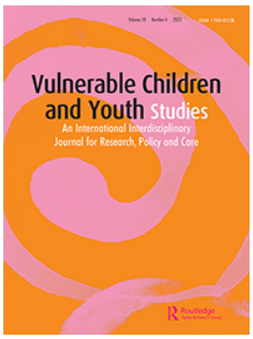

Taylor & Francis
Taylor & Francis Group

Vulnerable Children and Youth Studies

An International Interdisciplinary Journal for Research, Policy and Care

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/rvch20

Supporting HIV self-management in adolescents to be resilient and thrive: an intervention development study

Talitha Crowley & Frances de Lange-Cloete

To cite this article: Talitha Crowley & Frances de Lange-Cloete (2023) Supporting HIV self-management in adolescents to be resilient and thrive: an intervention development study, Vulnerable Children and Youth Studies, 18:4, 530-544, DOI: 10.1080/17450128.2023.2206172

To link to this article: https://doi.org/10.1080/17450128.2023.2206172

VULNERABLE CHILDREN AND YOUTH STUDIES
2023, VOL. 18, NO. 4, 530–544
https://doi.org/10.1080/17450128.2023.2206172

Taylor & Francis
Taylor & Francis Group

ARTICLE

Supporting HIV self-management in adolescents to be resilient and thrive: an intervention development study

Talitha Crowley [a] and Frances de Lange-Cloete[b]

[a]School of Nursing, Faculty of Community and Health Sciences, University of the Western Cape, Cape Town, South Africa; [b]Department of Nursing, Faculty of Medicine and Health Sciences, Stellenbosch University, Cape Town, South Africa

ABSTRACT

Self-management programs or interventions focus on self-empowerment to improve skills, abilities and behaviors needed to control a chronic condition and may be of great value for adolescents living with HIV (ALWH). The aim of this study was to develop a self-management intervention called Self-Management in Adolescents to be Resilient and Thrive (S-SMART), for ALWH aged 15 to 19 years using the principles of intervention mapping (IM). We conducted a needs assessment and developed a logic model for change based on factors influencing self-management amongst ALWH on the level of the individual and environment. Program outcomes and objectives were identified based on formative qualitative and quantitative research, a systematic review and theory. We then selected theory-based models and practical strategies and developed a 12-week program consisting of individual activities completed in a workbook or smartphone application, five peer-group sessions and three individual coaching sessions. Content validity was determined by consulting nine local and international experts and 18 key stakeholders (11 ALWH and seven healthcare workers) through four focus groups in the Cape Metropole of the Western Cape, South Africa. The intervention will now be pilot tested for feasibility and acceptability.

ARTICLE HISTORY
Received 19 August 2022
Accepted 17 April 2023

KEYWORDS
Adolescents; HIV; intervention development; program; self-management

Introduction

Globally an estimated 1.7 million adolescents aged 10 to 19 years were living with HIV in 2021 (UNICEF, 2022). The proportion of adolescents living with HIV (ALWH) is growing due to the cohort of adolescents who acquired HIV through mother-to-child transmission entering adolescence and the relentless trend in new infections (150,000 in 2020 and 160,000 in 2021) (United Nations Children's Fund, 2022). Adolescents remain vulnerable to acquiring HIV due to risk factors associated with their developmental stage. Although the proportion of ALWH remains relatively small, the prevalence of HIV amongst older adolescents (aged 15 to 19 years) in South Africa has increased from 3.2% in 2012 to 6.5% in 2017 (Mabaso et al., 2021). ALWH is a group with high care needs and poor treatment outcomes. In South Africa in 2017, only 65.4% of ALWH were

CONTACT Talitha Crowley tcrowley@uwc.ac.za School of Nursing, Faculty of Community and Health Sciences, University of the Western Cape, 14 Blanckenberg Street, Belville 7535, South Africa

on antiretroviral treatment (ART) and of those on treatment, only 78.1% were virally suppressed (Zungu et al., 2021). In addition to dealing with HIV, ALWH are negotiating the complex challenges of peer pressure, identity, and stigma in the developmental phase of adolescence and are transitioning from child to adult health care whilst exposed to an environment of poverty, violence, and crime (Cluver et al., 2018). Support structures such as the family and adolescent-friendly health care services may be absent or ineffective (Zanoni et al., 2019). Consequently, retention in care (the process of ongoing participation in health care) is the lowest among ALWH in sub-Saharan Africa (Slogrove et al., 2018).

