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Development of a cultural and contextual appropriate HIV self-management instrument using interpretive phenomenology and focus group cognitive interviews

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ABSTRACT

Qualitative methods are valuable to ensure the important cultural and contextual appropriateness of research instruments but not often used. Interpretive phenomenology (IP) and focus group cognitive interviews are well placed to inductively develop and refine items used to measure adolescent HIV self-management in a South African context. IP was used to situate the experiences of adolescents, caregivers and healthcare workers, as narrated in individual interviews and focus groups, in their social and cultural context. Components of adolescent HIV self-management were developed based on the participants' experiences, behavioural theory and literature. The components and items were further validated in focus groups using cognitive interviews to refine, revise and add items as suggested by the participants. This study contributes to qualitative research methods and the rigor of instrument development by unpacking how to use IP and focus group cognitive interviews meaningfully in instrument development.

1. Background

Instrument development studies aim to develop instruments that validly and reliably measure complex constructs in a target population. The essence of instrument validity is tapping all the dimensions of the construct under study and maximising the relevancy and usefulness of the instrument by employing rigorous methodological approaches (Sousa & Rojjanasrirat, 2011). Qualitative methods provide an important vehicle to understand the construct of interest from the emic viewpoints of the target population in a context-specific and context relevant way. There seems to be a paucity of studies described that uses qualitative methods to develop instrument items from the bottom up (Kearney, 2016).

Self-management has become a central concept related to person-centered care for persons living with chronic health conditions (Sawin, 2017; Grady & Gough, 2014). Sub-Saharan Africa is the region most affected by the HIV epidemic globally and adolescents living with HIV (ALHIV) represent a growing proportion of persons living with HIV (UNICEF, 2018). ALHIV need several self-management skills to ensure their survival, development into productive adults, and the lifelong management of their chronic illness (Mofenson & Cotton, 2013; Sattoe

et al., 2015). However, ALHIV generally have poor treatment outcomes and self-management skills (Denison et al., 2015). No self-management instrument could be found that has been used in ALHIV and most other self-management instruments have been developed and applied in high-income countries (Sawin, Bellin, Roux, Buran, & Brei, 2009; Schilling et al., 2009; Wallston et al., 2011; Webel et al., 2012; Van Staa, 2012). The measurement and quantification of self-management of ALHIV may inform tailored strategies to improve their health and well-being.

Self-management is a complex construct described slightly differently by various frameworks (Sawin, 2017; Grady & Gough, 2014; Modi et al., 2012; Sattoe et al., 2015; Schulman-Green et al., 2012). For the purpose of this study, the authors adopted the definition provided in the Individual and Family Self-Management Theory (IFSMT) that describes the construct of self-management as the ability of an individual to manage the physical, social and lifestyle consequences of living with a chronic disease in conjunction with their family, community and health care professionals; with the ultimate aim to ensure health and well-being (Ryan & Sawin, 2009; Sawin, 2017). The IFSMT describes self-management as three interrelated processes namely: i) knowledge and beliefs (such as illness knowledge and self-efficacy); ii) self-regulation skills and abilities (such as goal-setting and problem-solving); and iii)

social facilitation (such as social support and negotiated collaboration). Individuals utilise self-management processes to achieve health-related outcomes. The proximal outcomes of self-management include self-management behaviours whereas distal outcomes include, for example, quality of life (Sawin, 2017). Self-management processes are influenced by several contextual factors related to the individual, sociocultural (family and community) and health system (Sawin, 2017; Modi et al., 2012). Consequently, contextual factors, as experienced from persons from the target population, need to be taken into consideration when developing an instrument to measure self-management.

When using qualitative research in instrument development, the researcher focuses on how participants understand the concepts, which limits the influence of the researcher's assumptions on how it is measured (Kearney, 2016). When developing new instruments, one needs to consider cultural assumptions and beliefs about health and well-being. Historical or political events may cause changes in the language, knowledge base, societal norms, values and attitudes that may influence how participants interpret questions. Population characteristics that may have an effect on instrument measurements are age, gender and education level (Switzer, Wisniewski, Belle, Dew, & Schultz, 1999). Carefully exploring the abovementioned factors are important to ensure that instruments are user-friendly, accurate and meaningful in the particular study context.

While self-management has received a lot of attention in the developed world (Sattoe et al., 2015), there is a paucity of research on self-management in the African context (Aantjies, Ramerman & Bunders, 2014). One of the key research priorities in the field of self-management is the identification of valid and reliable self-management measurement instruments (Grady & Gough, 2014). We sought to inductively develop an adolescent HIV self-management instrument that will be contextually and culturally relevant. Qualitative methods were therefore the most appropriate to achieve this aim.

Although many authors have used qualitative methods in instrument development, decisions regarding philosophical and theoretical underpinnings are rarely unpacked. In this paper, we describe why we selected and used specific qualitative methods such as interpretive phenomenology (IP) and cognitive interviewing to develop an instrument to measure adolescent HIV self-management. The focus is on providing researchers with practical examples and highlight some important issues to consider when using these methods in instrument development studies.

2. Methods

2.1. Study setting and participants

We recruited adolescents, between the ages of 13 and 18, who attended HIV services at two public health care clinics, from an urban multilingual community in the Western Cape, South Africa. Caregivers of adolescents and healthcare workers were included if they had at least one year of with experience in caring for or managing ALHIV. The sample included five adolescent focus groups (n = 36), 18 individual interviews with adolescents (n = 6), caregivers (n = 6) and healthcare workers (n = 6) and three focus groups for cognitive interviews (n = 11). We purposively selected participants to ensure representativeness according to language, gender and age (see Table 1).

Health Research Ethics Committee (HREC) approval for the study was obtained from Stellenbosch University, reference number: (S15/03/054). Informed consent for adult participants and assent as well as parental consent were obtained for adolescent participants under the age of 18. Ethical principles such as privacy and confidentiality were respected throughout the study and participants were reimbursed for their time.

Table 1
Demographics of participants.

