ORIGINAL PAPER

Measuring Adolescent HIV Self-management: An Instrument Development Study

Talitha Crowley[1] · **Anita Van der Merwe**[1] · **Martin Kidd**[2] · **Donald Skinner**[3,4]

Abstract

Adolescent HIV self-management is a complex phenomenon that has been poorly researched. A mixed-method explorative sequential research design was used to develop an instrument to measure adolescent HIV self-management in the context of the Western Cape, South Africa. The development and validation was undertaken in four phases: (i) individual interviews and focus groups with adolescents aged 13 to 18, their caregivers and healthcare workers (n = 56); (ii) item identification; (iii) item refinement through cognitive interviewing (n = 11), expert review (n = 11) and pilot testing (n = 33); and (iv) psychometric evaluation (n = 385). The final scale consists of five components with 35 items encompassing the construct of adolescent HIV self-management. The developed scale had acceptable reliability (0.84) and stability (0.76). Factor analysis indicated a good model-fit that support the structural validity (RMSEA = 0.052, p = 0.24; RMR = 0.065; CFI = 0.9). Higher self-management was associated with better HIV-related and general health outcomes, which supports the criterion- and convergent validity of the instrument.

Keywords Adolescents · HIV · Self-management · Instrument development

Introduction

Approximately 2.1 million adolescents between the ages of 10 and 19 were living with the Human Immunodeficiency Virus (HIV) in 2016 worldwide, of which 80% are from sub-Saharan Africa [1, 2]. Adolescents represent a growing proportion of people living with HIV globally, with 30 new infections every hour [2]. The distribution of HIV among adolescents in sub-Saharan is uneven—one in three newly infected young people comes from either Nigeria or South-Africa [3]. South Africa is home to 20% of the global adolescent HIV-infected population [1].

Global care for adolescents living with HIV (ALHIV) lacks in effectiveness, as indicated by the increase in Acquired Immune Deficiency Syndrome (AIDS) related deaths amongst adolescents. AIDS is now the leading cause of death amongst adolescents in Africa [1]. South Africa too, has made insufficient progress to reduce HIV/AIDS mortality among the youth [4].

The clinical outcomes of ALHIV are generally poor, especially in settings with high reported unemployment, poverty, violence and crime [2, 5]. Support structures such as the family and adolescent-friendly health care services may be absent or ineffective [6, 7]. Lost-to-follow-up rates are the highest amongst ALHIV in sub-Saharan Africa [8].

The 'All Into End Adolescent AIDS' agenda was launched in 2015 to better position the global AIDS response to end the AIDS epidemic among adolescents by 2030. One of the aims is to reduce AIDS related deaths amongst adolescents by 65% by 2020 [1] and will require innovative strategies to identify and support adolescents who are taking antiretroviral treatment (ART) to remain in care and to adhere to treatment. Adolescents need assistance to live optimally in their pursuit for social and economic participation despite HIV [9]. It is therefore imperative to have an adolescent-centered approach to treatment and care.

✉ Talitha Crowley
tcrowley@sun.ac.za

1 Department of Nursing and Midwifery, Stellenbosch University, Cape Town, South Africa

2 Centre for Statistical Consultation, Stellenbosch University, Cape Town, South Africa

3 Human Sciences Research Council, Cape Town, South Africa

4 Department of Public Health, Stellenbosch University, Cape Town, South Africa

With the advent of ART, HIV is managed as a chronic condition and self-management is an important component of care [10, 11]. Self-management as a patient-centered approach to care is supported by empirical evidence that confirms improvement in health outcomes of individuals and families who engage in self-management [12]. The individual and family self-management theory (IFSMT) [13] describes self-management as a process through which individuals and families use condition-specific knowledge and beliefs, self-regulation skills, and social facilitation and negotiation to achieve health outcomes. These outcomes can be proximal (self-management behaviors such as taking treatment and managing symptoms) or distal (e.g. health status and health-related quality of life). Certain contextual factors (i.e. the condition, individual, family and environment) influence self-management [13]. Self-management encompass skills, abilities and responsibilities that vary depending on the illness trajectory and the developmental stage of the adolescent [13]. Experts in the field recognize that self-management extends beyond the individual to their socio-cultural environment and the social ecosystem that adolescents are connected to. Risk and/or protective factors in the microsystem (i.e. school family, peers, health system) and macro system (e.g. culture, social norms) may influence self-management [11].

Adolescence is characterized by many physical, cognitive and social changes [8]. Living with a chronic illness such as HIV may alter adolescent development, for example, delaying puberty, impairing neurocognitive development, prompting behavioral problems and hindering identity-formation or socialization [3, 8]. Important to note is the increased role peers and social networks play in the lives of adolescents [8].

Management of adolescents living with HIV is complicated by several challenges such as motivating despondent adolescences to adhere to lifelong treatment and encouraging them to stay positive while managing complications from HIV [9, 14]. Adolescents, especially those infected perinatally, need to transition from being dependent on adults for their care, to becoming more self-reliant in adult or mixed care settings where no specialized care for their age group is available [15]. This transition combines with their own developmental pursuit of identity formation and independence, and involves a large amount of daily work by adolescents and families to cope with stressors and adaptive tasks imposed by the chronic condition. Chronic disease often adversely affects social participation and health-related quality of life of adolescents [16]. Studies exploring how growing up with a chronic disease affects the lives of adolescents are still scarce.

Self-management as a construct is poorly researched amongst ALHIV. On the other hand, there is a plethora of research focusing on treatment adherence. Contrary to adherence, self-management is a broader concept that does not only focus on medical management, but includes emotional and role management [17]. Engagement of the individual in their own care and collaborative decision-making are important, opposed to the mere adherence to medical instructions [12]. However, self-management may impact health outcomes through adherence [11]. Research on self-management interventions for young people living with chronic conditions has also focused predominantly on medical management, neglecting the psychosocial aspects [17]. Self-management interventions for people living with HIV has not been a research priority in sub-Saharan Africa and there is little evidence to inform such [18]. Evidence from high-income countries may not be transferrable to the sub-Saharan African context due to the differences in burden of disease and available resources [18].

