paper-based workbook at adolescent can take home with them</p> | <p>Parameters for effectiveness:</p> <p>To negotiate with participants – consider duration and timing e.g. time of year.</p> <p>To consider incentives for completion of activities.</p> <p>To consider using a hybrid approach – using both paper-based and phones to see what works.</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|----|--------------------------------|---|--|---|
| | | <p>This is how education is delivered, so of course it works in that sense. But it is not addressing what it needs to. And it will be more effective for less at risk young people (without learning challenges or difficulties caused by their intellectual and socio-economic circumstances).</p> <p>Consider a hybrid approach, smartphone and paper based, to see which one works the best, this could be a tertiary finding, my guess is kids are WAY ahead of us older folk in terms of preferring phone? Would be interesting to know if one works better</p> | | |
| 16 | Programme leaders/facilitators | <p>I mark, "not feasible" as there is not enough info given about the process: Will the HCW be part of the health system, or from an NGO? If an NGO, how will it be ensured that the adolescents and peer facilitators see congruency in messaging and the program of the NGO & PHC Clinic?</p> <p>Will the group sessions be mixed gender?</p> <p>Will the counsellors / HCW be from the local clinic or separate (from the study)?</p> <p>I would also consider a care team approach where there are others (perhaps parents of the adolescent Peer facilitators) who also contribute to the team approach and provide interventions to family/caregivers of adolescent participants so that they can promote optimal health, self-management, and transition at home.</p> <p>Everything hinges on these people. How will they be identified? How will you ensure that they have underlying belief systems that are supportive of change – e.g., what will their views on gender equity be? Knowing that addressing</p> | <p>2 Peer facilitators (older ALHIV aged 18-24 who can function as role models) To conduct peer group sessions Peer leaders will be trained to facilitate discussions, role play and model behaviour</p> <p>Counsellors / health care workers (doctor/nurse) To supervise peer group sessions To conduct individual coaching sessions using the 5A's approach or motivational interviewing Health care workers will be trained to facilitate the individual sessions</p> | <p>Parameters for effectiveness:</p> <p>To consider who will be responsible, roles of NGO's and HCWs – higher level support for peer facilitators.</p> <p>To consider a team care approach.</p> <p>Careful selection and training of facilitators.</p> <p>To discuss same or mixed gender sessions.</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|----|---|--|--|---|
| | | <p>this is essential to genuinely addressing health inequalities in our context? Similarly, will they be able to identify and effective harmful cultural practices/traditions.</p> <p>love the modelling that can occur w/ peer leaders, would have back up/higher level support available in case any trauma or suicidal ideation emerges, have some direct line queued up to ensure higher level mental health support as/if needed.</p> | | |
| 17 | Setting | <p>For us in the rural areas, confidentiality is always an issue raised by adolescents. As well as transport access to clinic – link sessions with existing visits for medication, clinical consultation, contraception etc.</p> <p>I would add in for the peer groups – need to be a space that is large enough to accommodate everyone comfortably where there are few interruptions.</p> <p>This is fine. Although important to know what other associations/affiliations this space has, e.g., is it also used by the local ward counsellor meaning politics might be conflated with the programme?</p> <p>SNACKS :) so important.</p> | <p>Setting - The setting for the peer groups can be in the community or at the clinic – the group should decide on a convenient place, but should consider confidentiality and safety</p> <p>The setting of the individual sessions should be in the consultation room of the counsellor or health care worker</p> <p>Refreshments - Snacks should be provided at group sessions</p> | <p>Parameters for effectiveness:</p> <p>Consider confidentiality, transport costs and access.</p> <p>Linking sessions with other health-related appointments.</p> <p>Large enough space to accommodate everyone with few interruptions.</p> |
| 18 | <i>Adolescent HIV self-management intervention: programme content and materials</i> | <p>Nine sessions of 90 minutes is a large investment for adolescent (see above). I anticipate a large drop-out. I would suggest to check the acceptability by youngsters.</p> <p>Group session 2, materials to be used/adapted - Have a resource list available for the specific community; Week 6: Group session 3: Participation - HCW's working with adolescents to attend this session - They should have a</p> | <p>Session 2 – have a resource list available for the specific community.</p> <p>Training of HCW and peers involved should be performed beforehand.</p> <p>Ensure congruency between messages of HCWs and peer facilitators.</p> <p>Linking with MSF/ANOVA on previous work and programmes done. ANNECCA handbook and guide. pM+</p> | <p>Parameters for effectiveness:</p> <p>Obtain views of participants.</p> |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|--|--------------------|--|--|-------------|
| | | <p>separate session beforehand – trained in the skills you are wanting them to show/use in the consultation of the adolescents. Facilitators/peer leaders should also attend and be trained in the same skills.</p> <p>Congruency of the message, between HCWS and the health system/program, is so important ; Week 7 Workbook/Smartphone application:</p> <p>Biomedical management - MSF, Anova Health Institute have done a lot of work on this aspect – perhaps link with them, rather than designing a whole new program.</p> <p>I would include other disease and Health issues – not just HIV. Week 8, Group session 4: Biomedical management - Discussion and role play: We have once asked adolescent to teach their peers about their ART – share the knowledge they have learnt; what is relevant to them about all the biomedical treatment?;</p> <p>Week 10 - Group session 5: Coping and self-regulation, disclosure discussion guide: MSF & Anova and other HIV-NGOs have done work on this and developed tools.</p> <p>It looks like some of the activities are specific to HIV and some are general health-related activities. The content looks appropriate for the sessions, but it was not clear in the objectives and components above that some content is general and some is specific to HIV. Giving examples and acknowledging differences are always helpful for adolescents. I hope my responses were helpful.</p> <p>Just some thoughts around language (will written materials be available in other languages?)"</p> | <p>To consider translation of materials in other languages.</p> <p>To consider how materials will be suitable for participants with learning/reading challenges. May have to consider more interactive (non-writing) activities to keep adolescents engaged.</p> | |