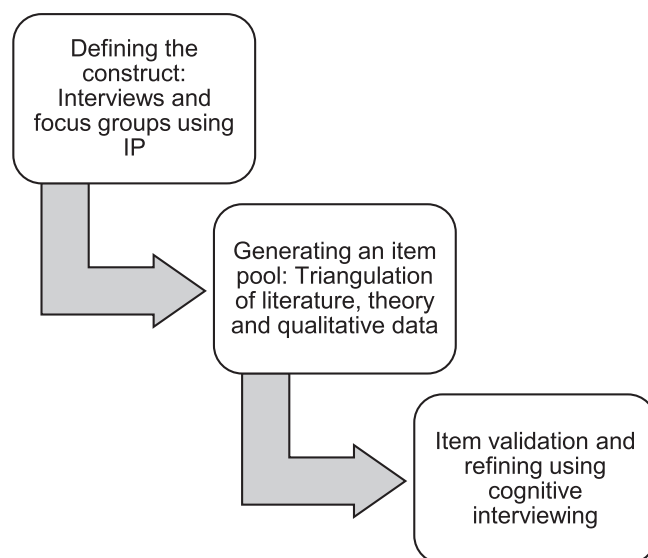| Individual interviews and focus groups		Cognitive interviews	
Adolescents			
Gender		Gender	
Male	18	Male	3
Female	26	Female	4
Age		Age group	
Mean	15	13–15	2
		16–18	5
Caregivers			
Gender		Gender	
Female	6	Female	4
Age		Age	
Mean	38	Mean	36
Healthcare workers (2 doctors, 2 nurses, 2 counsellors)			
Gender			
Female	6		
Age			
Mean	44		

Fig. 1. Overview of qualitative methods.

2.2. Design

The qualitative research methods described here (Fig. 1) were part of a larger sequential mixed-method study that aimed to develop an instrument to measure adolescent HIV self-management in a South African context. The detailed methods of the larger study are reported elsewhere (Crowley, van der Merwe, Kidd, & Skinner, 2020). For this paper, the authors describe the first steps in inductive instrument development which include conceptualizing the construct, describing the behaviours underlying the construct and developing the initial instrument (Onwuegbuzie, Bustamante, & Nelson, 2010; De Vellis, 2012).

Firstly, the authors had to clarify how our worldview and research and discipline-specific philosophy may influence the instrument development process. The authors of this paper have a discipline background in nursing and psychology and therefore postulated that self-management may be complex and experienced in multiple contradictory, yet equally valid, ways by the target population. On the other hand, we acknowledged that there are existing frameworks for self-management that should be used to ensure that the breadth and depth of the construct is tapped. The first author had experience in working

with persons living with HIV and wanted to gauge this prior knowledge. The process of moving between the emic perspectives of the target population and the etic knowledge captured in the literature, existing frameworks and the authors' a priori assumptions resembled the hermeneutic circle of Heidegger (1962). Other Heideggerian concepts that were particularly relevant to this research were that of 'being-in-the-world' and 'situated freedom'. These concepts emphasise people's embeddedness and inseparability from the world and that the decisions of people are influenced by their contexts (Lopez & Wills, 2004; Horrigan-Kelly, Millar, & Dowling, 2016; Burns & Peacock, 2019). These notions resonated with the Individual and Family Self-Management Theory (FSMT) the authors chose to use as a theoretical framework (Ryan & Sawin, 2009; Sawin, 2017).

Zahavi (2019) states that phenomenologically-informed research should utilize a comprehensive theoretical framework of how individuals relate to themselves, others and the world around them. This will elucidate how their being-in-the-world is transformed by living with a chronic illness. The authors decided to use interpretive phenomenology (IP) as the philosophical lens and design for defining the construct of interest and describing behaviours underlying the construct. IP allowed for both 'top down' (deductive) and 'bottom up' (inductive) strategies to ensure the validity of the instrument (Kearney, 2016).

2.3. Individual interviews and focus groups: defining the construct of interest

Individual interviews and focus groups were conducted to explore self-management from the perspectives of adolescents, caregivers and healthcare workers. Focus groups have been used in several IP studies and can be beneficial in interpretive phenomenological research, since IP is not concerned with collecting "uncontaminated" participant accounts. Focus groups can be particularly useful when addressing shared experiences. In the context of HIV self-management, these shared experiences may include attending clinic visits and the adolescent stage of development. Focus groups in this study provided opportunities for participants to share of and reflect on their own and others' experiences, inclusive of clarification and checking for understanding between participants and between participants and the researcher (Bradbury-Jones, Sambrook, & Irvine, 2009).

Since self-management is an abstract and complex construct, characterized by several interconnected processes and behaviours, the first author and fieldworker explained it as 'taking care of yourself'. A semi-structured interview guide was designed to explore the process components of self-management and the contextual factors that may influence it. Interviews and focus groups were conducted in the language of preference of the participants (English, Afrikaans or isiXhosa) by the first author and a field worker.

The interviews and focus groups allowed for contextualizing key self-management processes and behaviours, while the authors could use the theoretical framework, the IFSMT, as a fore-structure to explore all the theoretical domains of self-management.

Hermeneutics allows for the expert knowledge of the researcher to guide the inquiry (Heidegger, 1962; Lopez & Wills, 2004; De Witt & Ploeg, 2006; Burns & Peacock, 2019). The inductive-deductive combination allowed the authors to use pre-determined categories to contextualize the phenomenon in the unique cultural and historical context of the participants' lifeworld. Knowledge about the phenomenon is co-created through the interaction between the researcher and participants (Burns & Peacock, 2019). Although interview questions were structured around self-management categories, participants were allowed to speak freely. The ancillary views of caregivers and healthcare workers assisted to provide a more rich description of the phenomenon. The focus was on describing daily lived self-management activities or experiences of the ALHIV and how the community, family and healthcare context influenced these experiences using the analysis steps described by

Christ and Tanner (2003). Data collection continued until the authors was confident that saturation of all the self-management categories were achieved.

2.4. Creating and item pool: describing processes and behaviours underlying the construct

The first author mapped the themes identified during the interviews and focus groups to the theoretical framework and other literature where applicable. This process included iterations between the literature and the qualitative data, taking care to include the participants' views until saturation of each component of self-management was reached. Self-management processes were well described based on the literature and contextualized with the participants' experiences. The first author then identified key statements that described each self-management process category based on participants' verbatim data (Kearney, 2016). The two co-authors moderated this whole process.