One possible intervention to improve the clinical outcomes of adolescents is to provide self-management support through educational interventions or programs. Self-management programs focus on self-empowerment to improve self-efficacy, skills, abilities, and behaviors needed to control a chronic condition (Sawin et al., 2017). Self-management support is pertinent for young people living with chronic conditions, but research is needed to evaluate the effectiveness of such interventions, particularly interventions where the program content and expected outcomes are appropriately matched (Sattoe et al., 2015). This means that the content of intervention programs should be specifically designed to result in the expected behavior change and resultant health outcomes.

There is a lack of self-management interventions for ALWH in the sub-Saharan context (Crowley & Rohwer, 2021). Although there are programs focused on improving the continuum of care for ALWH, including adherence to ART and retention in care (Zanoni et al., 2022), there are no known interventions focused on improving the self-management skills of ALHW in South Africa. The aim of this study was to develop a self-management intervention, called Self-Management for Adolescents to be Resilient and Thrive (S-SMART), for ALWH aged 15 to 19 years.

Methods

Intervention development

We used the principles of Intervention Mapping (IM) to guide the development of the S-SMART intervention. IM consists of 6 steps: 1) Needs assessment; 2) Formulation of change objectives; 3) Selection of theory-based methods and practical strategies; 4) Intervention development/program design; 5) Adoption and implementation plan and 6) Evaluation planning (Fernandez et al., 2019). We engaged with the intervention development and validation processes over a period of three years (2019 to 2021).

Step 1: needs assessment

A needs assessment includes an assessment of the needs, resources and context of the target population. Through this process, the health problems that the intervention will address are identified and prioritised. It also includes formulating goals for the intervention. We conducted qualitative and quantitative research in the study context on the lived experiences and self-management of ALHW from the perspectives of adolescents, healthcare workers and caregivers (Crowley et al., 2019, 2020, 2021). We also conducted a systematic review of self-management of interventions for ALWH in order to identify effective interventions in settings with a high burden of HIV (Crowley & Rohwer, 2021).

The Individual and Family Self-Management Theory (IFSMT) (Sawin et al., 2017) underpinned the study and was used to identify contextual factors influencing the self-management of ALWH. At the end of the needs assessment, we identified program goals and objectives.

Step 2: formulation of change objectives

In step 2, the program goals and objectives were broken down into individual and environmental level performance- and change objectives. The selection of performance and change objectives was informed by the at risk determinants identified through the literature review and formative research. Further, as the formative research identified five components of self-management, change objectives for each of these components were identified. This led to the creation of a logic model of change (See Figure 1).

Step 3: selection of theory-based methods and practical strategies

In this step, we identified theories and methods of behaviour change likely to assist with changing the at risk determinants in order to meet the change objectives. We explored methods used in existing programs developed for ALWH (Duffy et al., 2014; Fick et al., 2015; Gage et al., 2017; Parker et al., 2013) as well as the taxonomy of behaviour change methods, and matched these with each of the five components of self-management (Kok et al., 2015). We then linked practical strategies and delivery methods to each of the behaviour change methods.

Step 4: intervention development

The fourth step includes developing intervention content and materials. We developed a 12-week program consisting of a range of individual activities, peer group sessions and individual coaching sessions. The provisional program duration, format, setting and facilitators were identified.