In order to assess the components of adolescent HIV self-management, we require meaningful quality measurements. Instruments to assess self-management have been developed for use in adults living with HIV [19, 20] and for adolescents with chronic diseases such as diabetes [21] and spina bifida [10]. No instrument that assesses adolescent HIV self-management and its components, especially in low resource settings within a socio-cultural complex environment as in South Africa, could be found. Until now there has been no inductively designed and psychometrically-tested instrument to measure HIV self-management in adolescents. A valid and reliable instrument to assess adolescent HIV self-management can be useful as a clinical management tool to identify adolescents' self-management needs, and measure the effectiveness of adolescent self-management support interventions in high HIV prevalence settings.

Objective

This article describes the development of an instrument to measure adolescent HIV self-management in the context of the Western Cape, South Africa.

Method

Design

A mixed method multiphase (exploratory sequential) design and established scale development methods were used [22–25]. Figure 1 describes the development of the Adolescent HIV Self-Management (AdHIVSM) scale.
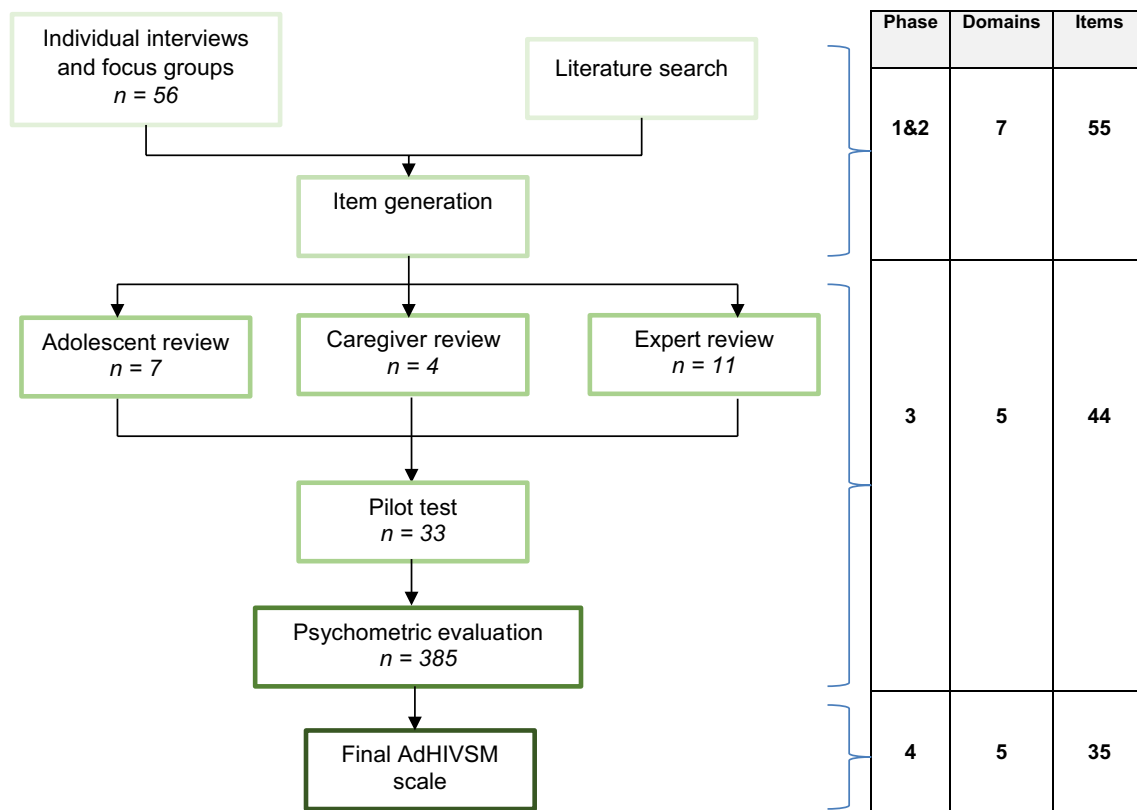
Phase	Domains	Items
1&2	7	55
3	5	44
4	5	35

Fig. 1 Development of the adolescent HIV self-management scale

Participants' Eligibility Criteria

Participants included ALHIV, caregivers, healthcare workers and experts. Adolescents had to be between the ages of 13 and 18, attending an ART clinic and aware of their HIV status. Caregivers and healthcare workers needed to have at least one-year experience in assisting or attending to the adolescent. Experts were chosen based on their area of expertise.

Recruitment

Purposive sampling was used to recruit participants of different genders, language and age groups for qualitative interviews and focus groups. For item refinement, sampling of adolescents and caregivers was convenient—based on their availability to attend a workshop. Experts were purposefully selected based on their experience in adolescent HIV management, school nursing, adolescent psychiatry, psychometrics and self-management. The experts included international and local clinical practitioners and academics. For the cross-sectional study (psychometric evaluation), participants were recruited from 11 healthcare facilities in the Cape Metropole of the Western

Cape, South Africa. Participants were recruited serially over a period of 5 months and completed questionnaires at routine clinic appointments.

Data Collection

Phase 1: Qualitative Interviews and Focus Groups

In the first study phase, self-management was conceptualized, and processes and behaviors underlying these variables were identified and described [26]. This was achieved through individual interviews with adolescents (n = 6), caregivers (n = 6) and healthcare workers (n = 6) and five focus groups with adolescents (n = 38) (Total n = 56). Interviews and focus groups that were conducted by the researcher and an assistant using a semi-structured interview guide were audio recorded and transcribed verbatim. Interpretive phenomenology was used to identify self-management constructs from the narratives and are described in detail elsewhere [27].

Phase 2: Item Generation

The qualitative findings and the literature were used to provide an initial framework for the conceptual domains and

items. The researcher constructed items based on the participants' narratives, the literature, theoretical framework (the IFSMT) and established self-management instruments, while taking into account general guidelines for item writing [25, 28]. There were 55 items in the list across seven domains (Fig. 1).

Phase 3: Item Refinement

Items were refined through cognitive interviewing with 7 adolescents and 4 caregivers who had participated in the first study phase. Following this, a group of 11 experts reviewed the items. The purpose was to ascertain item validity, contextual and developmental appropriateness and item clarity.

During the workshop with adolescents and caregivers, an additional 10 items were added to the list as participants identified that some questions needed to be separate items; several items were refined. There were 65 items after the feedback of the adolescents and caregivers was carefully considered.

