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ORIGINAL RESEARCH

Discourses of Mental Wellness Among Adolescents Living with HIV in Cape Town, South Africa

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Background: Adolescence is a unique period of development where individuals transition from childhood to adulthood, and where they are at heightened risk for developing mental health problems and engaging in risky behaviours. In addition, adolescents living with HIV (ALHIV) must learn to cope with challenges related to the biological impact of a chronic condition, adhering to lifelong treatment, and managing HIV-related psychological and social challenges. Mental wellness as a precursor to mental wellbeing, is vital to facilitate persistent adherence and engagement in care for optimal treatment outcomes for ALHIV. However, little is known about how ALHIV understand and talk about mental wellness in the context being on HIV treatment.

Methods: We conducted a photovoice study with 12 groups, consisting of 43 ALHIV, aged 15–19 years, and receiving HIV treatment at three public primary health care facilities in the Western Cape Metropole in South Africa.

Results: Through discourse analysis, we identified six themes that depicted mental wellness concepts that were prominent in their experiences, namely, connectedness, spirituality and mindfulness, social coherence and awareness, self-esteem, self-acceptance, and sense of coherence. In addition, the adolescents gave accounts of six mental wellness behaviours namely, self-efficacy, coping, resilience, life purpose, engagement in enjoyable life activities and physical functioning.

Discussion: These concepts and behaviours are similar to those identified in targeted interventions aimed at ALHIV. These mental wellness concepts and behaviours are critical to improving health outcomes for ALHIV and should be targeted in the delivery of youth friendly services and integrated HIV care in public healthcare facilities in South Africa and the sub-Saharan African continent.

Keywords: photovoice, HIV, adolescents, mental health, mental wellness

Introduction

Improved HIV treatment regimens and successes of prevention of mother-to-child transmission, have increased the life expectancy of HIV-infected children who are now surviving into adolescence.[1,2] In 2019, it was estimated that approximately 1.7 million [1,200,000–2,300,000] adolescents (age 10–19 years) were living with HIV, which includes 11,000 [8300–14,000] younger adolescents, age 10–14 years.[1] However, globally reports indicated that more deaths were recorded for adolescents living with HIV (ALHIV) than any other population group.[3] In Sub-Saharan Africa (SSA), HIV has been identified as a leading cause of adolescent morbidity and death, with 20,000 [14,000–29,000] AIDS related deaths recorded in 2020 in East and Southern Africa.[1] This suggests that there are critical gaps in the treatment cascade for ALHIV, living in low to middle-income countries (LMICs) that are yet to be addressed.[4]

Optimal adherence to antiretroviral therapy (ART) is necessary to achieve virological suppression, halt disease progression and decrease AIDS-related mortality.[5] Adolescents are challenged to persist in adherence due to various individual, social and health system level factors including poor mental health resulting from HIV related stigma and disclosure.[4–10]

Maintaining long term adherence is a process that affects adolescents' physical and mental wellness. There has been an increased focus on investigating the mental health challenges that adolescents face. The World Health Organization (WHO) reports that approximately 10–20% of people will develop mental health conditions during adolescence, with an estimated 50% of all mental health conditions starting before the age of 14 years.[11] Furthermore, mental health conditions

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during this period are associated with a range of risk behaviours, including tobacco and alcohol use, drug misuse, risky sexual behaviours and violence. For ALHIV these risks are compounded by the biological impact of having an infectious disease, the chronic nature of the treatment, HIV-related social and environmental stressors induced by stigma, and the myriad of psychological and social aspects of living with HIV, which negatively affect their mental health.[9] ALHIV are therefore experience heightened risk of developing mental health problems, which could lead to mental illness co-morbidities. This [poor mental health] is, in turn, associated with lower retention in care and adherence to ART, and lower rates of viral suppression.[4,9,12,13]

Adolescent research to date has focused on the prevalence and nature of mental illnesses. In this context, mental illness is often used as a euphemism for mental health, despite only representing a [smaller] segment of mental health. For ALHIV, threats to optimal adherence and engagement in care are often related to challenges to their mental wellness (ie, self-esteem, connections to others, hopefulness, etc.) which impact motivation. Left unchecked, poor mental wellness may worsen, leading to feelings of hopelessness, anxiety and depression, which can evolve into mental illness.[9] As such, addressing challenges and promoting mental wellness can help to prevent the development of long-term mental illness and improve adherence outcomes for ALHIV.[14–16] In our systematic review of mental wellness instruments used for adolescents, we identified 12 mental wellness concepts which were measured in the instruments, namely: life satisfaction, mental wellbeing [general], resilience, self-efficacy, self-esteem, connectedness, coping, self-control, mindfulness/spiritual, hope, sense of coherence, happiness, and life purpose.[17] In the current paper, we report on how ALHIV talk about mental wellness as experienced in their daily lives, and how these mental wellness behaviours are expressed.