Items were included across the qualitative themes identified and consistent with the domain definition and written according to the Patient-Reported Outcome Measurement Information System (PROMIS, 2013) guidelines. Items were written in a table that links theory extracted from the literature (etic viewpoint, deductive logic) with the information provided by participants (emic viewpoints, inductive logic) (Onwuegbuzie et al., 2010).

2.5. Item validation and refinement through cognitive interviewing

Items were refined using cognitive interviewing techniques to ensure understanding, readability, translatability and literacy (PROMIS, 2013). Cognitive interviews are effective for identifying problems in question wording, comprehension and recall and for ensuring items capture the underlying construct. It provides the researcher with a window into the cognitive processes of the participant and proves useful in testing newly developed items (Lippman et al., 2014). Cognitive interviewing is usually done on a one-on-one basis. However, in this study, three focus groups were used as an alternative method (Polit & Beck, 2017) in order to elicit a range of ideas about developing new items and re-wording items or statements. The authors observed during the first phase of the study that adolescent focus groups yielded richer data when compared to individual interviews. This further supported the use of focus groups for the cognitive interviews. We included adolescents and their caregivers as we wanted to explore if it would be meaningful to create a caregiver version of the HIV self-management instrument.

Participants were presented with the items/statements in a questionnaire format with statements divided in sections. The procedure involved presenting one section at a time, asking the participants to answer the questions individually and then rating the list of questions from most important to least important. The item scale used was 1 = no, certainly not; 2 = no, probably not; 3 = yes, probably; 4 = yes, certainly. For the "goals" domain, the scale used was: 1 = never a goal; 2 = sometimes a goal; 3 = definitely a goal; 4 = I've met this goal. After the participants individually answered and rated the questions, cognitive questioning was performed in the group. The process was repeated for each of the seven sections.

During the cognitive questioning session, participants were asked what they understood by each item/statement presented to them and if they thought the questions were clearly phrased. They were given the opportunity to suggest how statements can be rephrased where necessary, discuss their answers to the questions and state their reasons for giving a particular answer. The facilitator further asked participants what the most and least important items were for them and why. Finally, the participants were asked if they felt that the list was incomplete, for example, if there were any important things left out in each section. Allowance was made for new self-management processes or behaviours if the participants felt they needed to reword or add new

Table 2
Extract of item table.

Items (Description of process or behavior)	Etic perspective: Theoretical sources	Participant data: Sub-theme	Participant data: verbatim quotation
Domain 1: Knowing and believing *(may include self-efficacy, outcome expectancy and goal congruence)* Ryan & Sawin, 2009; Schulman-Green et al., 2012 (SCALE: Yes, certainly; Yes, probably; No, probably not; No, certainly not – Van Staa, 2012)			
1a KNOWING AND UNDERSTANDING			
6 I understand why I am taking antiretroviral treatment (ARVs).	Barnes et al., 2013, Swendeman, Barbara, Ingram, & Rotheram-Borusa, 2009; Sattoe et al., 2015; Van Staa, 2012; Buran, Brei, Sawin, Stevens, & Neufeld, 2006; Jena, 2014	Knowing and Understanding – Treatment	'I think if you are not taking your pills the virus increases in your body.' [Adolescent, Focus group 3]
7 I know my regimen (tablets).	Barnes et al., 2013, Swendeman et al., 2009; Sattoe et al., 2015; Van Staa, 2012; Buran et al., 2006	Knowing and Understanding – Treatment	'Yes I know all my tablets, how they look and their names.' [Adolescent, Focus group 3]
1b BELIEVING AND VALUING			
16 I can have a normal long and healthy life.	Sattoe et al., 2015; Jena, 2014; Li et al., 2010	Believing and valuing – HIV, normalcy	'You need to know that it is not the end of life when you are HIV-positive and you can achieve your dreams.' [Adolescent 4, Male, 16 years] 'I feel free like normal kids.' [Adolescent 2, Male, 14 years]
17 I can take care of my health on my own.	Sattoe et al., 2015; Modi et al., 2012; Jena, 2014	Believing and valuing – HIV, normalcy	'If you are HIV-positive it's not the end of your life, just take it as it came to you, you just need to take care of yourself.' [Adolescent 4, Male, 16 years]
Domain 2: Self-regulation *(Goal setting, self-monitoring, reflective thinking, decision making, planning and action, self-evaluation, emotional control)* Ryan & Sawin, 2009; Van Staa, 2012 ; Schulman-Green et al., 2012			
2a SELF-REGULATION AND PROBLEM SOLVING *(level of independence or collaboration with caregiver)*			
23 Sometimes I decide not to take my treatment (e.g. when I feel tired of taking it or when I am going to a party I do not take my treatment) *(REVERSE)*	Sattoe et al., 2015; Cox et al., 2014; Jena, 2014	Self-regulation – Adherence	'I was like no man, I do not want to take the tablets, I am healthy, why must I take tablets?' [Adolescent, Focus group 1]
24 I take my treatment most of the time, even when I do not want to.	Modi et al., 2012; Schulman-Green et al., 2012	Self-regulation – Adherence	'I feel sometimes, I feel like I'm feeling tired, but then I think the other side that I just have to drink my pills for my health.' [Adolescent 3, Female, 13 years]
27 I plan how I will take my treatment when I am not at home (e.g. when I am visiting friends or if I go on a school camp).	Evidence-based guideline for chronic care: Self-Management. Guideline 30; Jena, 2014	Self-regulation – Adherence	'Yes, I take my tablets with me, or I drink it at home, and then the morning when I come back, and then I drink it again.' [Adolescent 3, Female, 13 years]
28 I decide who I want to tell about my HIV status.	Swendeman et al., 2009; Schulman-Green et al., 2012; Jena, 2014	Self-regulation – Disclosure	'To disclose to your family, but to certain people not all of them, the ones you trust.' [Adolescent 3, Female, 13 years]
2b COMMUNICATION			
33 I ask the doctor or nurse if there is anything that I do not understand.	Sattoe et al., 2015; Modi et al., 2012; Cox et al., 2014	Communication – Healthcare worker	'Yes, I like to come to the clinic because sometimes I ask questions that I don't know about my sickness.' [Adolescent, Focus group 4]
37 I talk to my parents or caregiver about HIV and other things.	Cox et al., 2014	Communication – Parents/ caregivers	'Yes, if there is something I don't like, or something happens, something like that, if I want to complain I just speak up.' [Adolescent, Focus group 5]
2c COPING WITH THE CONDITION			
39 I can cope with it if people say hurtful things about people living with HIV.	Swendeman et al., 2009; Sattoe et al., 2015; Schulman-Green et al., 2012; Jena, 2014	Coping – Stigma	'You need not to think what people are saying about you, because you won't be healthy if you live your life for other people and not for yourself.' [Adolescent 6, Female, 18 years] 'Sometimes like when the LO teacher teaches about the sickness, I just feel ashamed but sometimes it's hard for me to deal with things like that sometimes, but I manage, especially when they talk about the sickness.' [Adolescent, Focus group 2]
2d. GOALS Schilling et al., 2009; Schulman-Green et al., 2012 **The following are goals for me:** (SCALE: Never a goal; Sometimes a goal; Definitely a goal, I've met this goal)			
44 To be independent.	Schilling et al., 2009	Self-regulation/Goals – Independence	'I need to have my own time table, have time for everything, and have time for my pills and time for taking care of other things.' [Adolescent 4, Male, 16 years]
Domain 3: Social facilitation, & resource utilization *(Influence, support, collaboration)* Ryan & Sawin, 2009; Schulman-Green et al., 2012 (SCALE: Yes, certainly; Yes, probably; No, probably not; No, certainly not)			
50			