Step 5: adoption and implementation plan

Adoption and implementation planning includes identifying the intervention's adopters, implementers and maintainers. We identified that the end users of the intervention would be ALWH aged 15 to 19 years, older peers aged 20 to 24 years to act as peer group leaders,

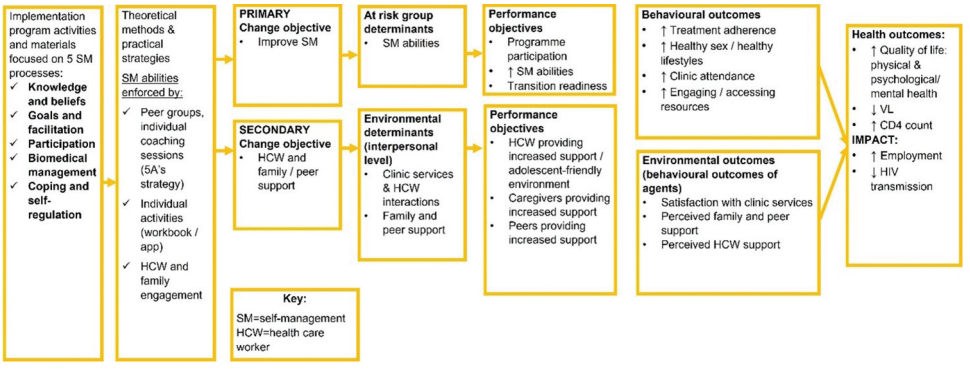

Figure 1. Logic model of change.

and health care workers (HCWs) working in HIV clinics or for non-governmental organisations (NGOs) in the community to provide the coaching sessions. We anticipated that the intervention would be implemented in public primary health care clinics as most ALWH in South Africa receive access services in the public health care system.

Step 6: evaluation planning

Lastly, we identified effectiveness measures for each of the program outcomes based on the logic model of change.

Empirical phase

Expert review

In order to validate the developed intervention and further refine it, we conducted an expert review. Fourteen experts (researchers and academics) in adolescent health care, HIV management, self-management, care transitioning and intervention mapping were purposively selected based on their expertise and publications in the relevant fields (see Table 1). These experts assessed the intervention's content validity and provided feedback on the proposed program objectives, methods, and practical strategies. Nine of the 14 experts provided feedback via a structured questionnaire where they had to rate the relevancy and clarity of the intervention components on a scale of 1=not relevant/unclear through 4=highly relevant/very clear, as well as open-ended questions. A content validity index for items (I-CVI) was used to establish the level of agreement. 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 (Polit & Beck, 2017). Open-ended comments were analysed thematically (Braun & Clarke, 2006). Eight experts subsequently participated in an online feedback session that lasted 78 minutes.

Table 1. Biographical data of experts

Gender	Age	Qualifications	Country	Primary Area of Expertise
Male	51	PhD, RN	Belgium	Research in healthcare transition
Female	48	MBChB	South Africa	Family medicine, with a focus on HIV, TB, non-communicable diseases
Female	63	PhD, RN	United States	Adolescent and young adult oncology, Oncology nursing; Self-management
Female	52	MBChB	South Africa	Paediatrics, HIV, Adolescent psychiatry, Self-management: HIV
Female	38	MBChB	South Africa	Family medicine - with a particular interest in paediatric and adolescent HIV care
Female	42	MSC Nursing, MS 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 program 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

Table 2. 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

Key stakeholder review

Following the review by experts, we developed program materials, including an adolescent Workbook containing the individual activities and a Facilitator Guide. We conducted focus groups with key stakeholders in the Cape Metropole of the Western Cape, South Africa. The stakeholders included a purposive sample of ALWH or youth (aged 15 to 24 years), HCWs and NGO representatives with experience working with adolescents (see Table 2). Participants were recruited through two community gatekeepers who were HCWs working in the community. The aim was to recruit a mix of HCWs of different categories, caregivers and ALWH of varying ages and genders. We recruited 13 HCWs and 24 ALWH. Of those recruited, seven HCWs and 11 ALWH attended the focus groups. Since the study was conducted during the COVID-19 pandemic, the recruitment of participants was challenging; although we recruited caregivers and registered nurses, they could not attend on the scheduled days.

