Conceptualisation and operationalisation of mental wellness: Developing an instrument to measure mental wellness among adolescents living with HIV in South Africa

Zaida Orth

Student number: 3743915

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Supervisor: Prof. Brian van Wyk

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Photovoice Participatory
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Positive psychology
Systematic review

DECLARATION

I declare that this work, 'Conceptualisation and operationalisation of mental wellness: Developing an instrument to measure mental wellness among adolescents living with HIV in South Africa,' is my own work.

I declare that this work has not been submitted for any degree or examination in any other university and all sources I have used or quoted have been indicated and acknowledged by complete references.

Student…… Date: 31 December 2022

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ACRONYMS AND ABBREVIATIONS

ALHIV	-	Adolescents living with HIV
ART	-	Antiretroviral therapy
CC	-	Chronic Condition
CDI	-	Child Depression Inventory
CFQ	-	Cystic Fibrosis Questionnaire
CHQ	-	Child Health Questionnaire
CMD		Common mental disorders
CYRM	-	28 - Child Youth Resilience Measurement
DoH	-	South African Department of Health
FLZ	-	Questions on Life Satisfaction
HIC	-	High-Income Countries
HOPES	-	Hunter Opinions and Personal Expectations Scale
HRQoL	-	Health-Related Quality of Life
LMICs	-	Low- and Middle-Income Countries
MWM-ALHIV	-	Mental Wellness Measure for Adolescents Living with HIV
MY-Q	-	Monitoring Individual Needs in Diabetes Youth Questionnaire
NGO	-	Non-governmental organisation
PedsQL-DMTM	-	Paediatric Quality of Life Inventory Diabetes Module
PLHIV	-	People Living with HIV
PLC	-	Quality of Life Profile for Chronic Diseases
PMTCT	-	Prevention of mother-to-child transmission
PROMIS	-	Patient-Reported Outcomes Measurement Information
SystemQoL	-	Quality of Life
SDGs	-	Sustainable Development Goals
SDQ	-	Strengths and Difficulties Questionnaire
SF-36	-	Short Form 36 Health Survey
SMoMW	-	Salutogenic Model of Mental Wellness
SOC	-	Sense of Coherence
SSA	-	Sub-Saharan Africa
TB	-	Tuberculosis

UNAIDS	-	The Joint United Nations Programme on HIV/AIDS (UNAIDS)
UNICEF	-	United Nations Children's Fund
WHO	-	World Health Organization
YFS	-	Youth friendly services

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ABSTRACT

Adolescents living with HIV (ALHIV) are a key population in the fight against HIV and AIDS. The comparatively poorer treatment outcomes of ALHIV in relation to child and adult HIV populations indicate the need for a health response to improve adolescent ART service delivery. Research suggests that improving mental wellness may be imperative to improving HIV-treatment behaviours such as long-term adherence and engagement in care. However, little is known about what mental wellness means for ALHIV. It is further unknown what critical mental wellness concepts should be targeted in adolescent interventions. Ultimately, understanding mental wellness in ALHIV is essential to design programmes that will help them navigate their chronic condition to lead healthy and productive lives. Furthermore, there is a need for valid and culturally appropriate mental wellness instrument(s) for ALHIV in hyper-endemic HIV and resource-constraint settings in Africa. This doctoral research project aimed to conceptualise mental wellness for ALHIV and to develop an instrument for measuring mental wellness in a South African context.

The research project consists of three phases. In the first phase, we established the need for a measuring instrument through a systematic review of mental wellness instruments for adolescents. The findings from the systematic review were used to develop a preliminary conceptual framework of mental wellness constructs. In the second phase, we conducted a photovoice study with ALHIV from three public primary healthcare facilities in the Cape Town Metropole District, South Africa. The findings from the second phase were used to identify relevant mental wellness domains for ALHIV and to refine the preliminary mental wellness framework from phase 1. The mental wellness framework was then used to guide the integrative review search strategy, which aimed to identify mental wellness concepts in literature focused on ALHIV in the African context. The findings from phases 1 and 2 aided in establishing the theoretical foundations and conceptualisation of mental wellness for ALHIV in the African context. Using these findings, we developed a Salutogenic Model of Mental Wellness (SMoMW) which, in turn, informed the development of the Measure of Mental Wellness for Adolescents Living with HIV (MWM-ALHIV) instrument. We established the content and face validity of the MWM-ALHIV through a Delphi study and cognitive interviews with a sample of ALHIV, respectively.