Table 2 (continued)

Items (Description of process or behavior)	Etic perspective: Theoretical sources	Participant data: Sub-theme	Participant data: verbatim quotation
I receive support from my family (e.g. my family remind me about taking my treatment, coming to the clinic, doing homework).	Swendeman et al., 2009; Schilling et al., 2009; Cox et al., 2014; Jena, 2014; Li et al., 2010	Social facilitation – Support – Family	'Yes, my granny helps me, and my family.' [Adolescent 3, Female, 13 years] 'My sister is very supportive. She always supports me in any situation I have. I trust her, and when I need anything, I can ask her. Sometimes I talk to my mother, but I can't tell my mother about everything.' [Adolescent, Focus group 1]
52 I receive support from my peers at the clinic (e.g. through the support group I can share my experiences/feelings).	Webel et al., 2012; Swendeman et al., 2009; Sattoe et al., 2015; Cox et al., 2014; Jena, 2014; Li et al., 2010	Social facilitation – Support – Peers/Groups	'In this group, you can share your feelings, like how do you feel about the illness, and like outside you can't share it because you don't know who to talk to, and people will judge you.' [Adolescent, Focus group 1]
53 I participate in sports or cultural activities at school or in the community in my free time.	Sattoe et al., 2015; Sattoe et al., 2015	Social facilitation/resource utilisation – Community	'There is more like a youth group setup where the kids can go somewhere once a week that's near their house, where they can just kind of hang out and socialise and learn about things or do things together in a group. Just so that it's a bit more normal.' [Healthcare worker 3]

items or behaviours. The process was led and monitored by the facilitator in each group and each focus group lasted approximately four hours with tea and lunch breaks in-between. Facilitators made notes of the qualitative responses regarding the question format and comprehension and sessions were audio recorded. Due to the long duration and conversational style of the workshops, targeted transcriptions of participant responses to questions were made of the audio recordings. The first author listened to the recordings and transcribed all the participant responses to the questions as they verbalised it.

2.6. Trustworthiness

We used measures of trustworthiness specifically applicable to IP. Balanced integration was ensured through integrating the philosophical assumptions and theoretical framework in the data analysis process and making sure that there was a balance between the voice of the participants and the interpretation (De Witt & Ploeg, 2006). Reflective journaling about decisions made in the research process assisted in ensuring openness. This is often described in IP research as "opening up the study to scrutiny" and is a systematically explicit process of reflecting on decisions made throughout the study (De Witt & Ploeg, 2006). Thick descriptions of the findings assisted with concreteness and resonance, which can be recognized when study findings position the reader in the context of the phenomenon and connects with experiences from their own life world. The "felt-effect" of reading the study findings of IP is termed resonance. It is a combination of understanding the meaning of the text and understanding one-self (De Witt & Ploeg, 2006). Phenomenological interpretation does not end when the study is completed and actualization implies that it will be interpreted by readers in the future. No formal way to record actualization exists (De Witt & Ploeg, 2006).

3. Findings

Items for the adolescent HIV self-management instrument were generated by defining the construct of interest and describing underlying processes and behaviours. These items were then further validated and refined through focus group interviews. The participant demographics are provided in Table 1.

3.1. Defining the construct of interest

Individual interviews led to the identification of five themes with seven categories which are reported elsewhere (Crowley, van der Merwe, & Skinner, 2019). The qualitative interviews and focus groups allowed us to, for example, explore how abstract self-management processes are 'lived'. We were able to interpret the experiences of the participants and meaningfully relate them to the higher level concepts in the IFSMT, while at the same time generate practical examples of how these somewhat abstract concepts such as 'self-regulation' are realized in the study context. IP therefore allowed us to keep a balance between the emic and etic perspectives. Utilizing secondary sources such as caregivers and healthcare workers assisted to understand self-management from various viewpoints. Caregivers and healthcare workers often had different views on adolescents' self-management skills and abilities compared with how the adolescents viewed their own abilities.

3.2. Creating and item pool and describing underlying behaviours

Based on the qualitative data and a literature review, a list of 55 items were identified and grouped into the three main process domains similar to that of the IFSMT. Each of the domains had categories, with a total of seven categories that covered the identified self-management components, namely, knowing and understanding; believing and valuing; self-regulation; coping; communication; goals; and social

Table 3
Findings from cognitive interviews.