Questionnaires were emailed electronically to experts and 11 out of 12 participants responded with feedback. A content validity index was calculated for each of the 65 items. The content validity index for individual items (I-CVI) is the proportion of experts who gave a rating of 3 = relevant or 4 = very relevant to an item. It was decided that the minimum acceptable index would be 0.8 [29]. The S-CVI is defined as the proportion of total items judged content-valid and is calculated by averaging the I-CVI value since it focuses on the average item quality. The average content validity index (S-CVI/Ave) of the scale was 0.94 (acceptable value 0.9) therefore confirming the content validity of the initial 65 items. However, based on the item content validity and clarity indexes [29] and qualitative feedback, 21 items were removed and a number refined resulting in a final list of 44 items (Fig. 1). The wording of the options for the four-point Likert scale used for measurement was also revised slightly. The developed

questionnaire (AdHIVSM) and the other measures (see Table 1) were then translated into the three local languages and piloted with a representative sample of 33 conveniently selected adolescents who met the study inclusion criteria. Only minor changes were made to the questionnaire following the pilot study.

Phase 4: Psychometric Evaluation of Items

The self-management items (AdHIVSM) and other measures were administered to a sample of 385 HIV-positive adolescents. In total, 467 adolescents were approached; 385 of them completed questionnaires; 42 refused to do so or were in a hurry and 27 were not eligible (for example not informed about their HIV status; uncertain why they were taking treatment; and some whose parents considered the child as 'slow' and not able to comprehend questions). There were four instances when the parental/guardian consent could not be obtained and 10 did not complete the questionnaire. Adolescents who attended the clinic for a second time (n = 63) during the data collection period were approached to complete the questionnaire again to assess stability/test–retest reliability.

Measures

In addition to the developed AdHIVSM items and biographical data, other measurement instruments with known reliability and validity were included to test the validity of the developed instrument. The measures were chosen based on the components of the IFSMT [13]. Permission was obtained to use, adapt if necessary and translate the measures. These measures are depicted in Table 1. The latest viral load documented in the participant's folder was recorded. Participants were considered to be virally suppressed if their viral load was below 400 copies/ml blood.

Table 1 Measures used in the questionnaire based on the components of the Individual and Family Self-Management Theory (IFSMT)

Context	Process	Proximal outcomes	Distal outcomes
Biographical data: individual, family and condition-specific factors Symptoms [30] Medications Healthcare provider and general satisfaction with healthcare Stressful life events (SLE) [31] Strengths and difficulties (SDQ) [32] Stigma (HSSC-8) [33]	AdHIVSM (processes) HIV treatment self-efficacy (HIV-ASES) [34] Resilience (CYRM-12) [35]	AdHIVSM (behaviours) Treatment adherence [36, 37] Sexual behaviour and substance use [38] Clinic attendance record	Health-related quality of life (KIDSCREEN-27) [39] Viral load

SLE stressful life events, *SDQ* strengths and difficulties questionnaire, *HSSC* HIV stigma scale for children, *AdHIVSM* adolescent HIV self-management (the developed measure), *HIV-ASES* HIV treatment self-efficacy, *CRYM* child and youth resilience measure

Data Analysis

Phase 4 data were entered directly into Statistical Package for Social Sciences (SPSS) version 25 for Windows [40] and cleaned before any analyses were conducted. A random selection of 10% of questionnaires entered were checked against the original questionnaires for correctness. Where problems were identified (e.g. incorrect data capturing of isiXhosa item responses), targeted checks of other questionnaires were performed.

Descriptive statistics of all variables and reliability analysis of established scales were performed. Analysis of the developed AdHIVSM scale included basic item analysis and factor analysis [29]. Item performance involved the scoring of each item, item-scale correlations, item-variances and item-means [25]. First, Confirmatory Factor Analysis (CFA) was performed using covariance-based structural equation modelling (CB-CEM) and Robust Maximum Likelihood (RML) estimation in LISREL 8.8 [41] to establish the model-fit with the pre-established framework. CFA results did not indicate a good model-fit to the theoretical structure and therefore exploratory factor analysis (EFA) was performed to further explore the factor structure. Exploratory factor analysis (EFA) was performed using Principal Component Analysis (PCA) [25, 42].

Total missing data for the AdHIVSM scale ranged from 0 to 11 (2.9%) for most of the items. Missing value patterns identified higher missing values for the items that applied to participants taking ART only and those who were sexually active. In order to conduct EFA, missing values were managed by selecting 'pairwise' deletion in SPSS. Imputation was used to replace missing values before CB-SEM was performed.

The suitability of the data for factor analysis was assessed and revealed the presence of correlation coefficients of 0.3 or more in the correlation matrix. The Kaiser-Mayer Olkin (KMO) value was 0.794, exceeding the recommended value. The Bartlett's Test of Sphericity was statistically significant ($p < 0.001$) which indicated patterned relationships between the items and supported the factorability of the correlation matrix [42].

Factors were retained based on Kaiser's criterion and Catell's scree test [42]. MonteCarlo PCA for parallel analysis [43] was used to generate a set of random eigenvalues that was compared with the corresponding criterion values. CFA was again performed on the final structure. For CFA, the indices used were the model Chi square test, Root mean square error of approximation (RMSEA), the adjusted goodness-of-fit statistic (AGFI) and the Root mean square residual (RMR)0 [44]. Coefficient alpha was performed for the total scale and sub-scales to test reliability.

The instrument was scored by summing responses for each item and dividing the total by the number of items within each sub-scale. This allowed for comparison between components of adolescent HIV self-management, with higher scores reflecting higher levels of reported self-management. Correlations between the subscales of the instrument was performed by computing a reliability coefficient. Test–retest reliability for the total scale and sub-scales was assessed using Pearson product moment correlation and the Intraclass correlation coefficient (ICC).

In order to test the validity hypotheses (see Table 2), the individual scores of *Symptoms*, *Barriers to adherence*, *Treatment self-efficacy*, *Stressful life events*, *Health-related quality of life*, *Total difficulties*, *Total strengths* and *HIV stigma* were correlated with the AdHIVSM-35 and sub-scales.