The proposed MWM-ALHIV instrument, upon piloting and translation to local languages, could be used to identify unique mental wellness needs of ALHIV living in various South African contexts and used in conjunction with interventions to improve HIV treatment

outcomes as well as for [general] mental health promotion. The MWM-ALHIV instrument may be used as a tool to screen mental wellness among ALHIV in the South African context and identify those who may benefit from interventions and mental health promotion services to prevent the development of mental health problems. Furthermore, the instrument can be used to monitor the progress and efficacy of such interventions and mental health promotion services. Instrument development is a time consuming and expensive undertaking – therefore the benefit of the MWM-ALHIV in its current state is that it can be used by other researcher to advance research on mental wellness among ALHIV by further developing the tool in different contexts or to lay the groundwork for the development of similar tools.

SECTION I: OVERVIEW

CHAPTER 1

Understanding mental health and adherence to antiretroviral treatment among adolescents living with HIV in South Africa

Background

Adolescence is a unique developmental period. During the transition from childhood to adulthood, adolescents aged 10-19 years experience rapid physical, cognitive, emotional, psychological, and social growth [1]. They learn that as you get older, your world becomes bigger, bringing with it exciting new opportunities, experiences and challenges which need to be managed – the choices they make, the skills they acquire, the support they receive and the way they connect with others during this period sets the foundation for their health and wellbeing later in life. UNICEF reports that an estimated 1.3 billion adolescents are living in the world today, comprising 16% of the global population – making them the largest youth generation in history [1]. The growth in the global adolescent population is attributed to successful public health efforts to increase the survival rates among infants and children [2]. However, the growth in adolescent populations has shifted focus to recognising their unique health needs [2]. Adolescents are currently prioritized in the global health agenda - as arguments are made that investing in adolescent health and wellbeing will have a triple return on investment by optimizing the health, social and economic benefits during adolescence, which will carry across the life course [2, 3]. Therefore, adolescents' health and well-being are crucial drivers of change to create healthier, more equitable and sustainable communities [2, 3].

Improving adolescent health and wellbeing is not without challenges, as economic, social and environmental changes have given rise to new opportunities and threats to adolescent health [2]. Adolescents face multiple biological (HIV/AIDS, obesity, pollution, climate change and rise in non- communicable diseases such as diabetes and mental illnesses), psychological (suicide, depression, self- harm and substance use), and social (risky sexual behaviour, exposure to violence, poverty, gender inequalities, bullying, childhood neglect, food insecurity, teenage pregnancy and education exclusion) risks and stressors [2–4]. It is estimated that the effects of these duplicitous risks may have serious implications on their health and potential to thrive across the individual's life course. Reports estimate that over 1.5 million adolescents died in 2020 - most of which were preventable or treatable [5]. Adolescents are a heterogenous group

whose health profiles vary considerably across global contexts [6]. For example, UNICEF data from 2019 indicated that the top causes of death among adolescent boys and girls aged 15-19 years were road injury, interpersonal violence, tuberculosis (TB), maternal conditions and self-harm, respectively [6]. In comparison, regional reports indicate that the leading causes of death among the same groups in Sub-Saharan Africa (SSA) were road injury, TB, interpersonal violence for boys, and maternal condition, HIV/AIDS, and TB for girls [6]. The heterogeneity in the causes of death and disease among adolescents globally highlights the need for disaggregated data to monitor and improve health service delivery to be responsive to the rapidly changing needs of adolescents. As Kalmakova states, it is critical to developing national, regional and global responses that recognise the unique needs of adolescents and provide tailored services to help them thrive as individuals [7].