Themes/Issues of importance	Description	Example items	Participant quote or comment
The influence of age	Older adolescents were more confident in providing feedback which may be due to more developed cognitive processes. Older adolescents may interrogate items more whereas young adolescents tend to select answers without deep contemplation.	I can describe the future consequences/concerns of my illness (HIV)	**Young adolescent:** *'Yes, certainly, because it is important… my concerns of my health is important to me.'* **Older adolescents:** *'I understand do I know the consequences of my illness in the future… I do not know the consequences.'* *'The word 'concerns' is confusing.'*
Caregiver perspectives	Some caregivers were not in a position to respond on behalf of the adolescent. Caregivers tended to self-identify with some of the questions and interpreted some of the questions differently to the adolescent.	I understand the consequences of not taking my treatment every day I can cope if someone say hurtful things about people living with HIV	**Caregiver:** *'No, probably not since my child does not take his pills very well.'* **Caregiver:** *'No probably not. I will not interfere, I will just be quiet and not say anything'* **Adolescent:** *'Yes I can because we are all the same, even do not listen to people to what they say, some people will say nasty things, you are the same and it is just the virus inside of you.'*
Clarity and relevance of items	Questions that were specific and connected to experiences or behavior were easier to understand. Process or ability questions were more open to different interpretation. Some items were not relevant as a process or behavior indicative of self-management.	Being independent is a goal for me I participate in decisions regarding my own health and treatment I can tell which doctor or nurse at the clinic/hospital treats me	**Older adolescent:** *'There are two types of independence. When you are an adult and the independence that we have when we do not ask others for help, for example, asking a friend to blow your hair. Then there is the other independence also like do you pay rent?'* **Young adolescent:** *'It is nice to be alone so that you can experience things alone and not with your mom.'* **Adolescent:** *'Perhaps an example should be included, for example, being asked whether they should switch you to once daily dose. I do participate because I said I wanted to go to the once a day dose.'* **Adolescent:** *'Do we have a choice? Basically they just take our files and call our names.'* **Caregiver:** *'There is nobody specific, you meet different people.'*
Response variability and response options	Tendency for positive responses; not all participants responded consistently to positively vs negatively (reverse) phrased items that measure similar behaviors.	I only take my treatment when other people e.g. my parents tell me to take it. I remember to take my tablets every day without someone reminding me (e.g. I use reminders like a pill box or my phone).	One adolescent selected the same response option for both questions.

facilitation. The items were mapped according to the theoretical sources that support the item and the qualitative data (themes and participant quotations). A possible item scale was also suggested for each domain based on the literature. An extract from this table of items is depicted in Table 2.

3.3. Item validation and refining through cognitive interviews

The cognitive interviews were conducted in three groups with participants that previously participated in either the focus groups or interviews. The first group was with adolescents aged 13–15 (n = 2), the second with adolescents aged 16–18 (n = 5) and the third with caregivers (n = 4).

The authors grouped the feedback provided by the participants on the items and the first author's and fieldworker's observations into four themes or issues of importance: The influence of age; caregiver perspectives; clarity and relevance of items; response variability and response options. Previous studies that have explored cognitive processes of adolescents and how it may influence interpretation of items (Lippman et al., 2014) guided the exploration of the themes. The results are summarized in Table 3.

3.3.1. Influence of age

The age of the adolescents seemed to influence how they responded in several ways. Firstly, there was a difference in confidence between older and young adolescents when providing feedback on the items. Secondly, adolescents' responses and their cognitive processes when interpreting the items differed according to age. The responses of older and young adolescents regarding whether items should be rephrased were markedly different. The young adolescents had no comments or suggestions for rephrasing items and reported that all the items were very clear to them. The older adolescents interrogated most of the statements and discussed the meaning of statements amongst each other. Lippman et al. (2014) also found that adolescents, particularly younger adolescents, were willing to provide responses even if they were not able to fully articulate their understanding of the question and provide a reason for their answer. It is, therefore, important that items should be as clear and unambiguous as possible. However, young adolescents may still have more positive responses compared to older adolescents due to them not interrogating the items deeply and this should be kept in mind when analysing participant responses.

3.3.2. Caregiver perspectives

With regards to item content, feedback from caregivers indicated that they may not be well-positioned to answer questions related to self-management on behalf of their adolescents. They had a tendency to underestimate or overestimate the adolescents' ability to self-manage. Further, it was noted that HIV-positive caregivers self-identified with many of the questions and tended to answer questions on behalf of themselves. Caregivers and adolescents' interpretation of certain items also differed, resulting in mixed feedback regarding the relevancy and clarity of some items. The accuracy of a caregiver's response depends on how well they know the adolescent and whether the question relates to an observable behaviour (Lippman et al., 2014). However, even if a caregiver knows the adolescent very well, there may be differences in their reasoning when selecting an appropriate answer or they may be unable to separate their own opinions and experiences from those of their adolescents. This is particularly the case in this context where most of the caregivers were also living with HIV. Feedback from the perspective of caregivers therefore support the notion that adolescents

should answer questions themselves and that a caregiver version of the instrument may not be meaningful (Van Staa, 2012).

3.3.3. Clarity and relevance of items

Feedback regarding the clarity and relevancy of items assisted in refining the items for the target group. Questions that were clear and specific were better understood by participants. The quality of the data may be compromised if a question lacks specificity. For example, the question "I can have a normal long and healthy life", were left unanswered by some adolescents since they did not know how to answer it. One adolescent said: '*I do not know what the future holds for me, what will happen that can affect my health*'; another responded: '*Why normal*?' The word 'normal' was specifically included due to the emphasis placed on being normal in the qualitative data. However, it appeared that using the word 'normal' in the item made the adolescents feel that they were being compared to other people and slightly offended some of them. It was suggested that 'normal' be removed from the sentence. One of the caregivers responded: '*Yes, because if you take your tablets, eat healthy, do the right thing then you can live.*' The question was therefore ambiguous and had to be revised to ensure that it is more specific with regards to the meaning.