On the day of the focus groups, the participants received a hard copy of the suggested intervention, objectives, outcomes, and practical strategies. They also received a hard copy of the draft adolescent Workbook and the Facilitator Guide. A semi-structured interview guide was used to facilitate discussion. 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?' (See Box 1: Semi-structured interview guide).

The researchers are fluent in English and Afrikaans, and an isiXhosa-speaking interpreter was used during the adolescent focus groups. The focus groups lasted between 60 and 120 minutes with breaks as needed and were audio-recorded. Thematic analysis was performed on the transcribed data (Braun & Clarke, 2006). The themes and sub-themes were used to refine the various intervention components. The principles of trustworthiness such as credibility, dependability, confirmability and transferability were applied.

Ethics

Ethical approval for the study was obtained from the Health Research Ethics Committee of Stellenbosch University (N18/06/064) as well as the Western Cape Department of Health to access adolescents and healthcare workers through the gatekeepers in the Cape Metropole of the Western Cape. Written informed consent was obtained from all participants. For participants younger than 18, participant written assent and parental/guardian informed consent were obtained. Participants received reimbursement for their travel costs to and from the venues and refreshments. COVID-19 procedures were adhered to during focus groups and a referral system was in place should any participants become distressed. No personal identifiers were collected, and all data and information were saved into password-protected folders to ensure the protection of personal information. Feedback to the participants is ongoing through continued engagement with the study setting.

BOX 1 Semi-structured interview guide questions

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 program 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 smartphone 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, and 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 4: Please provide us with your view on the program duration and timing.
Probes:

- Do you feel that the duration and timing of the program of 12 weeks are 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 5: What is your opinion on the format of the program – the delivery thereof
Probes:

- Do you feel that the format of the program is appropriate and/or feasible? (Probes: workbooks vs Smartphone, the contact sessions)

- Tell us about 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 program 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 6: Regarding the facilitators in the program:

- What is your take on the leaders and facilitators of the program? (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 7: 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 8: Please reflect and tell us more about program content and suggested materials for 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 the 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?

Results

Intervention development

Steps 1 and 2: needs assessment & formulation of change objectives

For the program, we defined self-management as '*the processes and behaviors adolescents engage in to take care of their chronic illness with the assistance of their caregivers, health workers, family, friends, peers and educators*'. Based on the needs analysis and subsequent expert and stakeholder feedback, the following program outcomes and objectives were devised:
Primary outcomes:

• Performance objectives: Improved adolescent HIV self-management as measured by the AdHIVSM-35 (Crowleyet al., 2019)

• Behavioral outcomes: Improved treatment adherence; less risky behaviors (sex and alcohol/drug use)

• Health outcomes: Decrease in viral load (VL); increased cluster of differentiation-4 (CD4)

Secondary outcomes:

• Behavior outcomes: Improved clinic attendance/retention in care

• Performance objectives: Improved satisfaction with services; transition readiness; improved perceived support from HCWs family/peers and the community

• Health outcomes: Improved health-related quality of life (HRQOL); improved mental health.

Table 3 depicts the program component outcomes and Figure 1 the logic model of change developed for the intervention, including the change objectives, at risk determinants, performance objectives and outcomes.