Methods

We used a Photovoice methodology to explore how ALHIV experienced taking ART and adhering to treatment. Photovoice is a participatory method, which allowed participants to capture their experiences through photographs, thereby directing the narratives throughout the interview.[3,18] From these interviews, discourse around mental wellness emerged naturally as participants discussed what motivated them to adhere to treatment, as well as the challenges they experienced. Therefore, the Photovoice methodology was appropriate as it provided adolescents with a creative way to express themselves and allowed them to direct the group discussion to what was important from their own perspective.[3,18] We used the COREQ (COnsolidated criteria for REporting Qualitative research) Checklist to ensure the methodological rigour of the study.

Participants

We worked with three healthcare workers (a medical doctor and two nurses who were trained to initiate patients on ART) who acted as gatekeepers at the respective health facilities to recruit participants who met the criteria for the study. The three public primary health care facilities were purposively selected, because they were accredited youth-friendly services sites and provided ART adherence support programmes in the form of youth clubs or a family clinic.[18,19] The criteria for participants were: they must be living with HIV, between the ages of 10–19 years at the time of the study, receiving ART at the facility, and have been disclosed to [about their HIV status]. The current analysis focus on the older participants between 15–19 years.

Procedure

The research team (four members) received training in photovoice techniques and procedures by an experienced HIV researcher who applied photovoice methods in US settings, and these techniques were adapted to South African setting.[20] A pilot study was conducted in one facility as part of training the research team in photovoice methods and to test the adaption of methods to the setting.[3]

Three contact sessions were made with adolescent participants. In the first contact session, the health worker-gatekeeper introduced the researchers to eligible adolescent participants. This procedure differed from setting to setting. In one facility, these introductions were made one to one and coincided with ALHIV picking up their medication at the clinic. In the other two facilities, these introductions took place during the adherence club sessions. In these cases, the researchers obtained prior permission to attend and observe the adherence club session. Permission was obtained from all participants to record the procedures of the session (through written notes only). At the introductory session, the

researchers described the research to the participants and invited their participation, if they are within the designated age range. Those who agreed to participate, were provided with information sheets about the study in a language of their choice (Afrikaans, English or isiXhosa) as well as consent forms for themselves and their parent or guardian (if they were under 18 years).

A follow-up meeting was arranged with all interested adolescents. During the second meeting, the adolescents returned with their signed consent forms. At this meeting, we provided them with a cell phone with camera capabilities. We provided them with instructions on how to be safe with the cell phones, how to obtain permission to take photos (if these involved people), and how to use the cameras (which most of them were well-versed to do in any case). We gave them instructions to take at least five pictures which described their daily experiences - depicting both the good and challenging moments in living with HIV and being on treatment. We concluded this meeting by agreeing to a final meeting date – which was usually a week later – where they would meet as a group to present and discuss their photos.

Data Collection

At the third, final meeting the adolescents shared their pictures and discussed their stories with the group. The photos were uploaded on a laptop, and displayed on a projector. Each participant took a turn to present their photos, with discussion and inputs from the group and facilitators. Participants were allowed to express themselves in a language they felt most comfortable A translator (first language isi-Xhosa speaker) attended all group sessions to assist with facilitation, where needed.

In line with traditional focus group requirements, we structured each session to include 3–5 participants per group. We organized the participants by age (older adolescents 15–19 years vs 10–14 years) and sex (male vs female).

During the session, researchers would ask participants probing questions such as “what does this picture mean to you” or “how does this picture relate to your journey living with HIV?”. Each photovoice session lasted approximately 40–60 min; was digitally recorded, transcribed verbatim and translated where necessary.

Data Analysis

All transcripts with pictures were uploaded to Atlas.ti and subjected to discourse analysis (DA). As an analytical approach, DA is aimed at analysing language in relation to the social context, focusing on how meaning is created in different social contexts.[21] Therefore, this analytic process allowed us to interrogate and explore how mental wellness was discussed, positioned, and constructed by adolescent participants who were living with HIV and on treatment. Two researchers (the authors) were involved in the data analysis process. Firstly, we familiarised ourselves with the theory and literature around mental wellness by conducting a systematic review on measures of mental wellness among adolescents. This helped us to develop a preliminary framework of mental wellness concepts.[21,22] We also familiarised ourselves with the context of the healthcare facilities by conducting interviews with key healthcare workers.[19] This allowed us to develop an understanding of the real-life context of the discourse which emerged from the photovoice groups. Following this, we closely examined the transcripts, paying attention to words, sentences, paragraphs, and overall structure – and relating them to the attributes, themes, and patterns relevant to adolescent mental wellness.

Ethics

This project, which forms part of the first-author’s doctoral research project, follows the ethical principles set in the Declaration of Helsinki (1964) and received ethical clearance from the University of the Western Cape Biomedical Research Ethics committee (BM19/09/18). Prior to participation informed consent and assent was received by a relevant parent/guardian and the adolescent participant respectively. By signing the consent and assent forms, adolescent participants and their parent (s)/guardian (s) agreed to be recorded during the interview and that the results from the study may be published, while still ensuring the anonymity and confidentiality of the participants. In line with the Declaration of Helsinki, we aimed to protect the confidentiality of the participants by replacing all real names with pseudonyms and removing any identifying information.