Some questions were considered confusing and required clarification. For the question, "I would recognize signs and symptoms of a decline in my health", both older and young adolescents were not sure what signs and symptoms would indicate a health decline. The older adolescents mentioned that it could be physical symptoms but that they did not know any. One adolescent mentioned symptoms of a cold sore in the mouth, fever and coughing. Another said that she had not been sick in three years. One adolescent said that her mother would recognize when there is something wrong with her, for example, when she does not want to eat. The young adolescents did not understand this question at first, but one adolescent answered, '*When you have headaches and stomach aches*' after the Xhosa field worker explained it as '*signs of being unhealthy.*' This also indicates that questions need to be on a literacy level that is understandable for both young and older adolescents. There may be differences in how older and young adolescents interpret questions based on different literacy levels if the reading level of the questions are set too high.

Adolescents seemed to interpret items better when the items were connected to their experiences or behaviour and if examples were provided. For example, older adolescents responded that the questions related to communication were more straightforward. These included questions such as "I ask the doctor or nurse questions if there is anything that I do not understand." However, if too many examples were used, some participants answered based on part of the question only. For the question, "I tell the doctor or nurse about private things (e.g. if I have missed my medication, if I am having sex or using drugs/alcohol or if I feel depressed/thinking too much about something)", one adolescent responded:

> *Yes, probably I will since my drugs does not affect me physically so it must affect me in some other way and psychological and emotional problems lead to suicide.* [She added that she will definitely not tell the doctor if she has missed her medication, since she will be reprimanded.]

Some double-barrelled questions were identified, for example, "I know when and why the doctor or nurse changes my treatment." The adolescents felt that this question should be separated into two questions. Items must also have clear reference points, otherwise participants create their own.

With regard to relevancy, some less relevant items were identified. For the question "I can tell which doctor or nurse at the clinic/hospital treats me", it appeared that whom they were seen by depended on the clinic context. There was no continuity in healthcare providers from visit-to-visit and they did not have a choice regarding which healthcare provider they wished to see. It may therefore not be relevant for adolescents to know which provider treats them in this context. Another item that appeared to be less relevant was the question related to knowing what will happen when the adolescent transfers to adult care. Participants felt that the healthcare workers should inform them of this.

3.3.4. Response variability and response options

Concerning variability in responses, it was noticed that none of the participants selected the option, 'No, certainly not' for any of the statements. Since most the items were positively phrased, this may be explained by the small sample size and that the selected group consisted of participants who regularly attended support groups at the clinics. Regular attendance of the clinic may mean that the participants have better self-management and therefore had positive responses. Since all the adolescents were infected perinatally, most of them have been attending the clinic from a very young age and have received numerous messages from caregivers and healthcare workers about what constitutes desirable behaviour. They may therefore have been inclined to select socially desirable response options. On the other hand, it may also indicate the participants selected positive options without reflecting more deeply on the questions. Social desirability can be addressed through including high threshold items which are more difficult for participants to respond to affirmatively (Lippman et al., 2014). The list of items contained some negatively phrased items, for example, "I only take my treatment when other people e.g. my parents tell me to take it". Some adolescents identified that this question was similar to the previous question "I remember to take my tablets every day without someone reminding me (e.g. I use reminders like a pill box or my phone)". All except one participant provided opposite answers for these two questions e.g. 'yes, certainly' vs 'no, certainly not'. DeVellis (2012) noted that negatively phrased items are sometimes difficult for participants to answer due to changing the answer polarities. Although reverse/negative items may therefore help to limit social desirable responses, they may also confuse participants. Further, frequency scales capture greater variability, especially for socially desirable items (Lippman et al., 2014). It was therefore decided that it would be better to change the scale to frequency responses if the item concerned behaviours.

The data from the cognitive focus groups helped the authors to i) refine items so that they were clearer and concrete, with specific reference points, avoiding words that could lead to misunderstanding; ii) revise items that were ambiguous or open to multiple interpretation and iii) add additional items as suggested by the participants. Following the focus groups, 10 items were added to the questionnaire. These items included questions such as "I know at what times I should take my treatment"; "I know if I can take my tablets with or without food"; and "To make the right decisions is a goal for me." There was also a discussion amongst the adolescents about using alcohol and drugs to cope that led to the inclusion of the question: "I manage my stress by eating too much junk food, using drugs (e.g. dagga), smoking cigarettes or drinking alcohol." Although participants deemed some items to be less relevant, these items were retained. This allowed for an exhaustive list of items related to adolescent HIV self-management. Cognitive interviewing was followed by a Delphi study (of experts and clinicians), a pilot test (adolescents) and cross-sectional survey (adolescents) to further test the validity of the items (Crowley et al., 2020).

4. Discussion

Phenomenology insists on an open-minded and non-biased approach to the world and acknowledges that the individual is embedded in their social and cultural context (Zahavi & Martiny, 2019). The qualitative methods unpacked here enabled us to contextualize adolescent HIV self-management in a South African setting. It assisted to make an abstract concept and its processes tangible according to the reality and lived experience of the persons who daily undertakes the task of taking care of themselves and their illness. For each of the

interrelated self-management processes, namely, knowledge and beliefs; self-regulation skills and abilities; and social facilitation, items could be identified that resonated with the contextual realities of the participants. The methods used provided insights into the target population's context and cognitive processes in understanding (Kearney, 2016). It further elucidated how to best administer the instrument, for example, that proxy questionnaires completed by caregivers may not be valid to measure an adolescent's self-management, and how results may be interpreted, particularly across age groups. We described why we choose IP and cognitive interviews using focus groups and how this was meaningful in the instrument development process. Describing philosophical and theoretical underpinnings enhance the rigor of the qualitative methods. Authors do not often report the details of these instrument development steps. This paper makes an important contribution by describing a systematic approach to using qualitative methods in instrument development.

Phenomenology can be applied to clinical nursing by providing access to the complex world of the patient and aid in diagnosis and treatment (Zahavi & Martiny, 2019; Feeley, 2019). It assists to make abstract concepts more concrete in the patient's experiential life. In this study the authors illustrated how phenomenology can aid in the development of a self-management instrument that could have clinical value.

There are several methodological disputes in relation to IP and differences between the applications of IP amongst prominent methodologists has been noted (Burns & Peacock, 2019; Zahavi, 2019). The authors of this study did not follow the approach of a specific methodologist, but rather drew on the Heideggerian tenets described across various authors. Zahavi and Martiny (2019) states that in a non-philosophical context, the contribution that the application of phenomenological research makes to the scientific community and patients is more important than strictly adhering to Heidegger's (or other IP methodologists') guidance.