Table 2 Validity tests

Type of validity	Explanation of how it was ensured/tested
Content validity	Developed items from qualitative data and the literature; involved the target population in item development; determined content validity using the I-CVI and S-CVI
Structural validity	Confirmatory and exploratory factor analysis on the developed AdHIVSM scale
Criterion-related validity: concurrent validity	Tested whether the developed AdHIVSM measure negatively correlated with the viral load log value; tested for the difference in mean AdHIVSM scores between participants who were virologically suppressed versus not suppressed
	Tested if the developed AdHIVSM measure negatively correlated with *Barriers to adherence*; tested for the mean difference in AdHIVSM scores between participants who were adherent versus non-adherent
Construct validity: convergent validity	Tested for a positive correlation between AdHIVSM and *Treatment self-efficacy*, *Resilience*, *Health-related quality of life* and behavioural and emotional *Strengths*
	Tested for a negative correlation between AdHIVSM and *Stressful Life Events*, *HIV stigma*, and behavioural and emotional *Difficulties*
Construct validity: known groups validity	Tested for the difference in mean AdHIVSM scores between participants with behavioural and emotional *Difficulties* classified as "normal", "borderline", and "abnormal"
	Tested for the difference in mean AdHIVSM scores between participants demonstrating low versus high risk behaviour (e.g. alcohol use and sexual behaviour)

Pearson product moment correlations were used to measure the linear dependence between variables since AdHIVSM-35 scores were normally distributed. Appropriate statistical tests, such as the independent t test or one-way analysis of variance (ANOVA), were used to determine the relationships between self-management and viral suppression, adherence, risk behaviors, background, disease, treatment and health-care context variables.

Results

Biographical Data and Medical Characteristics

The sample included 58.2% (n = 224) females (sex documented at birth); 58.7% saw themselves as female, 40.3% as male and 1% choose not to say; none of the participants selected the transgender category. Most of the participants (77.1%; n = 296) were isiXhosa-speaking. The median age was 15 and the interquartile range (IQR) 14-16. Although most of the participants were in school, more than a third (n = 138, 36.2%) had not completed the appropriate grade for their age. Participants most frequently reported residing with their biological mother (n = 151, 39.4%). Regarding residence, 64.2% (n = 246) of adolescents were living with one or both parents and 22.2% (n = 85) had no contact with their biological parents. Half of the participants (n = 192, 50.1%) thought they were infected with HIV at birth and many (n = 159, 42.4%) reported that they found out about their status between the ages of 6 and 10. The majority of adolescents thought they were infected with HIV through mother-to-child transmission (n = 282, 73.2%), which is slightly higher than the number who reported being diagnosed with HIV before the age of 12 (n = 258, 63.3%). This indicates that some perinatally-infected participants may have been diagnosed/disclosed to after the age of 12. From the responses, it was clear that many participants were uncertain how they were infected, since they selected more than one option and 94 (24.4%) indicated that they did not know. Responses to the questions about when they were diagnosed, how they were infected, how long they have been on ART and their risk behaviors were used to establish the most plausible route of infection. The majority of adolescents (n = 344, 89.4%) appeared to have been infected either perinatally or early in life, for example, through breastfeeding.

The highest reported symptoms that were considered problematic to the participants (bothered them a little or a lot) were headaches (n = 180, 47.8%), skin problems (n = 164, 43.0%), and forgetfulness (n = 161, 42.4%). Dizziness or light-headedness were also frequently reported (n = 167, 43.9%). Since most of the adolescents were on treatment and were generally healthy, the symptoms,

especially skin problems, could be related to physiological and hormonal changes of adolescence and not attributed to HIV. Some symptoms mentioned, for example, headaches and dizziness were reported by adolescents as side-effects in the qualitative phase of the study. Further, forgetfulness (to take treatment) was frequently mentioned by caregivers and healthcare workers as a major challenge.

Almost a third of participants were on ART for more than 10 years and most (236, 62.8%) reported taking tablets once daily. When asked how many times they missed a dose in the last week, only 190 (51.4%) participants reported not missing a dose within the last week.

Item Analysis

There were no items with extreme values or variances close to zero (Table 3). The item on sexual behavior was excluded from analysis since it was responded to by only 120 (31.2%) of the participants (those who reported to be sexually active). It may however still be an important item to include in future studies. Four (4) items had item-scale correlations below 0.2, but were retained for factor analysis since they seemed to be important items [29]. Three of these items were the reverse scored items. Negative items appear to be a difficult cognitive task for younger participants since they may have been confused by reversing polarities [29].

Factor Analysis

The results of the initial CFA indicated that the model-fit to the conceptual framework was not optimal. The Chi square was $X^2(850) = 2175.12$ (p < 0.001) and the RMSEA for the hypothesized model was 0.065 (90% CI 0.062, 0.068), p < 0.05. The Comparative Fit Index (CFI) was 0.80, the Goodness of Fit Index (GFI) was 0.79 and the adjusted goodness of fit index (AGFI) = 0.76.

With the EFA, the Scree Plot suggested retaining five factors whereas parallel analysis indicated that six factors should be retained. When imposing a six-factor solution with orthogonal (Varimax) rotation, some components had few items with low internal consistency. Following an iterative process of imposing a four, five and six factor solution, and a discussion with the study supervisors and statistician, a five-factor solution was decided upon, since it yielded the best internal consistency of the sub-scales and was the most meaningful. This five-factor solution explained 34.5% of the total variance of the AdHIVSM measure.