Table 1 Gender Breakdown of Photovoice Groups by Health Facility

Health Facility	Females	Males	Total
X	3 (n=10)	2 (n=6)	5 (n=`16)
Y	2 (n=9)	2 (n=7)	4 (n=16)
Z	2 (n=8)	1 (n=3)	3 (n=11)

Findings

We conducted 12 photovoice groups (N = 43) with ALHIV across the three sites (Table 1). At this point data saturation was reached as no new themes emerged from the data. From the photovoice discussions we identified six mental wellness concepts namely: connectedness, spirituality and mindfulness, social coherence and awareness, self-esteem, self-acceptance, sense of coherence as well as six behaviours indicating mental wellness namely, self-efficacy, coping, resilience, life purpose, engagement in enjoyable life activities and physical functioning.

Connectedness

Connectedness is regarded as one of the key elements of mental wellness because it is associated with [higher] self-esteem and [increased] empathy for others.[23] In our study, adolescents described their connectedness with family members (eg, grandmother, sister, mother) and how this experience of emotional and instrumental support made them feel loved, esteemed, and valued, and evoked a reciprocal response. In the photovoice sessions, they presented pictures of their "loved ones" and described how these relationships provided a sense of purpose for living. One adolescent took a picture of her grandmother and presented to the group:

> The one I took with my granny … [It] is because [I] still [want to] see her continuously when I open my eyes. Through God's grace I want to see her here in front of me, waking me up saying "Come you must finish for school"; "Come, you must wash up." That is why I took a photo of her because she is my everything. Without her I do not know really." (Lesley, Girl, 15)

Another participant presented a picture of her sister and described how her love and [sense of] connectedness to her sister motivates her to persist in treatment adherence so that she can live a full life.

> Oh, this is my sister. You know, when I look at her, there's a moment that I want to be myself. You know she gave me hope. Like she's so young and I am sure she does not want to lose her sister. And I still want to see her grow and be beautiful and all this stuff. (Amy, Girl, 16)

Other adolescents, as seen in quote below, expressed that their connectedness to their family contributed to positive mental wellness and motivated them to persist in adherence to their [HIV] treatment regime, so that they would be well.

> So, it's like, family is like to me it's important to me. Every time I see them, all of them, I am always reminded of why I am doing this and why I am taking the medication. Every time I see them it motivates me to never give up. And even though, if I start to not to take [my medication] now, it will get worse and it will affect them also. (Imka, Boy, 15)

By extension, some participants expressed a sense of purpose in their desire to reciprocate the care and support that they received from their parents, by taking care of them in the future, as well as their siblings in the present.

> My mother is the greatest born creation. Like she does everything for me. So, actually, one day I have to do the same thing for her when she's old. (Kaya, Girl,16)

> The only reason why I still keep going is because of my father. Because my mother passed away and I am his only child. So, it's obvious I do not want to let him down. So that is the reason why I keep going. (Elaine, Girl, 19)

> Me as the oldest, I have grown up, I my mother used to leave me and my two sisters at home because she is a single mom. I want to make her proud one day. (Jason, Boy, 15)

Friends were also significant source of happiness for adolescents living with HIV. Many participants presented pictures of their best friends and described the positive impact that having these relationships had on their mental wellness.

> This is my best friend in this picture. This was the first day in school this term. I thought about the photovoice thing, and I asked her if I can take photo of her. And we took a lot of pictures, and this is one of them. And I am very happy when I am with her. (Alexa, Girl, 16)

> It's not like I am meant to die. So, I have two best friends and they know about this pill. So, like they motivate me every day to get well. At like six o'clock the send me a message "take your pills". (Amy, Girl, 16)

In some instances, participants reported that they trusted their friends sufficiently to disclose their HIV status to them. This resulted in them gaining a friend who is supportive to them on their HIV journey, by encouraging them through difficult times and motivating them to persist with treatment.

> This morning she came to me, and she told me to be strong for this stuff. And she told me I have to be strong and as I was sitting there, she sends me a message because I told her I am now here at the programme. So, she said she's proud of me because I am not a person who like to still talk to people. I am very quiet. I keep my stuff to myself. But she said she's very proud of me doing this and talking to other people (Maya, Girl, 15)

> They make sure that we attend our appointments. So they remind me say our appointment is tomorrow then tonight I told them already last week look here me and my sister must go to the hospital and if they ask me then I tell them maybe Friday then on Thursday they remind me they say yay you must go Friday to the hospital and when we go to the hospital, when we come here to the hospital they bring us halfway, till where we get the taxi, they put us in the taxi and so. (Jess, Girl, 16)

Participating adolescents also described having close connections with people in their community, such as the school and health service, who were sources of encouragement and supported them as they navigate living with HIV.

> Well, there is my accounting teacher. She's very supportive. My marks were dropping, it was like, because I was a top learner and then it started dropping. So, then she asked me "what's wrong, what's going on?" and those were the days that I was not taking my pills. And then we talked about it, and she was like "It's not the end of the world, you can still achieve your dreams whether you're HIV positive or not". So, I just realised that I still have my full life to live." (Amy, Girl, 16)

As the participants in this study frequent clinic settings, relationships with clinic staff were also discussed. The participant below described how having a close relationship with one of the nurses encouraged her to persist in treatment.