Table 3. Program component outcomes

Component	Objectives (as per adolescent Workbook)
Knowledge and beliefs	• To increase my positive beliefs. • To increase my positive attitudes. • To increase my feelings of control (self-efficacy and confidence) to self-manage. • To increase my knowledge about my health. • To increase my knowledge about my illness and the importance of antiretroviral therapy (ART). • To increase my knowledge about how to navigate the health care system. • To increase my knowledge about when to seek care.
Goals and facilitation	• To increase my internal and external motivation for self-management by setting individual health and life goals. • To increase my confidence in meeting goals. • To communicate my goals to others to garner appropriate support and to revise my goals when support is lacking. • To improve my communication skills with my family, health care workers, peers, and friends. • To improve my ability to identify resources and support. • To increase my awareness of social support from my family, health care workers, peers, and friends to take care of my health.
Participation	• To improve my confidence to be actively involved in health care decision making as much as I desire and, consequently, my participation in decision making. • To improve my confidence to be actively involved socially as much as I desire and, consequently, my social participation. • To increase activities aimed at general self-care and to proactively take steps to enhance my general health status for improved long-term health outcomes.
Biomedical management	• To improve my knowledge of and motivation to understand whether I am doing well on treatment or not. • To gain knowledge and understanding of biomedical outcomes such as viral load and knowledge of the names of my antiretroviral drugs (ARVs). • To be able to self-monitor my taking of treatment, side-effects, and viral load. • To collaborate with health care workers as a support team to manage my HIV. • To identify the risks of not taking treatment and the barriers to adherence and to develop action plans to manage these.
Coping and self-regulation	• To improve my coping skills to manage HIV stigma. • To improve my ability to manage emotions. • To improve my decision-making skills about disclosure. • To identify possible risks of and barriers to self-management of my HIV and to develop strategies to overcome these. • To develop strategies to integrate taking treatment into my daily routine. • To understand where and how to seek out help.

Steps 3: theory-based methods and practical strategies

We selected theory-based models and practical strategies for each of the self-management components (see Table 4).

Step 4 to 6: program development, implementation planning and evaluation

The 12-week program is indicated in Table 5. We developed a workbook with individual activities that are being translated into a smartphone application.

Table 4. Behavior change methods and practical strategies (Kok et al., 2015)

Component of self-management	Behavior-change methods	Practical strategy
Knowledge and beliefs	Technical knowledge Belief selection Modelling Group discussion	Individual activities Peer group sessions
Goals and facilitation	Goal setting & action plans Role modelling Peer support Relationship building Mobilizing social networks	Coaching/motivational interviewing using the 5A's approach: Assess, Advise, Agree, Assist, Arrange Caregiver & HCW involvement
Participation	Self-reflection & journaling Guided practice Contingent rewards	Individual activities Peer group sessions
Biomedical management	Technical knowledge Self-monitoring Group discussion	Individual activities Peer group sessions
Coping and self-regulation	Self-assessment of risk & journaling Decision-making & problem-solving skills training and role play	Individual activities Peer group sessions Coaching/motivational interviewing

Table 5. S-SMART program

Week	Program	Workbook/Smartphone activities
1	Introduction to program Pre-assessment Meeting your coach 1	Information about myself and my life context Self-management checklist
2	Theme: Believing and Knowing Group session 1	Who am I and what do I know about myself? Mental health symptom screener HIV knowledge self-assessment Positive living tips Self-care guide Nutrition tips
3	Theme: Goals and Facilitation	My psychosocial development journal My positive living journal Health and social resources worksheet
4	Theme: Goals and Facilitation Group session 2	
5	Theme: Participation Coaching session 2	My participation journal Comprehensive self-management checklist Readiness for change My personal action plan
6	Theme: Participation Group session 3 with involvement of HCWs	'I' messages and active listening My participation record
7	Theme: Biomedical management	Knowing my treatment worksheet Adherence diary
8	Theme: Biomedical management Group session 4	My biomedical management journal
9	Theme: Coping and self-regulation	My alcohol and substance use journal My sexual and reproductive health journal Continuum of risk Personal stressors worksheet Coping strategies worksheet
10	Theme: Coping and self-regulation Group session 5	Stigma action plan Disclosure journal My decision-making worksheet My emotional health journal
11	Coaching session 3 with caregiver/buddy present	Comprehensive self-management checklist Readiness for change My personal action plan (revised)
12	Feedback, graduation, and post-evaluation.	

Expert and stakeholder feedback

The content validity and relevancy indexes of the program rated by the experts are depicted in Table 6. The I-CVI for the intervention components were between 0.8 and 1.0. Seven items had clarity ratings below 0.7 and these were subsequently revised based on the qualitative feedback before the final feedback session to experts and presentation to stakeholders. For example, the primary and secondary outcomes were more clearly operationalized.