The identified component structure could be interpreted meaningfully using the study theoretical framework confirming face validity. Items with a factor-loading above 0.2 were considered to load on a factor. Four items did not load meaningfully on any factor or did not make theoretical sense and were therefore subsequently removed. An additional four

Table 3 EFA descriptive statistics and item factor loadings

	Item	Description	Mean (SD)	1	2	3	4	5	Communalities
				Rotated Component Matrix					**Communalities**
1. Believing and knowing	6	My faith helps me to stay positive about myself and my future.	3.64 (0.63)	**0.654**	0.108	0.110	0-.068	-0.092	0.465
	7	I am confident I can take care of my health.	3.62 (0.66)	**0.623**	0.132	0.095	-0.027	-0.189	0.451
	5	I can achieve as much as other people who don't have HIV.	3.52 (0.78)	**0.614**	0.020	0.037	0.003	0.067	0.384
	3	I know the date of my next hospital or clinic appointment.	3.55 (0.75)	**0.591**	0.081	0.080	-0.055	0.029	0.366
	34	I know at what times I should take my ARVs.	3.70 (0.56)	**0.544**	0.334	-0.073	0.060	0.153	0.440
	2	I can get information about HIV.	3.46 (0.74)	**0.543**	0.108	0.081	0.055	-0.013	0.316
	36	I understand what will happen if I don't take my ARVs every day.	3.49 (0.81)	**0.515**	0.253	0.052	0.155	0.167	0.384
	32	I understand why I am taking ARVs.	3.60 (0.72)	**0.455**	0.225	-0.026	0.153	0.193	0.319
	9	I would tell my parents or teacher if I were being bullied (physically or verbally) and it felt out of my control.	3.19 (0.94)	**0.386**	0.091	0.110	0.115	0.115	0.196
	4	I know how to contact the doctor or nurse if I need to.	3.11 (0.92)	**0.332**	-0.063	**0.381**	0.135	-0.180	0.310
2. Goals and facilitation	17	I feel confident that I can meet my health and life goals.	3.61 (0.76)	0.227	**0.606**	0.119	0.092	-0.106	0.453
	26	My family support me to live with HIV.	3.59 (0.86)	0.017	**0.599**	0.041	0.087	0.030	0.369
	16	I aim to be successful (for example, finishing school, studying further or getting a job).	3.75 (0.62)	0.285	**0.583**	0.020	-0.096	-0.041	0.432
	27	Doctors, nurses and counsellors at the clinic support me to live with HIV.	3.58 (0.81)	0.138	**0.547**	0.159	0.046	0.215	0.392
	15	I aim to enjoy life, feel good and have fun.	3.58 (0.76)	0.128	**0.473**	0.190	-0.006	0.121	0.291
	12	Doing things I like (for example, listening to music, reading or playing sport) helps me to cope.	3.48 (0.86)	0.208	**0.456**	0.001	-0.049	0.098	0.263
	28	Other adolescents at the clinic (for example, in my support group or club) support me to live with HIV.	3.13 (1.12)	0.021	**0.434**	0.258	0.179	0.084	0.294
	13	Things like eating junk food, smoking cigarettes, drinking alcohol or taking drugs help me to cope.	3.56 (0.91)	0.038	**0.426**	-0.124	-0.179	-0.441	0.430
	14	I aim to independent (taking care of myself).	3.35 (1.0)	0.032	**0.250**	0.235	-0.161	**0.323**	0.249
3. Participation	21	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).	2.86 (1.14)	0.081	0.084	**0.639**	0.079	0.068	0.433
	24	I tell the doctor or nurse when I miss a dose of my ARVs.	2.55 (1.22)	0.054	0.033	**0.572**	0.059	0.184	0.368
	22	I ask the doctor or nurse questions when there is anything that I don't understand.	3.10 (1.03)	0.020	0.214	**0.544**	0.020	0.057	0.346

Table 3 (continued)

	#	Item	Mean (SD)						
	31	I would find help in my community if I needed it (for example, a social worker if I had problems at home or at school).	2.86 (1.14)	-0.012	0.183	**0.542**	0.120	-0.056	0.345
	25	I tell the doctor or nurse about private things (for example, If I am having sex or using drugs or alcohol).	2.14 (1.25)	0.081	-0.081	**0.524**	0.063	0.275	0.368
	23	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).	3.09 (1.04)	0.101	0.307	**0.386**	0.184	0.180	0.320
	18	I do things to improve my health (for example, by exercising or eating healthy foods).	3.41 (0.83)	0.081	0.332	**0.384**	0.068	-0.117	0.282
	19	I attend clinic appointments on my own.	2.87 (1.21)	0.231	-0.145	**0.367**	-0.105	0.151	0.243
	30	I participate in activities at school or in my community.	2.96 (1.12)	0.117	0.307	**0.366**	0.077	-0.035	0.249
	29	I have regular contact with friends (for example, at school or in my community).	3.0 (1.16)	-0.023	0.235	**0.332**	0.039	0.118	0.182
	20	I attend clinic appointments on scheduled dates (for example, I use a calendar, phone or my clinic card to remind myself).	3.44 (0.89)	0.155	0.294	**0.288**	-0.037	-0.011	0.195
4. HIV Biomedical management	38	I know what my viral load should be.	2.69 (1.08)	0.045	-0.017	0.102	**0.807**	-0.020	0.665
	37	I know what my viral load is.	2.53 (1.03)	0.070	-0.004	0.201	**0.742**	-0.111	0.608
	33	I know the names of my ARVs.	2.73 (0.98)	0.198	0.053	0.064	**0.520**	0.045	0.319
	42	I aim to understand why my viral load is high or low.	2.81 (1.12)	-0.053	0.120	-0.002	**0.476**	0.304	0.336
	35	I know what to do when I miss the time to take my ARVs.	3.20 (0.89)	0.428	0.059	0.148	**0.322**	0.117	0.325
	39	I rely on other people to remind me to take my ARVs.	2.88 (1.15)	0.275	-0.098	0.005	-0.326	-0.286	0.273
	40	Other things interfere with my plans to take my ARVs (for example, when I go to a party or sleepover or when I do drugs).	3.30 (0.98)	0.064	0.221	-0.110	-0.063	-0.441	0.301
	1	I know the signs and symptoms of my illness (HIV) (for example, when I am sick or have side-effects from my ARVs).	3.04 (0.85)	0.252	-0.169	0.207	0.270	0.244	0.268
5. Coping and self-regulation	11	I can cope with it if people say nasty or hurtful things about people living with HIV.	2.36 (1.16)	0.065	0.134	0.077	0.102	**0.541**	0.331
	10	I decide by myself whom I want to tell about my HIV status.	2.69 (1.24)	0.216	0.172	0.082	-0.092	**0.528**	0.370
	43	I take my ARVs even when I don't want to (for example, when I feel depressed or am tired of taking them).	3.11 (1.18)	0.113	0.306	-0.020	0.045	**0.507**	0.366
	41	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).	3.04 (1.08)	-0.081	0.373	0.182	-0.006	**0.354**	0.304
	8	I would cope if I tell someone about my HIV status and that person didn't accept it or ignored me.	2.56 (1.08)	0.158	-0.099	**0.283**	0.165	**0.290**	0.226

The shades in the Table highlights the different components identified; items not highlighted were not included in the final sub-scales

items lowered the internal consistency reliability of the identified sub-scales and were consequently deleted. The rotated component matrix with retained and un-retained items are shown in Table 3. The final AdHIVSM scale had 35 items.