| | Programme outcomes | Summary of comments | Summary of revisions | Changed to: |
|--|--------------------|--|----------------------|-------------|
| | | <p>It looks like a very thorough program and well thought through. However it will rely on quite significant "buy in" from the teenagers – and my not be suitable for some teens with some learning challenges / some family backgrounds. It is quite reliant on verbal/written communication of learning method.</p> <p>I would also consider reviewing ANNECCA's handbook and pocket guide for psychosocial support for children and adolescents.</p> <p>More interactive (non-writing) type activities and that a range of modalities within each session if key to keeping them interested.</p> <p>Might be too long. You may have drop out, although if valuable to kids you will not have ANY DROP OUT, as we all know...just thinking out loud and also w PM+ the five sessions might be too short, so as this is a pilot I would err on longer, to learn, perhaps after this it can drop to 8 or 9 weeks, but you need to start somewhere.</p> | | |

Summary table mapping objectives, methods/strategies

| Component | Objectives | Methods and strategies | Content of sessions (see draft programme) |
|--|---|--|---|
| <p>6. Believing and knowing</p> | <p>To increase positive beliefs</p> <p>To increase positive attitudes</p> <p>To increase feelings of control (self-efficacy and confidence) to self-manage</p> <p>To increase adolescents' knowledge about their health</p> <p>To increase adolescents' knowledge about their illness and the importance of ART</p> <p>To increase knowledge about how to navigate the health care system</p> <p>To increase knowledge about when to seek care</p> | <p>Belief selection (week 2)</p> <p>Modelling (week 2)</p> <p>Technical knowledge (week 1 & 2)</p> <p>Discussion (week 2)</p> | <p>Workbook/smartphone- Who am I (identity & self-esteem) and what do I believe about myself (acceptance, positive self-esteem, dreams for the future, career, other goals) [Materials: Life context form; Knowing self - JOHARI window; Mental health symptom screener]</p> <p>Peer group session – [Materials: Group leader share beliefs to reinforce positivity, optimism, future orientation, that they can achieve as much as a person without HIV]</p> <p>My chronic illness - what do I know and what do I need to know more about (what is HIV, taking treatment, attending appointments, managing stress, safe sex, general healthy living, nutrition, where to get more information) [Materials: HIV knowledge self-assessment Positive living tips Self-care guide Food for health nutrition tips]</p> <p>Peer group session: How can I live a healthy life with HIV and how can others live healthy lives with me (sexuality, partners). [Materials: Group discussion - Facilitator shares own experiences and assess general knowledge transferred through workbook and shared general agreement of content; Discuss where to go if they need more information]</p> <p>Individual coaching session: HCW/lay health worker to reinforce self-efficacy and confidence that adolescent can</p> |