> She is my favourite nurse. Every time that I come to the hospital, I always go to her first and greet her. And she is the one who told me that I must not stop taking my tablets. (Jess, Girl, 15)

Spirituality and Mindfulness

Participating adolescents reported how their sense of spirituality and/or actively practicing their religion contributed to their mental wellness.[24] They expressed spirituality as feeling a connection with a higher power (God) and through meaningful practice of their faith as illustrated in the quote below:

> So, it helps - because I found God. And reading the Bible helps me. You know the words of the Bible. So, it just makes me feel much better than it is, because there's someone that cares about me. (Annika, Girl, 16)

One girl explained how her religion helped her come to terms with her HIV diagnoses and accept it without self-blame.

> It's that everyone, ok it was, I was supposed to get it, it was God's plan, so I don't have to blame myself, so yeah. (Amahle, Girl, 15)

Social Coherence and Awareness

Social coherence and awareness emerged as a theme as participants discussed social issues of interest to them.[25] Sizwe (16), for example, demonstrated social awareness and coherence by showing a picture of environmental health risks in his community, and declared his desire to make a change (see Figure 1):

Figure 1 Making sense of living conditions.

> I was, I was very … curious about what happened in that, what happened in that place, and also, I was also sad because there are some children who get infected and bad diseases because of places like that … and also, when I took this picture, I was thinking about how … the people can let that happen when they are still there. (Sizwe, Boy, 16)

In similar vein, another Amy (16), discussed her outrage at the sexual violence problem in the country by referencing the assault of a university student, which made national news at the time of the study. Implicit to these discussions is the awareness that these problems are not the norm and that something can be done or should be done to improve it.

> And I don't like when these men do, you know. I mean it's not cool to rape someone who, remember Uyinene, I mean she still had a whole long future ahead of her, but yet he deprived her of her future. So, it makes me quite mad, angry. I even have a picture. (Amy, Girl, 16)

This in turn motivated her to take action by organizing an event at her school to raise awareness about the issue:

> I want to be the voice of those voiceless people, those girls that went through this. We spoke to our Life Orientation teacher, and she told us that she just set a day and what the theme will be, and we had a personal speaker, we were singing some songs. We had this girl in my class, she was saying a speech. We had a teacher who's spoken a lot, and a teacher who also spoken a lot. And we were wearing purple ribbons. (Amy, Girl, 16)

Self-Esteem

In our study, participants brought up the way they feel about themselves in relation to their HIV status.[26] One girl showed a picture of herself, and explained to the group that despite being HIV positive, she feels good about herself:

> I love that picture and I love myself." (Amahle, Girl, 15)

As one participant indicated, moments where she feels good about herself help her feel "normal". This suggests that she may have internalised stigma around HIV, in which she sees herself as "less perfect" than others who do not have HIV.

> Okay, I enjoy taking pictures on snapchat [laughter] so uhm, whenever I take pictures, I just feel like this …. Slay queen and stuff like that and I imagine that I feel perfect and I, I forget that I'm actually sick, I feel like I'm a normal person - just like other people (Lerato, Girl, 17)

As adolescents develop, they learn more about themselves and who they want to be. Therefore, discussions around self-esteem are to be expected. Many adolescents may find fault with their appearance as they try to adhere to popularised beauty standards and base their self-esteem around that. Similarly, ALHIV may face certain general insecurities regarding their appearance. However, for some ALHIV, these insecurities may be directly related to being HIV-positive due to ongoing stereotypes and stigma. For participants in this study, increasing their self-esteem was related to overcoming internalised negative perceptions of HIV which in turn had a positive effect on their mental wellness as this led to increased self-acceptance.

Self-Efficacy

In this study, participants discussed the belief they have in themselves to achieve a particular goal or action.[27,28] These included realistic assessments of their current skill set or beliefs about their skills. As the quote below shows, the participant reflected on their own interpersonal skills and how these could be directed towards achieving their goals.

> [The reason I want to be] a social worker is because I love helping people. And I'm -, everybody says I'm very patient. I always listen to people and whenever someone talk to me, they can talk, and I can listen very carefully, and I can give them great advice. (Charlize, Girl, 17)

Like most adolescents, participants indicated that there are moments where they are not completely satisfied with their appearance. One participant demonstrated that self-efficacy played a role in her stopping the downward spiral of self-hate she experienced and moving in the opposite direction by changing her narrative and focusing on self-improvement and setting personal goals for herself.

> Well, I'm trying to lose weight, because yes, because during that period of time I was like eating a lot. So, I'm just trying to get back to my original self. (Amy, Girl, 16)

The participants described how having a sense of self-efficacy had positive effects on their mental wellness because their belief in their own skills and capacities helps them to maintain the motivation needed to achieve certain life goals. Like other adolescents, as the participants in our study engaged in the world around them, they developed more confidence in their skill sets.