Component 1

The component *Believing and knowing* included items from both the Knowing and understanding and Believing and valuing constructs identified in the qualitative phases and original framework. Items related to beliefs loaded stronger on this component and therefore 'Believing' was placed first.

Component 2

Goals and facilitation encompassed items related to self-regulation (including goals) and social facilitation. Item 14 "I aim to be independent" loaded stronger on component 5, but it was decided that it fitted better with component 2.

Component 3

Participation included items categorized in phases 1–3 as self-management behaviors or social facilitation that focused on participation in care, communication with healthcare workers and participation in the community. This component could possibly also be called 'active participation/activation'. Item 20 "I attend clinic appointments on scheduled dates" loaded stronger on component 1, but it was decided to group this under this component since it fitted better theoretically.

Component 4

This component, named *HIV biomedical management* was not categorized separately in the previous study phases. Items in this category specifically focus on managing the disease such as knowledge of one's viral load and the names of antiretroviral drugs (ARVs). The reason why this component was separated from the other knowledge items during phase 4 may be because the disease-specific knowledge for biomedical management such as knowledge of one's viral load is different from the knowledge necessary for daily living with HIV. Knowledge necessary for daily living includes the times tablets should be taken and a general understanding for why treatment need to be taken.

Component 5

Coping and self-regulation includes items specific to coping with HIV stigma and taking treatment even when one does not feel like it and planning to take treatment when not at home. Item 41 "I plan how to take my ARVs…" loaded

stronger on component 1, but it was decided that it was a better fit with this component.

Model Fit

CFA was performed on the new structure of AdHIVSM-35. The results indicated an acceptable model-fit: $X^2(550) = 1096.63$ (p < 0.001); RMSEA = 0.052 (90% CI 0.047, 0.056), p = 0.24; RMR = 0.065; CFI = 0.9 and AGFI = 0.84. RMSEA had a value below 0.06, with a non-significant p value that indicates model-fit and the RMR was below 0.07. However, the goodness of fit indexes should preferably be above 0.95 [44].

Inter-correlations between the sub-scales ranged from r = 0.16 to r = 0.6. *HIV biomedical management* had the lowest correlations with the other sub-scales. The *Participation* sub-scale had positive correlations with all of the sub-scales between 0.35 and 0.6, which supported the theoretical framework, since this sub-scale contained several items that can be considered to be self-management behaviors/proximal self-management outcomes. The final structure identified requires further testing on a separate sample of the target population to confirm its structural validity since CFA was performed on the same sample as EFA.

Validity Testing

Criterion-related and construct validity were assessed using hypotheses derived from the theoretical framework of the study. Pearson correlation coefficient was performed to compare the developed AdHIVSM measure with other continuous variables. From Table 4 it can be seen that the developed AdHIVSM-35 measure and sub-scales had several significant correlations in the hypothesized directions, supporting its validity.

To further test criterion validity, independent t-tests were performed to compare the mean AdHIVSM-35 scores of participants with suppressed and unsuppressed viral loads as well as those who were adherent versus those who reported non-adherence. For adherence, the two Likert scale items assessing missed doses were recoded into adherent versus non-adherent. Non-adherence meant that a participant did not take 100% of their doses whilst adherence meant that a participant was reported to never have missed a dose of treatment. Participants who were virologically suppressed (VL ≤ 400 copies/ml) (t(305) = 2.618; p < 0.01) and adherent (t(336) = 4.435; p < 0.001) had significantly higher self-management scores. For virological suppression, the effect size (Eta squared = 0.022) was small and for adherence (Eta squared = 0.055) it could be considered moderate.

In order to test for a known group's validity, independent t-tests were performed to compare the mean AdHIVSM-35 scores across categories of low versus high risk behaviors.

Table 4 Validity values of the developed AdHIVSM measure: Pearson correlations

| | Criterion-related validity (concurrent validity) | | Hypothesis-testing construct validity (convergent validity) | | | | | | | |
	Barriers to adherence	Viral load log value	Treatment self-efficacy	Resilience	Health-related quality of life	Total strengths	Stressful life events	Total difficulties	Symptoms	HIV stigma (negative self-image)
AdHIVSM-35	− 0.249**	− 0.137*	0.220**	0.369**	0.450**	0.274**	− 0.05	− 0.104	− 0.141*	− 0.181**
Sub-scale 1: believing and knowing	− 0.308**	− 0.129*	0.261**	0.336**	0.269**	0.187*	− 0.153*	− 0.122*	− 0.111*	− 0.263**
Sub-scale 2: goals and facilitation	− 0.164**	− 0.126*	0.225**	0.398**	0.437**	0.290**	− 0.136**	− 0.155**	− 0.077	− 0.220**
Sub-scale 3: Participation	− 0.170**	− 0.040	0.095	0.289**	0.375**	0.240**	− 0.029	− 0.122*	− 0.106*	− 0.076
Sub-scale 4: HIV biomedical management	− 0.138*	− 0.034	0.073	0.107*	0.127*	0.661	0.046	0.033	− 0.141**	− 0.090
Sub-scale 5: coping and self-regulation	− 0.112*	− 0.079	0.094	0.164**	0.248**	0.191*	0.054	0.005	− 0.015	− 0.071

*p value significant at 0.05 level (2-tailed)

**p value significant at 0.01 level (2-tailed)

Risk behaviors were recoded to display low-risk versus high-risk. Responses such as "I can't remember" and "Not applicable" were excluded from the analysis. High risk groups had lower self-management scores, but the mean difference between the groups were not significant, except for consistent condom use ($t(95) = 1.947$; $p = 0.05$)–but with a small effect size (Eta squared = 0.038).