| Component | Objectives | Methods and strategies | Content of sessions (see draft programme) |
|--------------------------------|---|---|--|
| | | <p>Modelling / Peer education (week 4)</p> <p>Mobilising social support/networks (week 3)</p> <p>Discussion / Peer education (week 4)</p> <p>Mobilising social support/network linkages (week 6 & week 11) Advocacy</p> | <p>Identification / journaling of social support network (smartphone application/ workbook)</p> <ul style="list-style-type: none"> • Who are the people I trust? • Who are the people supporting me? • Who are my role models and why? <p>[Materials: My positive living journal Guide to health and social resources]</p> <p>Peer Group session: How can I increase my support system? How do I build strong trusting relationships? What are possible barriers for attaining goals and how can I overcome them? What resources are there in my community that can help me attain my goals? [Materials: Group discussion of experiences Facilitator shares own experiences Have a resource list available for the specific community]</p> <p>Video/scenario of young person who needs help – brain-storm where he/she can go for help.</p> <p>HCW(s) to interact with adolescent at one group session. Goal to provide HCW with some insight into needs of adolescents (Group session week 6).</p> <p>Interaction with caregiver (or confidant) at one individual coaching session (week 11)</p> <p>Goal to foster communication and support.</p> |
| <p>8. Participation</p> | <p>To improve confidence to be actively involved in health care decision-making <i>as much as the</i></p> | <p>Self-reflection (Week 5 & 6)</p> | <p>Workbook: How can I take responsibility for my own care? Identifying own responsibility</p> |

| Component | Objectives | Methods and strategies | Content of sessions (see draft programme) |
|--|---|---|--|
| | <p>To identify risks/barriers for not taking treatment and develop action plans to manage barriers to adherence.</p> | <p>Motivational interviewing/Coaching (Week 5 & 11)</p> <p>Group discussion (Week 8)</p> | <p>ARVs, frequency of taking them, VL, CD4 count Medication adherence diary Medication worksheet My biomedical management journal]</p> <p>Skills building - Personalised feedback about self-monitoring provided during individual coaching session</p> <p>Group discussion. What if I feel like not taking my ARV's anymore? Identify risks/barriers for not taking treatment (adherence) and solutions) [Materials: Discussion and role play; Group leader shares experience]</p> |
| <p>10. Coping and self-regulation</p> | <p>Improve coping skills to manage HIV stigma.</p> <p>Improve ability to manage emotions</p> <p>Improve decision-making skills about disclosure.</p> <p>Identifying possible risks/barriers to self-management of HIV and health and develop strategies to overcome barriers.</p> <p>Develop strategies to integrate taking treatment into one's daily routine.</p> <p>To understand where and how to seek out help</p> | <p>Identification of risk behaviours / Risk perception. Self-assessment of risk; journaling (Week 9 & 10)</p> <p>Group and individual discussions for consciousness raising (week 9 & 10)</p> <p>Decision-making / Problem solving (Week 9 & 10)</p> | <p>Workbook: What are my health risks and how do I overcome them? Risk behaviours – sexual activity, alcohol/drug use, missing treatment [Materials: Alcohol and substance abuse journal; Sexual and reproductive health journal]</p> <p>Peer group discussion around risk behaviours.</p> <p>Identification of problems and action plans (Smartphone application/workbook) Specifically focused on barriers to taking treatment and planning treatment when not at home/going out etc. Managing negative emotions. [Materials: Stigma action plan Decision-making activity worksheet Emotional health journal Emotional health – normal feelings and danger signs]</p> <p>How do I cope with my illness and life?</p> |