Table 6. Results of expert feedback

ITEM	Clarity	Relevancy
Program 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
Methods and practical strategies		
Believing and knowing	0.6	1.0
Goals and facilitation	0.8	1.0
Participation	0.5	1.0
Biomedical management	0.8	1.0
Coping and self-regulation	0.8	0.9
Program duration, format, setting and facilitators		
Program duration and timing	0.6	0.9
Program format	0.6	1.0
Program facilitators	1.0	0.9
Setting	1.0	1.0
Adolescent HIV self-management intervention: program content and materials	0.9	0.9

Whereas the experts focused more on the intervention components overall, the stakeholders provided more detailed comments on the program content, format,

practical strategies, facilitators, timing and duration. The themes and sub-themes of the stakeholder focus groups are depicted in Table 7.

Table 7. Themes and sub-themes of focus groups

Themes	Sub-themes
Program aim and outcomes	• Possible benefits of program outcomes • Importance of considering the context
Program content, format, and practical strategies	• Benefits of having broad (encompassing) components and objectives • Workbook preferences and criteria for effectiveness • Application preferences and criteria for effectiveness • Peer group preferences and criteria for effectiveness • Individual counselling/coaching preferences and criteria for effectiveness
Program facilitators, duration and setting	• Criteria for the effectiveness of using peer facilitators • Communication and language preferences • Human resources • Timing and duration • Selection of participants • Criteria for effectiveness for the setting

Experts and key stakeholders agreed on the need for and importance of the intervention, emphasizing the focus on ALWH's well-being as an outcome and intervention objectives and content beyond HIV. The practical strategies appeared acceptable and feasible, but individual coaching may require additional human resource support. Although there was general agreement, participants also had diverse feedback on some aspects. For example, with regard to the size of the workbook, ALWH preferred the larger (A4) book to have more space for writing and making notes, and the HCWs suggested a smaller (A5) book for confidentiality reasons. Regarding the smartphone application, some adolescents preferred to use a smartphone to complete activities whilst others had concerns since they use caregiver phones. The main concern of HCWs was the safety of the adolescents walking around in communities where phones get lost or stolen. We tried to harmonize the feedback from the participants and captured it as criteria for effectiveness. Table 8 provides a summary of parameters of effectiveness for the various program components based on the qualitative feedback.

Table 8. Parameters for effectiveness of the intervention

Component	Parameters for effectiveness
Program components and objectives	• A comprehensive/holistic approach needed across all aspects of health • To consider community and context • Family involvement • Importance of different methods
Methods	
Coaching	Time to build trust, explore beliefs, supportive relationships, focused on individual needs, speak same language, goals to be within skill level
Peer groups	Support, confidentiality
Individual activities	Assess literacy, reading/writing ability, language and information format preferences, the willingness of social networks to engage
Workbook/ smart phone application	Both options to be available/hybrid, rewards/incentives for completion of activities
Duration and timing	
Duration	12 weeks acceptable, not during holiday/exam time, linking with other appointments/follow-up/flexible
Timing	Negotiated, Friday afternoons after school
Facilitators	
Peer leaders	Careful selection and training, consistent messaging, continuity and trust, speak same language, mixed gender groups, support provided by HCW and referral systems in place
Healthcare workers	Trained in coaching/motivational interviewing/adolescent communication, assign responsibility, additional staff needed e.g. use of non-governmental organisations (NGOs)
Setting	
Space	Away from clinic/joint agreement, large enough space, transport costs considered/covered
Refreshments	Healthy refreshments, tailored to needs