Furthermore, HIV continues to be a major health risk and represents a significant burden of disease and mortality for adolescents globally [8–10]. Adolescents are the fastest-growing age group of people living with HIV (PLHIV). South Africa currently has one of the highest populations of adolescents living with HIV (ALHIV) in the world, which was estimated at 320 000 [210 000 – 410 000] in 2021 [8]. Additionally, reports indicate that 33 000 [4 400 – 62 000] adolescents living in South Africa between the ages of 10-19 years were newly infected with HIV in 2021 [8]. ALHIV can be categorised into two groups based on the mode of HIV transmission – those who were behaviourally infected due to engaging in high-risk behaviours (i.e., unprotected sexual intercourse, substance use and sensation-seeking behaviours) and those who were perinatally infected (during birth, pregnancy or breastfeeding) [11, 12]. In South Africa, the prevention of mother-to-child transmission (PMTCT) programme was launched in 2004, which led to huge strides in curbing the incidence of HIV infection among infants [13]. Therefore, the increase in the prevalence of ALHIV can be attributed to ongoing new cases of behaviourally infected adolescents and increased access to antiretroviral therapy (ART), which enabled millions of perinatally infected children to survive and reach adolescence [14–17].

For ALHIV, the experiences and challenges of adolescence are also shaped by their experience living with a highly stigmatized, chronic condition [18, 19]. It is widely reported that ALHIV experiences worse mental and physical health outcomes than non-infected adolescent peers and other groups of PLHIV, such as adults and children [18, 20, 21]. Indeed, reports indicate that AIDS-related mortality is the leading cause of death among African adolescents [22]. Furthermore, UNAIDS reports that since the epidemic's peak in 2002, the

number of annual AIDS- related deaths among children has declined by 75%, while the number of annual AIDS-related deaths among adolescents has only decreased by 21% [23]. The discrepancy in AIDS-related deaths among ALHIV is especially concerning in the wake of improved access to and effectiveness of ART services and regimens that have transformed HIV from a deadly disease to a manageable, chronic condition [22, 24, 25]. The higher mortality among ALHIV is linked with sub-optimal rates of treatment adherence and retention in care, suggesting that they experience gaps in the HIV treatment cascade [16, 17, 26]. Therefore, we need to understand the type of care and support that ALHIV need to ensure sustained adherence to ART.

Adherence among adolescents living with HIV

Sustained adherence to ART is needed to achieve and maintain viral suppression of HIV [27, 28]. Two markers of ART, namely viral load (HIV RNA) and CD4 T lymphocyte cell (CD4) counts, are used to manage and monitor a patient's HIV infection and disease progression [29, 30]. Viral suppression is defined as having less than 200 copies/mL of HIV viral replication in the blood, while CD4 count refers to the amount of white blood T cells in the blood [29, 30]. According to the WHO, adolescents, adults and children aged 5 years and older are considered to have advanced HIV disease if they present with a CD4 cell count less than 200 cells/mm^3 [29, 30]. To be considered stable, patients should be on ART for one year, have no co-morbid illnesses, demonstrate a good understanding of lifelong treatment adherence, and demonstrate treatment success through two consecutive viral load measurements below 1000 copies/mL [29, 30]. Therefore, routine viral load testing, which is conducted at 6 and 12 months after ART initiation, followed by every 12 months after that, is recommended as the preferred method to confirm treatment failure as well as manage and monitor a patient's HIV infection status [29, 30]. However, in cases where routine viral load testing is unavailable, treatment failure should be diagnosed based on routine clinical monitoring, CD4 count and targeted viral load testing where possible [29, 30].

Sustained adherence to ART is a dynamic and complex process which involves following a treatment plan, taking daily medications as directed by a healthcare provider and following instructions regarding nutrition and other healthcare-related behaviours [15]. Recently, UNAIDS has launched the *Undetectable = Untransmittable* (U=U) campaign to raise awareness that having an undetectable viral load resulting from optimal ART adherence stops the transmission of HIV [31]. Achieving sustained adherence reduces the viral load to the point

of being undetectable in laboratory tests (HIV RNA <20 -75 copies/mL). As such, it is imperative to ensure that optimal adherence is achieved among ALHIV to counter rising HIV incidence rates in this age group, prevent viral rebound and HIV drug resistance and decrease mortality rates [27, 28, 32].