| Component | Objectives | Methods and strategies | Content of sessions (see draft programme) |
|-----------|------------|---|---|
| | | <p>Coping strategies (Week 9 & 10)</p> <p>Self-monitoring of behaviour - disclosure (Week 9 & 10)</p> <p>Skills training (Week 9 & 10)</p> <p>Modelling (Week 9 & 10)</p> <p>Coaching/MI (Week 9 & 10)</p> | <p>How do I cope with stigma? Who have I disclosed to, who would I like to disclose to and how? Identification of current coping strategies, formulating ways to cope better, barriers and how to overcome these; Group discussion [Materials: Identification of current coping strategies]</p> <p>Group session: How do I disclose my status?</p> <p>[Materials: Disclosure journal] How do I handle being HIV positive in a relationship?</p> <p>Group session: Guided practice/ role plays with feedback. Specifically focused on disclosing one's status – role playing disclosure, decisions, and actual disclosure - positive and negative reactions. [Materials: Discussion and role play Sharing of problem-solving strategies Disclosure discussion guide Sex and relationships discussion guide Group leader shares experience]</p> <p>Examples provided by group leader. Examples of coping, disclosure, overcoming adherence barriers.</p> <p>Coaching/MI session (with caregiver): Review previous action plan and determine way forward; Discuss how caregiver/close friend/confidant can assist adolescent</p> <p>[Materials: Comprehensive transitioning checklist; Guide on coaching/5A's; Tips for adolescent motivational interviewing;</p> |

| Component | Objectives | Methods and strategies | Content of sessions (see draft programme) |
|-----------|------------|------------------------|--|
| | | | Readiness for change ruler; My personal action plan; Family / caregiver checklist] |