Self-Acceptance

Through the discussions participants revealed that despite experiencing challenges around living with HIV, they have come to accept themselves as they are and have accepted that living with HIV is part of their journey.[29,30]

> Okay, this is a picture of a bin. A bin keeps … like dirty papers and stuff like, the things that are already used … You cannot put someone in a bin, that's not right. So, the fact that I am HIV-positive, I cannot be put in a bin, I am still going to live my life because I am not a paper after all. If my family knew that I am HIV-positive, they not going to throw me in the bin. I am still going to live because I am not a paper … The bin is only for papers, not for people. (Hope, Girl, 18) (see Figure 2).

Another female participant presented a picture of herself and reflected on how her initial reaction was to see herself as "different" to her peers when she first found out about her HIV diagnosis. These negative perceptions about the self were indicative of them experiencing internalized stigma when their HIV status was disclosed to them [since they were perinatally infected]. However, they were able to process this initial "shock" and come to accept themselves as both HIV positive and beautiful.

> Yes … okay that picture … I just see myself [as] beautiful … so when I first found out that I had HIV, I felt like I was different from all the kids, but seeing that picture - it makes me happy (Thandi, Girl, 16)

One participant discussed how she was bullied at school after one of her classmates found out about her status, and how this negatively affected her self-esteem. During the interview she reflected on finding out about her diagnoses and how she struggled with feelings of anger and blame toward her parents. Therefore, the bullying she experienced represented a breaking point, exacerbating the unresolved anger and sadness she felt regarding her diagnosis and her relationship with

Figure 2 People are not trash.

her parents. The culmination of her low-self-esteem and her struggling relationship with her parents resulted in suicidal thoughts (hopelessness) and led her to default on her treatment. However, her relationship with other key figures in her life, such as her sister, friends, and her favorite nurse, provided her with the love and support she needed to help her feel better about herself [self-esteem] and her situation [hope]. Through this, she learned to accept herself and her HIV status which motivated her to re-engage in her HIV treatment.

> I see him but I just don't care anymore. I don't care what he thinks about me or what he says about me. He doesn't define me (Amy, Girl, 16)

The abovementioned quotes indicate that self-acceptance and self-esteem go hand-in-hand to mediate towards positive mental wellness. As ALHIV attain self-acceptance, inclusive of their HIV status, they are able to buffer internal stigma and external [negative] messages and achieve higher levels of self-esteem and feel "normal".

Sense of Coherence

Participants demonstrated a sense of coherence by finding meaning in their lives – through embracing their status [accepting that living with HIV is part of their lives] and directing their energy towards living positively.[25] The quote below from Amy shows how she learned to reframe negative messages she received by replacing it with truths [comprehensability], and thereby finding "new" meaning for her life:

> So, Alex, again, told me that no-one's going to marry me because of the disease. And for a long time, I actually believed that but then I realised that it's not actually true. I mean you are going to meet someone and that will work. Because I mean my aunt died, she also had HIV. She had HIV and then she got married. And her husband still loved her. So, I want to have a husband with eight kids. (Amy, Girl, 16)

Others expressed that they have a sense of ownership [manageability] over their own lives, and they can maintain this by continuing to take their medication.

> "I know that it is my life, I'm doing this for myself - so I have to take my medication." (Thandi, Girl, 16)

Through the comparison with the flower, the participant demonstrates how she found meaning in her situation by indicating that they are aware that managing their health and wellbeing is a process which they must constantly engage in and nurture (see Figure 3).

Figure 3 Nurturing health.

> This flower is to show me how I am going to look if I keep on taking my medicine. It's like water to them. So if you water plants they will grow up and be beautiful like these so it reminds me every time I see those I should take my medicine so that I can be beautiful and strong like them (Stacy, Girl, 15)

This participant's quote demonstrates that maintaining a sense of coherence is a process which involves self-reflection to comprehend who they are as a person and what possibilities their future holds [meaning].

> "My favourite colour is pink, my hobby is dancing, I am very soft hearted, kind friendly outspoken straightforward and fun at all times. I like to go places I have never been yet before. I also like making new friends. Sometimes I just sit back and think to myself that this disease I am living will never go away. But if I take my medication always and on time, I will live a longer life and a life like anyone else. There are times I cried because I always think that I will not have friends, kids, husband or live a life like any woman but no I thought the wrong way. Sister Anne told me it will not be the way I thought it would be' (Emma, Girl, 15)

For ALHIV, a sense of coherence is tied with their diagnosis, as they need to overcome initial internal and external assumptions about living with HIV and engage in activities to make meaning of their situation and manage a lifelong condition while trying to live "normal" lives. Through the discussions, participants revealed that achieving a sense of coherence is a process in which they engage in self-reflection to understand themselves, who they want to be and what they want out of life in the context of living with HIV. This sense of coherence helped participants living with HIV to find meaning in their lives and identify future goals to work towards. This increased their hope for the future and positively contributed to their mental wellness.

Coping

While all adolescents may experience stressors in life and need to find ways to cope, ALHIV face specific stressors related to their condition.[31] This includes managing lifelong adherence to treatment and coping with external stressors related to stigma, disclosure and beliefs around living with HIV. The role of music as a coping mechanism among adolescents is well documented in research and many of the participants discussed using isolation time in combination with listening to music as ways to cope when life becomes too stressful.[31] Through engaging in this activity, they were able to regulate their [high] emotional states and return to states of mental wellness.