Achieving optimal adherence among ALHIV requires effective and comprehensive service delivery in all aspects of the HIV care continuum - testing, linkage to care, treatment and retention in care [24–26]. It is advocated that the mode of transmission may impact how ALHIV navigate through the HIV care continuum and how they experience care [12]. For example, perinatally infected ALHIV are typically diagnosed during infancy or early childhood, initiated on treatment in paediatric care and subject to full disclosure of their HIV status during early adolescence (around 11-12 years). On the other hand, behaviourally infected ALHIV need to seek out, and access testing services to know their status and initiate treatment – a process which may be hampered due to stigma, lack of information or difficulties in accessing services [12]. Despite the increased availability of ART, UNAIDS reports that only 54% of ALHIV globally were on treatment in 2020 [8]. Furthermore, sustained adherence among ALHIV is complex and often not a linear process as many ALHIV struggle to remain engaged in care and may become lost to follow-up (LTFU). For example, a recent retrospective cohort analysis of 16,108 ALHIV enrolled at ART clinics in the Ehlanezi district in South Africa, indicated that retention in care dropped over two years from 90.5% at six months to 76.2% at 24 months [33].

Therefore, despite the efforts to curb the HIV epidemic through an increase in HIV-testing campaigns and scale-up of ART programmes, evidence of the poorer health outcomes among ALHIV suggest that they are at risk of being left behind. Studies have shown that ALHIV faces unique challenges related to adherence and retention in care which is associated with various physical, social, and psychological barriers such as difficulties in accessing treatment, delayed disclosure of HIV status, stigma, lack of support, lack of resources, treatment fatigue, transitioning from paediatric to adult care, inadequate healthcare facilities, and mental health [32, 34–38]. The range of barriers to treatment ALHIV experience indicates that effective health service delivery should be holistic, integrated into families, communities and health systems, and tailored to adolescents' mindsets and needs.

Mental health and adolescents living with HIV

There has been an increase in research focusing on the relationship between mental

health and adherence – not only because poor mental health is associated with non-adherence but also because mental health is a significant driver of adolescent health in general [39, 40]. According to the World Health Organization (WHO) [40], common mental disorders (CMD) (e.g., anxiety and depression) are a leading cause of disability among adolescents accounting for 13% of the global burden of disease. At the same time, suicide is identified as the second leading cause of death among adolescents globally. Studies have shown that ALHIV may experience a double disease burden as reports indicate a high prevalence of co-morbid CMDs [18, 41–44]. Conversely, a growing body of evidence suggests that improved mental health outcomes among ALHIV are associated with improved treatment outcomes [34, 45–47]. For example, Findings from the VUKA family programme in South Africa indicate that adolescent participants aged 10-14 years improved on all measure's dimensions, including mental health and adherence to ART [48]. Similarly, findings from a mobile intervention to support mental health and adherence among ALHIV in Kenya found that participants' mental health and adherence improved after six months [49]. The abovementioned findings, along with the growing global recognition of the importance of adolescent health, have amplified calls to strengthen mental health promotion – to prevent the onset of mental health disorders through efforts to increase protective factors (mental wellness) and healthy behaviours – and to provide integrated mental health services for ALHIV on ART.

The increasing recognition of the mental health needs of ALHIV is evidenced in its inclusion in global health reports such as the WHO technical brief on *Safeguarding the future: Giving priority to the needs of adolescent and young mothers living with HIV* [50] as well as the UNICEF policy brief on *Mental health and antiretroviral treatment adherence among adolescents living with HIV* [51]. While this is a step in the right direction, various ongoing challenges are associated with policy uptake, implementation and providing adequate mental health care to ALHIV. For example, while there is a lack of targeted policies for ALHIV, the South African National Adolescent and Youth Policy emphasises that HIV treatment services should include support for 'mental illnesses' screening [52]. However, this vague recommendation does not provide clear guidance on how mental health should be screened, what constitutes 'mental illnesses' or what support services are available, especially for ALHIV who may show signs of mental health problems but are not diagnosed with a mental illness. Such considerations should be clarified as Cluver et al. [53] state there is a significant gap in mental healthcare for adolescents in general, especially in low and middle-income countries (LMIC). Consequently, only a small portion of ALHIV have access to and receive mental health

services. Additionally, there has been an increase in the provision of alternative care models aimed at increasing adherence and improving mental health outcomes among ALHIV, such as youth clubs and other psychosocial interventions (i.e., peer or family support models) [34, 54–58]. However, assessing the long-term effectiveness of such interventions is complicated due to the sustainability of the interventions and the measurement of mental health outcomes [59].