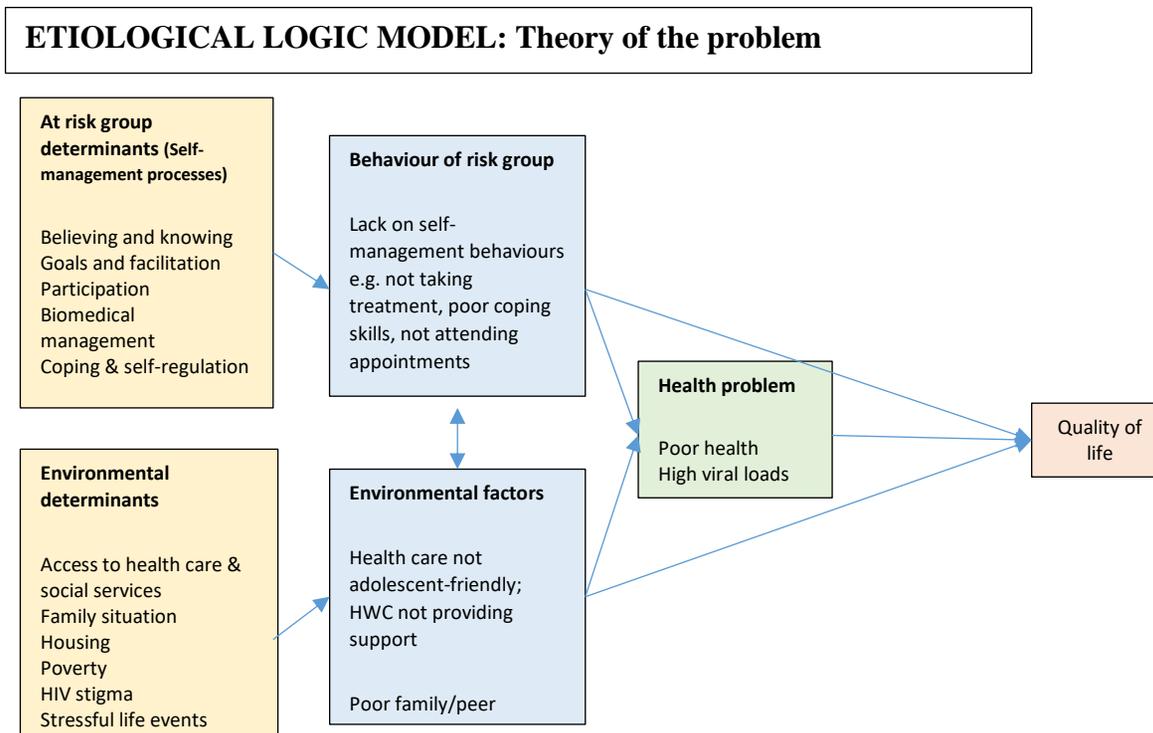


Figure 1: Logic model of the problem

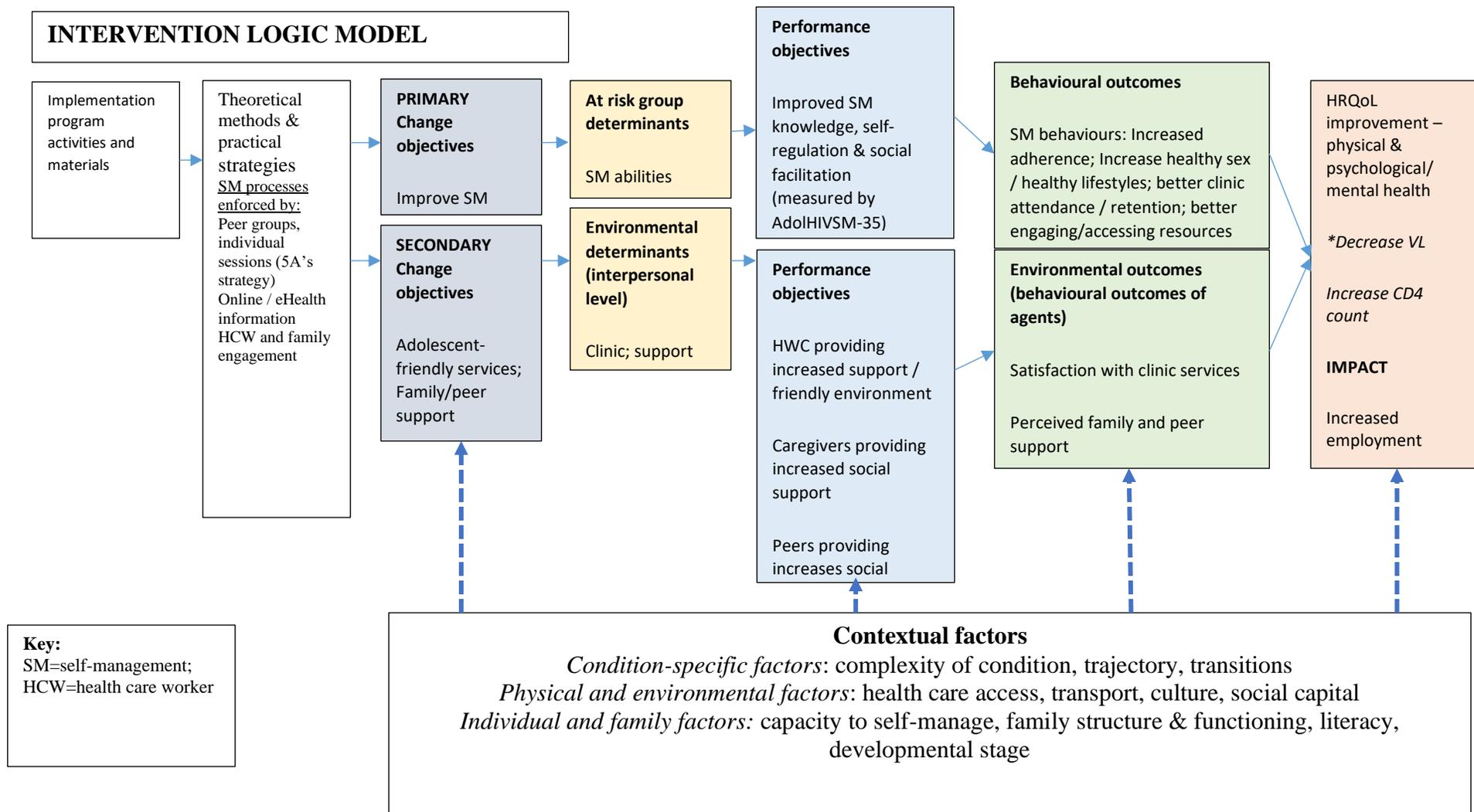


Figure 2: Intervention logic model

References

- Adams, A. L. (2019) *Exploring the self-management needs of adolescents living with HIV in the Nelson Mandela Bay area of the Eastern Cape*. Stellenbosch University. Available at: <https://scholar.sun.ac.za/handle/10019.1/106000>.
- Bernardin, K. N. *et al.* (2013) 'Self-management interventions for people living with human immunodeficiency virus: A scoping review', *Canadian Journal of Occupational Therapy*, 80(5), pp. 314–327. doi: 10.1177/0008417413512792.
- Cincinnati Children's Hospital (2007) *Evidence-Based Care Guideline: Chronic Care: Self-management*. Cincinnati Children's Hospital Medical Center. Available at: www.cincinnatichildrens.org/svc/alpha/h/health-policy/ev-based/chronic-care.htm.
- Crowley, T. (2018) *The development of an instrument to measure adolescent HIV self-management in the context of the Western Cape, South Africa*. Stellenbosch University. Available at: <http://scholar.sun.ac.za/handle/10019.1/103521>.
- Crowley, T. *et al.* (2019) 'Measuring Adolescent HIV Self-management : An Instrument Development Study', *AIDS and Behavior*, pp. 1–15. doi: <https://doi.org/10.1007/s10461-019-02490-z>.
- Crowley, T., van der Merwe, A. and Skinner, D. (2019) 'Adolescent HIV Self-management: Lived experiences of adolescents, caregivers and health care workers in a South African context', *Journal of the Association of Nurses in AIDS Care*, 30(4), pp. e7–e19. doi: 10.1097/jnc.000000000000098.
- Denison, J. A. *et al.* (2015) "'The sky is the limit'": adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers', *Journal of the International AIDS Society*, 18, pp. 1–6.
- Duffy, M., Bergmann, H. and Sharer, M. (2014) *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*. Arlington, VA: USAID's AIDS support and Technical Assistance REsources, AIDSTAR-One, Task Order 1.
- Fick, C. *et al.* (2015) *Working with adolescents living with HIV: A handbook for healthcare providers*. Johannesburg: Wits RHI and Southern African HIV Clinicians Society. Available at: http://www.wrhi.ac.za/uploads/files/ALHIV_12August2015-1.pdf.
- Kok, G *et al.*, 2015. A taxonomy of behaviour change methods: an Intervention Mapping Approach. *Health Psychology Review*, 10:3, 297-312, DOI: 10.1080/17437199.2015.1077155