> I don't talk to them in my personal time. Like I always listen to music, and I feel better. So, then I just walk to my room, switch off some lights and say I'm going to keep quiet. (Farai, Girl, 16)

> Sometimes I feel blank or white inside and then I just listen to music and ignore the world for that moment and then the music calms me down or makes me feel better than I was before. (Emma, Girl, 15)

Resilience

Participants discussed their capacity to adapt to life's challenges and withstand adversity.[7] For example, Girl (17) discussed how she overcomes her [emotional] challenges through reflection and accepting that these challenges are transient and out of her control, yet she can control her actions and make the best out of her situation.

> So, I took a picture of the rain so … when I'm sad and all that … about my condition, I actually get encouraged to take my medication. So, rain is like a blessing and without the rain nothing grows. So, I thought, why not embrace … like the storms of my life and actually accept my situation and actually take my pills (Lerato, Girl, 17) (see Figure 4)

ALHIV may be more exposed to adverse experiences around death which could negatively affect their mental wellness. However, as the participants in this study indicate, having a strong sense of resilience improved their mental wellness by acting as a buffer against negative effects, protecting against experiencing mental health problems and increased their motivation to be healthy and well.

Life Purpose/Goals

Like many adolescents, ALHIV have life goals they wish to achieve.To attain their goals, they are required to change their outlook on life and adhere to their treatment.[32] This was demonstrated in this study as many participants discussed that they were motivated to live healthy lives and adhere to their treatment so that they may achieve their goals. As is typical of adolescence, participants described their goals in ways that reflect their idealism – some wish to pursue dreams of fame and fortune while others simply wish to be successful despite not having a clear identified path. For example, one participant shared that she wishes to be successful in life so that she can afford to buy her dream car (see Figure 5). Regardless, having aspirations and goals to work towards fosters hopefulness for the future which has a positive effect on current mental wellness.

> I want to pursue my dreams. I want to like, live life and … yeah so … I don't want to die before I do something that I love most, which is singing. That's why I take my pills everyday (Thandi, Girl, 16)

> "And also, I want to complete my school … I want to complete school so that I can be successful one day" (Max, Boy, 16)

Figure 4 Weathering the storms of life.

Figure 5 Future goals.

The participants in this study demonstrated the beneficial effects of having life goals on their mental wellness through their motivation to stay healthy to achieve their goals.

Engaging in Enjoyable Life Activities

Like most adolescents, participants in this study discussed a range of activities which they frequently engage in and enjoy based on their personal interests, including playing sports, singing, dancing, reading, taking photographs and spending time with family and friends.

> "Uhm, it's my family and myself, yeah all of them is my family and uhm … the things I love to do which is singing and dancing" (Thandi, Girl, 16)

> "I Play Soccer and Sometimes I Play Chess, Rugby" (Kabelo, Boy, 16)

> "Mostly when I listen to songs … and I love singing so when I sing it also makes me happy" (Beth, Girl, 16)

Physical Functioning

The participants in this study are all living with HIV, therefore conversations around physical health and wellbeing emerged.[15,33–35] As previously mentioned, participants enjoy engaging in various activities like playing sports, dancing, and hanging out with their friends. To do this, participants need feel a sense of physical wellbeing. Participants in this study showed an awareness of maintaining their physical health. As the quote below illustrates, the adolescent is aware that to continue doing what he enjoys (playing soccer), he needs to take his medication (to keep him fit and healthy).

> I like to play soccer. But I have learnt in the past that if I don't take my medication, then my body get weak. Then I can't play soccer. So, this is another thing that motivates me to take my medication so that so that my body can … so that I can use my body to play soccer. (David, Boy, 16)

Another participant used an example of a tree to illustrate that his medication is a way of taking care of his health, which will give him a good life. He suggests that being strong and healthy will also influence his wellbeing in general.

> When taking the picture of the tree I felt that … when taking the picture that, I felt that it was a good example of a human being, because it start from the seed … and the human adult, when he is a grown up … the tree here tells me that if a human being continues to take his medication, he will grow up and feel free, and the trees have a good life and … and have a healthy, happy life, and the tree here is strong. That shows that when a human being … takes care of his or her body … will be strong, fresh, energetic … and feel good for their life (Bongani, Boy, 16) (see Figure 6).

Figure 6 Strength in nature.