Discussion

Self-management interventions that address various self-management skills and abilities have the potential to improve the health and treatment outcomes of ALWH. In this paper, we aimed to describe the development of a self-management intervention for ALWH based on the principles of IM. S-SMART is a 12-week multiple-level program. Based on the steps of IM, theory-based methods were selected that informed the components and practical strategies of the S-SMART program on the level of the individual and environment. The

strengths of the S-SMART intervention include the multiple-level/platform approach, strong evidence- and theory-based content that was inductively developed for the South African context. The program content is comprehensive with the potential to influence the health and wellbeing of adolescents beyond HIV, for example in the areas of mental health and resilience, leading to a thriving population of ALWH. We now need to do a detailed feasibility and acceptability evaluation of the S-SMART intervention and prepare S-SMART for a full clinical trial. This will lead to further refinement and possible larger scale roll out. One limitation of the stakeholder feedback was the limited time the participants had to engage with the program materials. The feasibility and acceptability pilot would offer an opportunity for the participants to fully engage with the materials to provide more detailed feedback.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This study would not have been possible without the financial support of the National Research Foundation (NRF) of South Africa [TTK180420323095]. Opinions expressed and conclusions arrived at are those of the authors and are not attributed to the funders.

Notes on contributors

Talitha Crowley is a Primary Care Nurse specialist and an Associate Professor at the School of Nursing, Faculty of Community and Health Sciences, at the University of the Western Cape, Cape Town. Her interest is in self-management support for persons living with chronic communicable and non-communicable diseases accross the lifespan.

Frances De Lange Cloete is a Primary Care Nurse specialist who completed her Master of Nursing degree at the Department of Nursing, Faculty of Medicine and Health Sciences, Stellenbosch University.

ORCID

Talitha Crowley http://orcid.org/0000-0002-2993-6553

Author's contributions

TC conceptualized the study. TC and FDL-C conducted research, including data collection and analysis. TC wrote the first manuscript draft and FDL-C provided feedback on subsequent drafts.

Ethics

Ethical approval for the study was obtained from the Health Research Ethics Committee of Stellenbosch University (N18/06/064). Written informed consent was obtained from all participants. For participants younger than 18, participant assent and parental/guardian informed consent were obtained.

References

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Cluver, L., Pantelic, M., Toska, E., Orkin, M., Casale, M., Bungane, N., & Sherr, L. (2018). Stacking the odds for adolescent survival: Health service factors associated with full retention in care and adherence amongst adolescents living with HIV in South Africa. *Journal of the International AIDS Society*, *21*(9), 1–8. https://doi.org/10.1002/jia2.25176

Crowley, T., & Rohwer, A. (2021). Self-management interventions for adolescents living with HIV: A systematic review. *BMC Infectious Diseases*, *21*(1), 431. https://doi.org/10.1186/s12879-021-06072-0

Crowley, T., van der Merwe, A. S., Esterhuizen, T., & Skinner, D. (2021). Resilience of adolescents living with HIV in the Cape Metropole of the Western Cape. *AIDS Care*, 1–8. Advance online publication. https://doi.org/10.1080/09540121.2021.1961115

Crowley, T., van der Merwe, A., Kidd, M., & Skinner, D. (2020). Adolescent human immunodeficiency virus self-management: Associations with treatment adherence, viral suppression, sexual risk behaviours and health-related quality of life. *Southern African Journal of HIV Medicine*, *21*(1), 1054. https://doi.org/10.4102/sajhivmed.v21i1.1054

Crowley, T., van der Merwe, A. V. D., Kidd, M., & Skinner, D. (2019). Measuring adolescent HIV self- management: an instrument development study. *AIDS and Behavior*, 1–15. https://doi.org/10.1007/s10461-019-02490-z

Crowley, T., van der Merwe, A., & 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), e7–19. https://doi.org/10.1097/jnc.0000000000000098

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. Retrieved from https://pdf.usaid.gov/pdf_docs/PNAEC759.pdf

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. https://doi.org/10.3389/fpubh.2019.00209

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. Wits RHI and Southern African HIV Clinicians Society. Retrieved from https://samumsf.org/sites/default/files/2018-10/Working%20with%20Adolescents%20Living%20with%20HIV%20Handbook.pdf