4.1. Limitations, lessons learned and suggestions going forward

With the use of interpretive phenomenology, bracketing does not occur, which opens the data collection and analysis processes to possible observational and confirmation bias from the authors. This was controlled for by keeping a reflective journal and peer debriefing. The authors also looked beyond the initial conceptual framework and applied hermeneutics when identifying domains and categories for the instrument as to stay true to the participants' experiences and include aspects not tapped by the framework. That being said, interpretation still remains relative and it may be that the participant experiences may be categorized differently by other researchers. The cognitive interviews and open nature thereof did however provide participants with the opportunity to confirm their experiences and add to the description of the concept. When conducting qualitative interviews, participants may react or respond differently due to the presence of the researchers (Hohl, Ceballos, Scott, & Thompson, 2019). We found that the focus groups with adolescents were meaningful in creating an environment of acceptance where they were able to share less desirable behaviours truthfully.

Self-management is a very complex and broad concept. We aimed to comprehensively describe adolescent HIV self-management with a specific focus on the self-management processes (e.g. knowledge, self-regulation skills and abilities, social facilitation). However, processes or abilities are more difficult to measure than behaviours. It is also difficult for participants (especially adolescents) to understand and rate their own self-management abilities. It is however important to measure self-management processes as these appear to be the most amenable to change and the focus of various interventions. The list of items generated captured both processes and behaviours. We decided to further explore this in the Delphi study and cross-sectional study using factor analysis and hypothesis testing.

Language plays an important role in qualitative research and instrument development (Hohl et al., 2019). South African is a multilingual country and the Western Cape has three official languages. The first author was fluent in two of the languages, but used a Xhosa-speaking interviewer for certain interviews and focus groups who also translated the interviews and responses during the focus groups. Xhosa-speaking interviewers also facilitated groups during the cognitive interviews. We do, however, acknowledge that language nuances may not have been adequately captured and transferred during the item generation process.

Cognitive interviews were performed in groups with English worded items and although this method yielded rich data, it is advised to repeat the cognitive interviews individually once the items are finalized, for example, during the pilot test. This would also assist to identify any issues with the forward and back translation of the items into other local languages. It would be advisable to do individual cognitive interviews with at least two young and two older participants of both genders across the different languages the items are translated in. A larger sample of participants may have also yielded more feedback on the items. Performing the cognitive interviews in a group may have caused some participants not to respond truthfully due to group pressure and may have hindered deeper analysis of individual cognitive processes.

5. Conclusion

IP and cognitive interviewing were meaningful to identify the components of adolescent HIV self-management and items that could be included in an instrument. This study contributes to qualitative research methods and the rigor of instrument development by unpacking how to use IP and focus group cognitive interviews meaningfully in instrument development. The authors tested this instrument further by doing an expert review (Delphi study), pilot test of translated versions, and item and factor analysis on a larger cross-sectional sample (Crowley et al., 2020).

Author contributions

TC conducted the research and drafted the article. ASvdM and DS was the supervisors for the research project and provided substantial feedback on the article.

CRediT authorship contribution statement

Talitha Crowley: Methodology, Investigation, Data curation, Writing - original draft. **Anita Van Der Merwe:** Conceptualization, Methodology, Supervision, Writing - review & editing. **Donald Skinner:** Conceptualization, Methodology, Supervision, Writing - review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijans.2020.100207.

References

Aantjes, C. J., Ramerman, L., & Bunders, J. F. G. (2014). A systematic review of the literature on self-management interventions and discussion of their potential relevance for people living with HIV in sub-Saharan Africa. *Patient Education and Counselling, 2014*(95), 185–200.

Barnes, W. M., Abramowitz, S., Lagrange, R., Chandwani, S., Moschel, D., & Koenig, L. J. (2013). Disease-specific knowledge among HIV-infected adolescents: What do they know and how do they learn It? *Journal of HIV/AIDS & Social Services, 12*(3–4), 314–332.

Bradbury-Jones, C., Sambrook, S., & Irvine, F. (2009). The phenomenological focus group: An oxymoron? *Journal of Advanced Nursing, 65*(3), 663–671.

Buran, C. F., Brei, T., Sawin, K. J., Stevens, S., & Neufeld, J. (2006). Further development of the adolescent self management and independence scale: AMIS II. *Fluids Barriers CNS, 3*(S37), https://doi.org/10.1186/1743-8454-3-S1-S37.

Burns, M., & Peacock, S. (2019). Interpretive phenomenological methodologists in nursing: A critical analysis and comparison. *Nursing Inquiry, 2019*(26), e12280. https://doi.org/10.1111/nin.12280.

Christ, J. D., & Tanner, C. A. (2003). Interpretation/analysis methods in hermeneutic interpretive phenomenology. *Nursing Research, 52*(3), 202–205.

Crowley, T., van der Merwe, A., Kidd, M., & Skinner, D. (2020). Measuring Adolescent HIV Self-management: An Instrument Development Study. *AIDS and Behavior, 24*, 592–606. 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–e19. https://doi.org/10.1097/JNC.0000000000000098.

Cox, E. D., Fritz, K. A., Hansen, K. W., Brown, R. L., Rajamanickam, V., Wiles, K. E., ... Moreno, M. A. (2014). Development and validation of PRISM: A survey tool to identify diabetes self-management barriers. *Diabetes Research and Clinical Practice, 104*, 126–135.

Denison, J. A., Banda, H., Dennis, A. C., Packer, C., Nyambe, N., Stalter, R. M., ... McCarraher, D. R. (2015). "The sky is the limit": Adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers. *Journal of the International AIDS Society, 18*(19358), 1–6.

DeVellis, R. F. (2012). *Scale development: Theory and applications* (3rd ed.). London: Sage publications.

De Witt, L., & Ploeg, J. (2006). Critical appraisal of rigour in interpretive phenomenological nursing research. *Journal of Advanced Nursing, 55*(2), 215–229.