Discussion

The emergence of both mental wellness concepts and behaviours provides support for mental wellness as a relational, multidimensional concept which includes mental (spirituality, self-acceptance, self-esteem, self-efficacy, sense of coherence), social (connectedness, social coherence) and behavioural/physical dimensions (coping, resilience, life purpose/goal, engaging in enjoyable activities, physical functioning).[36–38]

We observe that ALHIV in our study seem to emphasise both eudaimonic (social coherence, self-efficacy, sense of coherence, coping, resilience, life purpose/goal) and hedonic concepts (connectedness, spirituality, self-esteem, self-acceptance, engaging in enjoyable activities, physical functioning) of mental wellness. This aligns with previous studies indicating that a balance between hedonic and eudaimonic pursuits are necessary for optimal mental wellness and well-being.[36,37]

We propose the model in Figure 7 below to demonstrate mental wellness in ALHIV. In this, the green represents hedonic mental wellness and blue represents eudaimonic mental wellness. As shown in the figure, Sense of Coherence, Self-esteem, and Self-acceptance represent the Self – the ongoing constructions that ALHIV produce in the experiences and interactions with their inner and external worlds. These aspects of the self are related and associated with the other mental wellness concepts and behaviours that emerged from our findings. In other words, ALHIV may experience social coherence for example, but lack coping/resilience skills in which case they may adopt a pessimistic view of the world which, in turn, could increase hopelessness and other challenges to mental wellness. Therefore, increasing *Sense of Coherence* as a whole may be more beneficial to improve long term mental wellness than focusing on individual concepts or behaviours. From the model, we note that *Sense of Coherence* influences *Self-esteem* and has a relational effect on other mental wellness concepts and behaviours such as *Connectedness* or *Self-efficacy*. This means that having a high *Sense of Coherence* overall can lead to a high sense of *Self-esteem* which in turn is also influenced by the adolescents'

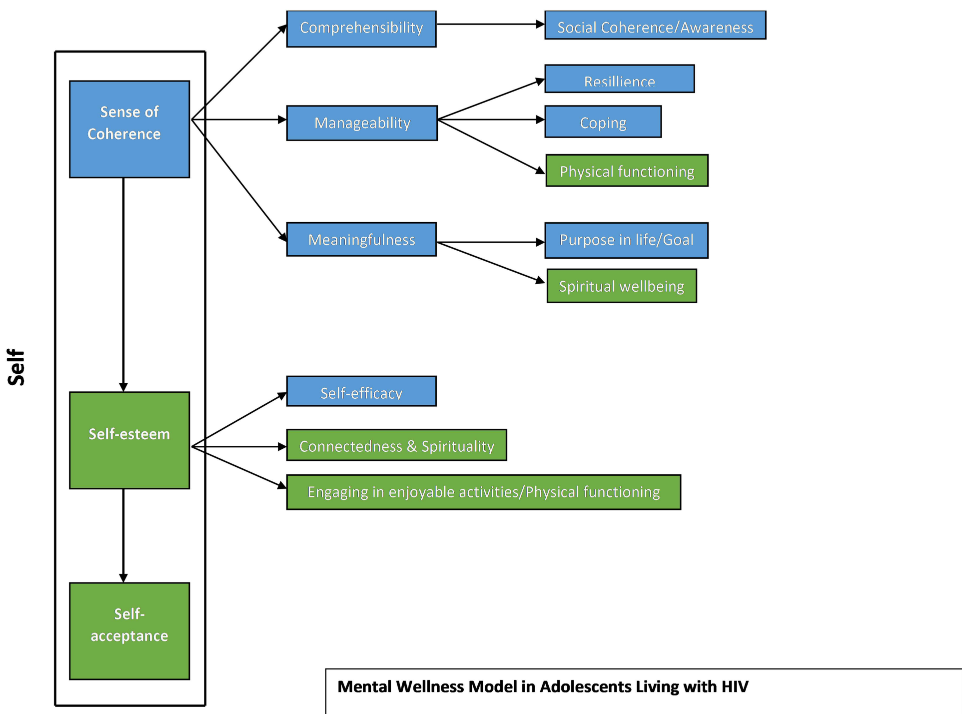

Figure 7 Model of mental wellness for adolescents living with HIV.

relationships with others, their confidence in their abilities and their overall physical wellbeing. As seen in the model, *Physical Functioning* and *Spirituality* are represented in both *Sense of Coherence* and *Self-esteem*. This indicates that these concepts play an integrating role at the different levels of Self. Therefore, interventions aimed at developing these two aspects in adolescents may yield double benefits by improving outcomes on both *Sense of Coherence* and *Self-esteem*, which in turn could have an overall positive effect on the related mental wellness concepts and behaviours. From this, *Self-esteem* influences *Self-acceptance* – while the literature describes these as being related, yet conceptually different, we argue that high *Self-esteem* is a pre-requisite for *Self-acceptance*. Literature on adolescent mental wellness often includes a focus on self-esteem, as evidence has consistently shown that higher self-esteem is associated with better emotional and behavioural adjustment, school performance and other educationally significant outcomes and improved social skills.[26,39]

There is much empirical evidence to support the merits of promoting self-esteem in adolescents. As such, self-esteem has become a popular measure of mental wellness in research with adolescents as demonstrated in a systematic review of mental wellness instruments used among adolescents, in which the Rosenberg Self-Esteem measure was used most frequently in comparison to other mental wellness instruments.[17] However, we argue that while promoting self-esteem is necessary to achieve mental wellness, it is not sufficient to maintain mental wellness. To maintain long term mental wellness, adolescents need to go beyond experiencing self-esteem to develop unconditional self-acceptance. Self-acceptance refers to a positive attitude toward yourself, following a "balance sheet" of integrating or reconciling both good and bad qualities of self that results in feeling content about your present in spite of the past. Adolescence is a period of experimentation and self-explorations; therefore, they may be more susceptible to external influences and may change aspects of themselves in order to be socially accepted, resulting in a higher sense of self-esteem. However, as seen in this study, ALHIV may feel the need to hide their status due to societal believes around HIV, which could result in internalizing stigma about HIV and thus negatively affect their self-acceptance and mental wellness. Therefore, self-acceptance is an important factor to consider as studies have shown that interventions aimed at improving mental wellness may be less beneficial for people with lower self-acceptance.[29,30] Unlike self-esteem, self-acceptance cannot be