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. Retrieved from https://www.measureevaluation.org/resources/publications/sr-16-134/index.html

Kok, G., Gottlieb, N. H., Peters, G. J., Mullen, P. D., Parcel, G. S., Ruiter, R. A., Fernández, M. E., Markham, C., & Bartholomew, L. K. (2015). A taxonomy of behaviour change methods: An intervention mapping approach. *Health Psychology Review*, *10*(3), 297–312. https://doi.org/10.1080/17437199.2015.1077155

Mabaso, M., Maseko, G., Sewpaul, R., Naidoo, I., Jooste, S., Takatshana, S., Reddy, T., Zuma, K., & Zungu, N. (2021). Trends and correlates of HIV prevalence among adolescents in South Africa: Evidence from the 2008, 2012 and 2017 South African National HIV prevalence, incidence and behaviour surveys. *AIDS Research and Therapy*, *18*(1), 97. https://doi.org/10.1186/s12981-021-00422-3

Parker, L., Maman, S., Pettifor, A., Chalachala, J. L., Edmonds, A., Golin, C. E., Moracco, K., Behets, F., & Study Team, S. (2013). Feasibility analysis of and evidence-based positive prevention intervention for youth living with HIV/AIDS in Kinshasa, Democratic Republic of the

Congo. AIDS Education and Prevention, *25*(2), 135–150. https://doi.org/10.1521/aeap.2013.25.2.135

Polit, D. F., & Beck, C. T. (2017). *Nursing research: Generating and assessing evidence for nursing practice* (10th ed.). Wolters Kluwer.

Sattoe, J. N. T., Bal, M. I., Roelofs, P. D. D. M., Bal, R., Miedema, H. S., & Staa, A. V. (2015). Patient Education and Counseling Self-management interventions for young people with chronic conditions: A systematic overview. *Patient Education and Counseling*, *98*(6), 704–715. https://doi.org/10.1016/j.pec.2015.03.004

Sawin, K. J., Brei, T., & Houtrow, A. (2017). Definitions, frameworks, and theoretical issues in self-management1. *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach*, *10*(3–4), 169–176. https://doi.org/10.3233/PRM-170461

Slogrove, A. L., Schomaker, M., Davies, M. -A., Williams, P., Balkan, S., Ben-Farhat, J., Calles, N., Chokephaibulkit, K., Duff, C., Eboua, T. F., Kekitiinwa-Rukyalekere, A., Maxwell, N., Pinto, J., Seage, G., Teasdale, C. A., Wanless, S., Warszawski, J., Wools-Kaloustian, K., Yotebieng, M., & Leroy, V. (2018). The epidemiology of adolescents living with perinatally acquired HIV: A cross-region global cohort analysis. *PLoS medicine*, *15*(3), e1002514. https://doi.org/10.1371/journal.pmed.1002514

United Nations Children's Fund. (2022). HIV and AIDS in adolescents - UNICEF data. Retrieved from https://data.unicef.org/topic/hivaids/adolescents-young-people/ [19 August. 2022]

Zanoni, B., Archary, M., Sibaya, T., Ramos, T., Donenberg, G., Shahmanesh, M., Celum, C., Pettifor, A., Bekker, L. G., & Haberer, J. (2022). Interventions addressing the adolescent HIV continuum of care in South Africa: A systematic review and modified delphi analysis. *BMJ Open*, *12*(4), e057797. https://doi.org/10.1136/bmjopen-2021-057797

Zanoni, B. C., Sibaya, T., Cairns, C., & Haberer, J. E. (2019). Barriers to retention in care are overcome by adolescent-friendly services for adolescents living with HIV in South Africa: A Qualitative analysis. *AIDS and Behavior*, *23*(4), 957–965. https://doi.org/10.1007/s10461-018-2352-6

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., The ALHIV Team. (2021). In *Adolescents living with HIV in South Africa*. Human Sciences Research Council. (14 August 2022). http://hdl.handle.net/20.500.11910/16404.