Reliability Testing

Reliability testing was performed on the sub-scales of the AdHIVSM-35 and the total AdHIVSM-35 following factor analysis. The internal consistency and test–retest reliability of the total 35-item scale and sub-scales are depicted in Table 5.

The AdHIVSM-35 had very good internal consistency reliability that was above 0.8. The reliability of sub-scales 1 to 3 was respectable, sub-scale 4 minimally acceptable and sub-scale 5 unacceptable [25]. It might be that adolescents found the components in sub-scale 4 and 5 more challenging, therefore there was more variability within the sub-scale. It had to be kept in mind that the reliability values were inflated as a result of using the same data as the EFA and might be lower in a subsequent sample.

Discussion

The article presents the development of the first instrument to measure adolescent HIV self-management. The science of self-management is still in a beginning stage [45], making this work important to inform further research on self-management and tailored interventions for ALHIV, especially in the African and sub-Saharan African context [18]. Patient empowerment, caregiver, family and peer involvement have been identified as potentially relevant components of self-management in the African context [18] and are supported by the findings of this study. The instrument includes all the theoretical components of self-management, resulting in a comprehensive self-management measuring tool that, contrary to other research [17], extends beyond medical management. The instrument development procedures followed ensured that the tool is contextually relevant, focused on patient needs and allowed for important mixed-method meta-inferences. This study has shown that the concepts of the IFSMT [13] are applicable in a South African context with an adolescent HIV-infected population group, increasing the parsimony of the theory. Findings support the notion that self-management programs may have a positive effect on physical, psychological, knowledge and behavioral outcomes of ALHIV [12].

Components of the AdHIVSM-35 consist of processes/behaviors such as Believing and knowing; Goals and facilitation; Participation; HIV biomedical management; and Coping and self-regulation. These components also resonate with other literature and will be discussed briefly.

Believing and knowing concerns adolescents' beliefs and knowledge about their illness and is similar to the disease-specific knowledge and beliefs component of the IFSMT [13]. Schulman-Green et al. [46], in their self-management framework that was based on a meta-synthesis of studies, refer to a concept they name "illness needs" that involves aspects such as learning and taking ownership of health needs. Personal belief in a positive future is an important motivator for treatment adherence and self-management [11, 47]. The *Believing and knowing* sub-scale had the highest positive correlations with the *Family and Free Time* and the *School and Learning* sub-scales of the Health-related

Table 5 Reliability of the developed AdHIVSM measure

	n	Cronbach's alpha	Test–retest Pearson correlation coefficient	Intraclass correlation coefficient[a]	n	p value
Original 43 item scale	333	0.831	0.674	0.781	54	< 0.001
Final AdHIVSM-35 item scale (Total sample)	340	0.839	0.635	0.757	55	< 0.001
Age group 13–15	191	0.838	0.714	0.817	25	< 0.001
Age group 16–18	149	0.843	0.553	0.692	30	< 0.01
Questionnaire language—Xhosa	111	0.849	0.818	0.801	9	< 0.05
Questionnaire language—Afrikaans	35	0.841	0.801	0.862	9	< 0.05
Questionnaire language—English	194	0.834	0.609	0.737	37	< 0.001
Sub-scale 1: believing and knowing (8 items)	369	0.761	0.458	0.612	60	< 0.001
Sub-scale 2: goals and facilitation (8 items)	378	0.708	0.611	0.750	62	< 0.001
Sub-scale 3: participation (10 items)	372	0.715	0.439	0.590	58	0.001
Sub-scale 4: HIV biomedical management (4 items)	374	0.651	0.283	0.427	60	< 0.05
Sub-scale 5: coping and self-regulation (5 items)	360	0.547	0.567	0.727	61	< 0.001

[a] *ICC:* two way mixed—absolute agreement

quality of life (HRQOL) scale, which may mean that beliefs and knowledge are not only influenced by the family but also by the school context. Schools are a resource that can foster resilience [48], although they may not be a good support resource due to HIV stigma [49]. Higher scores for the *Believing and knowing* sub-scale were also associated with knowing by which route one was infected, taking fewer tablets and a lower frequency of taking doses of treatment. Participants who were more satisfied with healthcare services were also more likely to have higher *Believing and knowing* levels. Less complicated regimens and positive interactions with healthcare workers have been identified as factors facilitating self-management [46, 50].

Goals and facilitation include aspects of internal and external motivation to take care of one's health. Social facilitation includes social influence, emotional-, informational- and instrumental support and negotiated collaboration [13] and enhances the capacity of the individual to change. It may be that the meaningful interactions with significant role players or the feeling that one is supported, enables adolescents to become motivated internally and have positive life goals. The strong positive correlations of this sub-scale with *Resilience* and total S*trengths* may mean that resources for resilience and resources for self-management co-vary or are similar in nature. Supportive family relations enable adaptation in the context of HIV/AIDS [48]. Adolescents with more emotional and behavioral *Strengths* and fewer *Difficulties* had higher *Goals and facilitation* scores in this study. Behavioral and emotional problems negatively affect self-management [11].

Participation means deliberate action to participate in one's healthcare and in life and relate to self-management behaviors such as managing various aspects of your disease. In this study, it does not include treatment-taking or disclosure, but focuses on participating and communicating in the healthcare context and in the community. It is similar to the concepts of "activated" or "informed, motivated and prepared patients and families" [51]. Patients need to access medications, self-monitoring tools, and acquire self-management skills within the triad of the individual/family, the healthcare system and the community context [51]. Productive interactions between prepared proactive healthcare providers and activated patients produce good clinical outcomes [51]. Schulman-Green et al. [46] refers to processes such as utilizing the healthcare system and obtaining social/community support as "activating resources". Active participation in decision-making improves the self-confidence of adolescents [52]. *Participation* correlated the strongest with *HRQOL*, particularly the *Physical Activities and Health* sub-scale which may mean that participation could be related to adolescents' feelings of general well-being and particularly their energy-levels. Variables such as mood, fatigue level, convenience and boredom influence to what extent

self-management 'work' is executed [53]. Further, adolescents who felt they were treated with respect by healthcare providers and were satisfied with services had higher levels of *Participation* that supports the notion that there is a positive interaction between an activated patient and a prepared proactive healthcare provider [51]. Interestingly, *Participation* was not associated with adherence or viral suppression. This may mean that an actively participating adolescent may not necessarily be an adherent one, as was discovered by Van Staa [16] in her investigation in the Netherlands of the competencies of adolescents with chronic illnesses. She discovered that the self-confident and autonomous adolescent, who appeared very capable of self-management and independent participation in consultations, might also consciously decide to be non-adherent since they felt that enjoying life and participating in normal activities were more important than adhering to treatment [16].