- Lorig, K. (2015) 'Chronic Disease Self-Management Program : Insights from the Eye of the Chronic Disease Self-Management Program : insights from the eye of the storm', *Frontiers in Public Health*, 2(June), pp. 1–3. doi: 10.3389/fpubh.2014.00253.
- Mutumba, M. *et al.* (2019) 'Perceptions of Strategies and Intervention Approaches for HIV Self-Management among Ugandan Adolescents : A Qualitative Study', *Journal of the International AIDS Society*, 18, pp. 1–8. doi: 10.1177/2325958218823246.
- Parker, L. *et al.* (2013) 'Feasibility analysis of and evidence-based positive prevention

intervention for youth living with HIV/AIDS in Kinshasa, Democratic Republic of the Congo.', *AIDS Educ Prev*, 25(2), pp. 135–150. doi: 10.1521/aeap.2013.25.2.135.

Strengthening High-Impact Interventions for AIDS-free Generation (AIDSFree) Project (2017) *Swaziland Integrated Teen Club Curriculum*. Arlington, VA: AIDSFree Project.

APPENDIX 9: FACILITATOR GUIDE FRONTPAGE

FACILITATOR GUIDE

Supporting Self-Management in Adolescents to be Resilient and Thrive.



UNIVERSITEIT
UNIVERSITH
STELLENBOSCH
UNIVERSITY

100
1918 - 2018

Supporting
Self-management

APPENDIX 10: WORKBOOK FRONTPAGE

WORKBOOK

Supporting Self-Management in Adolescents to be Resilient and Thrive.



UNIVERSITEIT
iYUNIVESITHI
STELLENBOSCH
UNIVERSITY

100
1918-2018

Supporting
Self-management

APPENDIX 11: LANGUAGE EDITING CERTIFICATE

Between lines editing

Leatitia Romero
Professional Copy Editor and Proofreader
(BA HONS)

Cell: 083 236 4536
leatitiaromero@gmail.com
www.betweenlinesediting.co.za

24 November 2021

To whom it may concern:

I hereby confirm that I edited the dissertation entitled: “The development of a self-management intervention for adolescents living with HIV in a South African context: views of experts and key stakeholders”. Any amendments introduced by the author hereafter are not covered by this confirmation. The author ultimately decided whether to accept or decline any recommendations I made, and it remains the author’s responsibility at all times to confirm the accuracy and originality of the completed work. Research participants’ verbatim quotes were not grammatically altered or checked for contextual accuracy. The author is responsible for ensuring the accuracy of the references and its consistency based on the department’s style guidelines.



Leatitia Romero

Affiliations

PEG: Professional Editors Group (ROM001) – Accredited Text Editor
SATI: South African Translators’ Institute (1003002)
REASA: Research Ethics Committee Association of Southern Africa (104)