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categorised into a high or low dichotomy therefore it does not fluctuate and can be considered a better predictor of mental wellness. We argue that interventions aimed at improving mental health among ALHIV should incorporate elements to improve and promote high self-esteem and then work on translating that positive affect to self-acceptance.

Additionally, experiencing high levels of one mental wellness concept or behaviour is not enough to ensure overall mental wellness. As shown in Figure 7, the mental wellness concepts and behaviours identified in this study do not exist independently. Rather, mental wellness represents a system in which each of the concepts and behaviours represents an interconnected part that moves and works together as a whole. Some of these parts may be prevail over others and can thus compensate or act as a fail-safe if there are any problems in other parts of the system. For example, an adolescent may experience a strong sense of connectedness to others, but after performing poorly in school may go through a phase in which they experience poor self-esteem. In this case, they can rely on their relationships with others to support them and seek help to better their performance which over time can help to increase their self-esteem. Conversely, a lack of connectedness may have allowed the adolescent to become overwhelmed by their feelings of low self-esteem which in turn could perpetuate other challenges to their mental wellness (ie, hopelessness, low self-worth, isolation etc.) leading to increased vulnerability for developing mental illness. In the case of ALHIV, such events can result in them becoming loss to follow-up (LTFU) and defaulting on treatment. Therefore, there is a need to develop and implement multicomponent interventions for ALHIV.

Evidence suggests that targeted interventions aimed at general adolescent populations include specific psychosocial components such as mindfulness (spirituality), stress management (coping), problem solving skills (self-efficacy) assertiveness training (self-esteem) and emotional regulation (sense of coherence, self-acceptance), are associated with more successful mental health outcomes in adolescent populations.[9] There are fewer studies exploring the impact of such interventions on targeted groups like ALHIV. A scoping review by Okonji et al[40] on psychosocial interventions aimed specifically at ALHIV identified four psychosocial treatment modalities aimed at improving adherence among ALHIV namely, individual counselling, support groups, family-centered services, and treatment supporters.[40] Our study supports previous research as we demonstrate that ALHIV have different psychosocial support needs in comparison to their peers – therefore, universal interventions targeting changing peer dynamics, goal setting, self-esteem or family dynamics may hold a different significance for ALHIV as they navigate issues around disclosure or planning for a healthy adult life.[9,40] Therefore, we argue that the mental wellness concepts and behaviours identified in our study can be used as building blocks to inform targeted interventions or adherence clubs specifically aimed at promoting positive mental health [mental wellness] in ALHIV which can help them to overcome life's challenges and establish healthy behaviours to protect them from risk in the present and their future adult lives.

Study Limitations

Due to the qualitative nature of this study, the limitations of conducting research with a smaller sample and in a particular socio-cultural context are noted. While our study was open to include as diverse a sample as possible, we were limited to the participants that attended and received treatment at the facility. Further all participants were fully engaged in HIV care at the time of the study; and thus, it is acknowledged that their perceptions and meanings of mental wellness within the context of an HIV treatment programme may differ vastly from those lost to follow-up or disengaged from care. To this end, we observed that many participants in our study had history of poor adherence and disengagement from care and re-engaged prior to participating in the study. It is worth mentioning that in two health facilities youth [adherence] clubs were implemented, which is known to activate peer support for ALHIV. In the other health facility, a family clinic intervention was in place, which facilitated family support for the adolescent on treatment. These interventions have been noted to provide critical psychosocial support for ALHIV on ART to various levels of effectiveness as reported in our previous review.[17] Participation in these interventions contributed to greater exposure to health education and treatment literacy, which may have influenced how participants in our study expressed mental wellness in the context of HIV.

Conclusions

Our findings illustrate critical mental wellness concepts and behaviours that shape the experiences of ALHIV on ART. We posit that the success of current psychosocial and adherence support interventions for ALHIV is dependent on how

these intervention modalities trigger activate key mental wellness concepts and behaviours. Therefore mental wellness should be measured as part evaluations of interventions to improve treatment outcomes for ALHIV on ART. We recommend that future interventions include exploratory qualitative studies to contextualise mental wellness and behaviours in their respective settings to inform the development and/or adaption of evidence-based interventions.

Ethics Approval and Informed Consent

This project, which forms part of the first-author's doctoral research project, received ethics clearance from the University of the Western Cape Biomedical Research Ethics committee (BM19/09/18). All participants provided written assent/consent.

Consent for Publication

All images in this paper are published with the participant's consent.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors report no conflicts of interest in this work.

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