HIV biomedical management relates to aspects specific to HIV care, which based on the qualitative data in phase 1, was generally viewed by most adolescents to be the domain of the doctor or nurse. This component was identified for the first time as being separate from the other disease-specific knowledge items in the fourth phase of the study. In both the qualitative and quantitative study phases, it was identified that very few adolescents had knowledge of their viral load or what it should be. A United States study also found that few adolescents knew their viral load or CD4 count and that discussions with the healthcare provider about CD4 and viral load were associated with higher HIV knowledge [54]. Participants who reported complete adherence (stating that they never skipped doses on the first Likert scale item), had significantly higher scores on this sub-scale ($t(269) = 2.128$; $p < 0.05$), but there were no differences observed in the other adherence questions or for viral suppression. This may mean that knowledge about biomarkers minimally influences adherence behaviors or that those adolescents who were not virologically suppressed may have more knowledge of these biomarkers due to undergoing intensified adherence counselling [55].

Coping and self-regulation includes being in control, recognizing illness and the need for further consultation, making independent decisions regarding your health and collaborating with others. Self-regulation includes decision-making, planning, goal-setting and self-evaluation. Items in this sub-scale were specifically directed at coping with HIV stigma and self-regulating more complex aspects of healthcare and living such as disclosure and dealing with negative emotions. The abovementioned issues have been identified as known challenges of living with HIV [49, 56]. "Living with a chronic illness", for example, coping, readjusting and integrating, is included in the components of the self-management framework identified by Schulman-Green et al. [46]. The ICC was high at 0.727, which may mean that

it is a more stable component of self-management and that adolescents' coping and self-regulation skills are unlikely to change unless these skills are taught to them. Their individual skills for *Coping and self-regulation* may be at different levels and dependent on the specific task. Adolescents may therefore have good self-management in one aspect, for example, planning to take their treatment when not at home, but have difficulty coping with HIV stigma or vice versa. A significant negative correlation was identified between this sub-scale and the HIV stigma sub-scale *Disclosure concerns* ($r = -0.152$, $p < 0.01$). Further, the *Coping and self-regulation* sub-scale positively correlated with the *Friends* sub-scale of the HRQOL scale ($r = 0.207$, $p < 0.001$). This may mean that quality friendships have a positive influence on adolescents coping and self-regulation skills. Skills and healthy behaviors should be taught/established during early adolescence before unhealthy or risk behaviors commence [57].

The total AdHIVSM-35 did not differentiate between participants of different genders or home languages. It was expected that older adolescents would demonstrate higher self-management, but the results showed no differences between the young adolescents (13–15) and the older adolescents (16–18). A reason for this could be that the young adolescents tend to answer questions without truly evaluating what the question required and that older adolescents perhaps have more self-knowledge or insight to respond accurately. This was demonstrated during the cognitive questioning performed in the focus groups in the third study phase and also reported elsewhere [58]. Another explanation could be the individual differences between adolescents. Adolescence is a phase where individual differences among peers of the same age are noticeable, which may be further influenced by the variable effect of HIV on development [7, 57].

One aspect that was not adequately addressed by the developed AdHIVSM-35 measure was risk behaviors. Only one question addressed risk behaviors and was not included for factor analysis due to it applying to about only a third of the participants. The question about using substances such as drugs or alcohol to cope was eventually deleted from the AdHIVSM measure due to it lowering the internal consistency of one of the sub-scales. This could have been due to it being a reverse-scored item. Further development and testing of the AdHIVSM-35 measure should focus on including items that could address risk behaviors. This measure or component should likely be kept separate since it may not apply to all adolescents.

Practice Implications

The instrument can be used in practice to identify adolescents at risk for poor self-management. The questions/items can be used to guide discussions or educational sessions around adolescent HIV self-management or develop a self-management program. The use of the IFSMT is recommended to further the understanding of the components of self-management in this context.

Limitations

The low variance extracted is a limitation in this study and may mean that the factors do not adequately tap the latent constructs. It may also be that a high percentage of variance are due to measurement error, for example, participants not adequately understanding the items or participant fatigue.

Due to the participants being from an urban setting and primarily perinatally-infected and isiXhosa-speaking, the data may not be representative of all population groups and further testing of the scale with different samples is needed. However, differences between these sub-groups were not forthcoming in the data. The consecutive sampling method and selection of only those adolescents who attended appointments may have further limited the generalisibility of the sample. The instrument was completed either individually, with some assistance or by reading the questions to the participants. This was neccesary due to the reading literacy variablity amongst participants and the participants' preferences. It would be better in future studies to use an approach that accommodates participants with poor reading literacy, for example, using computer-assisted self-interview software. Using routine data for measuring the viral load is another limitation as it may not reflect current self-management.

Conclusion

This paper presented the development of a scale to measure adolescent HIV self-management and provides evidence that higher self-management, as measured with the developed AdHIVSM-35, is associated with better adherence, health-related quality of life and virological suppression. The scale components were meaningful and could be related to the theoretical framework of the study. Reliability values were acceptable and factor analysis confirmed its structural validity. The scale and its components should be tested further through research in other settings and population groups.

Compliance with Ethical Standards

Conflict of interest The authors have no conflicts of interest to declare.

Ethical Approval Stellenbosch University Health Research Ethics Committee approval (Ref:S15/03/054) and Department of Health permission (Ref:WC_2015RP53_21) were obtained to conduct the study. Informed consent was obtained for all adult participants before data collection. Adolescent assent and parental consent (either in person or telephonically) was obtained for adolescents younger than 18. Adolescents and caregivers were reimbursed for their time and inconvenience (SA R80/USD 5.60 for interviews/focus groups and SA R30/USD 2.10 for completion of questionnaires). Participants could relate their experiences or complete questionnaires in their language of choice (English, Afrikaans or isiXhosa). All applicable international, national, and/or institutional guidelines for research on human beings were followed.

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