Evidence-based guideline for chronic care: Self-Management. Guideline 30, Accessed date: 22 August 2015.

Feeley, C. (2019). Freebirthing: A case for using interpretative hermeneutic phenomenology in midwifery research for knowledge generation, dissemination and impact. *Journal of Research in Nursing, 24*(1–2), 9–19.

Grady, P. A., & Gough, L. L. (2014). Self-Management: A comprehensive approach to management of chronic conditions. *American Journal of Public Health, 104*(8), e25–e31.

Heidegger, M. (1962). Being and time (J. Macquarrie & E. Robinson, Trans.). NewYork: Harper and Row.

Hohl, S. D., Ceballos, R., Scott, M. A., & Thompson, B. (2019). Developing a culturally informed survey instrument to assess biomedical research participation Among Latinos on the U.S.-Mexico Border. *Qualitative Health Research, 29*(3), 445–454.

Horrigan-Kelly, M., Millar, M., & Dowling, M. (2016). Understanding the key tenets of Heidegger's philosophy for interpretive phenomenological research. *International Journal of Qualitative Methods, 2016*, 1–8. https://doi.org/10.1177/1609406916680634.

Jena, P. P. (2014). *Exploring the lived experiences of adolescents living with vertically acquired HIV.* Master's thesisUniversity of South Africa.

Kearney, M. H. (2016). Under-appreciated steps in instrument development, part 1: Starting with validity. *Research in Nursing & Health, 2016*(39), 81–83.

Lippman, L.H., Moore, K.A., Guzman, L., Ryberg, R., McIntosh, H., Ramos, M.F., Caal, S.,

Carle, A. & Kuhfeld, M. (2014). Chapter 2. Cognitive Interviews: Designing Survey Questions for Adolescents. Flourishing Children. Springer Netherlands. Briefs in Well-Being and Quality of Life Research, pp. 25–43.

Li, R. J., Jaspan, H. B., O'Brien, V., Rabie, H., Cotton, M. F., & Nattrass, N. (2010). Positive futures: A qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. *AIDS Care, 22*(6), 751–758. https://doi.org/10.1080/09540120903431363.

Lopez, K. A., & Wills, D. G. (2004). Descriptive Versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge. *Qualitative Health Research, 14*(5), 726–735.

Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., ... Drotar, D. (2012). Pediatric self-management: A framework for research. *Practice and Policy. Pediatrics, 129*(2), 473–485.

Mofenson, L. M., & Cotton, M. F. (2013). The challenges of success: Adolescents with perinatal HIV infection. *Journal of the International AIDS Society, 16*(1), e18650.

Onwuegbuzie, A. J., Bustamante, R. M., & Nelson, J. A. (2010). Mixed Research as a Tool for Developing Quantitative Instruments. *Journal of Mixed Methods Research, 4*(1), 56–78.

Patient-Reported Outcome Measurement Information System (PROMIS). 2013. Instrument Development and Validation Scientific Standards. Version 2.0. National Institutes of Health. [Online]. Available at: http://www.nihpromis.org/Documents/PROMISStandards_Vers2.0_Final.pdf?AspxAutoDetectCookieSupport=1 [Accessed 17 March 2016].

Polit, D. F., & Beck, C. T. (2017). *Nursing Research: Generating and Assessing Evidence for Nursing Practice* (10th ed.). London: Wolters Kluwer, Lippincott Williams & Wilkins.

Ryan, P., & Sawin, K. J. (2009). The Individual and Family Self-Management theory: Background and Perspectives on context, process and outcomes. *Nursing Outlook, 57*(4), 217–225.

Sawin, K. (2017). Definition, frameworks, and theoretical issues in self-management. *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary approach, 10*(2017), 169–176.

Sawin, K. J., Bellin, M. H., Roux, G., Buran, C. F., & Brei, T. J. (2009). The experience of self-management in adolescent women with Spina Bifida. *Rehabilitation Nursing, 34*(1), 26–38.

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

Schilling, L. S., Dixon, J. K., Knafl, K. A., Lynn, M. A., Murphy, K., Dumser, S., & Gray, M. (2009). A new self-report measure of self-management of type 1 diabetes for adolescents. *Nursing Research, 58*(4), 228–236.

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., ... Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship, 44*(2), 136–144.

Sousa, V. D., & Rojjanasrirat, W. (2011). Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: A clear and user-friendly guideline. *Journal of Evaluation in Clinical Practice, 17*(2), 268–274.

Swendeman, D., Barbara, L., Ingram, B. L., & Rotheram-Borusa, M. J. (2009). Common elements in self-management of HIV and other chronic illnesses: An integrative framework. *AIDS Care, 21*(10), 1321–1334.

Switzer, G. E., Wisniewski, S. R., Belle, S. H., Dew, M. A., & Schultz, R. (1999). Selecting, developing, and evaluating research instruments. *Social Psychiatry Psychiatric Epidemiology, 34*, 399–409.

UNICEF. (2018). HIV epidemiology among children and adolescents: Data. [Online] Available: https://data.unicef.org/topic/hivaids/adolescents-young-people/.

Van Staa, A.L. (2012). On your own feet: Adolescents with chronic conditions and their preferences and competencies for care. Dissertation Erasmus University Rotterdam, the Netherlands. Hogeschool Rotterdam, Rotterdam.

Wallston, K. A., Osborn, C. Y., Wagner, L. J., & Hilker, K. A. (2011). The perceived medical condition self-management scale applied to persons with HIV/AIDS. *Journal of Health Psychology, 16*, 109–115.

Webel, A. R., Asher, A., Cucu, Y., Okonsky, J. G., Kaihura, A., Rose, C. D., ... Salata, R. A. (2012). Measuring HIV self-management in women living with HIV/AIDS: A psychometric evaluation study of the HIV self-management scale. *Journal of the Acquired Immune Deficiency Syndrome, 60*(3), 72–81.

Zahavi, D. (2019). Getting it quite wrong: Van Manen and smith on phenomenology. *Qualitative Health Research, 29*(6), 900–907.

Zahavi, D., & Martiny, K. M. M. (2019). Phenomenology in nursing studies: New perspectives. *International Journal of Nursing Studies, 93*(2019), 155–162.