Relatedly, a major challenge to providing and assessing care is how mental health is defined [59, 60]. Despite the depth of information on the topic, mental health remains an elusive concept, as is evident in the consistent lack of agreement over how mental health should be conceptualised. As shown in Box 1, there are various attempts to delineate the conceptual parameters of mental health – in line with the advent of positive psychology and salutogenic models of health – contemporary definitions share commonalities in recognition that mental health is more than the absence of illness, but also includes dimensions of positive functioning and feeling [60, 61]. Indeed, over the last few decades, there has been a proliferation of wellness and wellbeing discourses in both academic and public spheres, signifying a greater recognition of the importance of addressing health holistically to prevent disease and achieve health goals for all. Consequently, there have been increased calls to integrate mental health promotion strategies in public healthcare as a means to enable individuals and communities to improve their mental health as a state of wellness [61–65]. However, the discourse around mental wellness and mental health promotion are incongruent with the healthcare system's practices and values, which continues to perpetuate the pathogenic paradigm focusing on the prevalence, burden, and risk factors of the disease rather than building human potential to sustain good health [64, 66]. The pathological view of health and mental health is a pervasive and dominant paradigm in research and health service delivery – we tend to focus on what causes disease or how to improve individualised symptoms, thereby reducing people to the sum of their problems. Therefore, the possible scope of mental health promotion in health service delivery depends on how mental health is defined in this context.

Similarly, research on mental health among ALHIV tends to focus on recording the prevalence of CMDs or reducing the symptoms of mental illness, which deflects attention from the significance of promoting mental wellness. For example, both the VUKA programme and the Kenyan mobile intervention were aimed at improving mental health, yet instruments used to measure mental health in these studies are designed to measure symptoms of mental illness, like the Child Depression Inventory [48, 49]. Additionally, findings from systematic reviews

on psychosocial interventions for ALHIV indicate that activities such as motivational interviewing, cognitive-behavioural therapy (CBT), peer and family support groups, mindfulness techniques and financial empowerment show promise in reducing mental health problems and improving psychological wellbeing among ALHIV in the African context [38, 41, 55, 67]. However, such studies tend to report on a wide range of mental health outcomes, with depression and anxiety being the most frequent reported outcomes [38, 41, 55, 67]. Taking the WHO definition into consideration which states that 'mental health is more than the absence of illness' – we can argue that the improvements to mental health reported in these studies represent a reduction in mental illness symptoms rather than 'improved mental health' [40].

By only measuring mental illness symptoms, we risk developing a one-dimensional view of mental health among ALHIV, affecting the type of treatment and services they receive. Moreover, focusing on pathology alone underestimates the capacity of adolescents to be resilient and thrive despite their circumstances [68]. Therefore, we need to create a holistic understanding of mental health among ALHIV, which includes a comprehensive focus on understanding the mental health problems they experience and their mental wellness. As shown in Box 1, while there is a lack of agreement, existing definitions of mental health emphasise that pathology is a small part of the mental health paradigm. Good mental health includes aspects of positive functioning, empowerment, resilience and building capacities of individuals and communities. Such definitions provide a broad framework but do not fully operationalise what mental wellness means to adolescents, much less for ALHIV. To develop a holistic and comprehensive profile of mental health among ALHIV, we need first to understand what mental wellness is and how ALHIV experience it as both a state and resource to navigate everyday life.

Box 1. Examples of Definitions of mental health

World Health Organization (2000)**:** "state of well-being in which the individual realizes his or her abilities, copes with the normal stresses of life, works productively and fruitfully, and makes a contribution to his or her community" [4]

Barry and Jenkins (2007)**: "**A good state of mental health is a resource for everyday life and contributesto the quality of life and well-being" [69]

Margaret Barry (2009)**: "**a positive emotion or affect such as subjective sense of well-being, and feelingsof happiness, a personality trait encompassing concepts of self-esteem and sense of control, and resilience in the face of adversity and the capacity to cope with life stressors" [70]

Marie Jahoda (1958)**:** "positive mental health includes attributes such as an efficient perception of reality,self-knowledge, the exercise of voluntary control over behaviour, self-esteem and self-acceptance, and the ability to form affectionate relationships and productivity" [71]

Problem statement

There have been significant scientific advances to improve the efficacy of ART regimens and service delivery. For example, Dolutegravir (DTG) is the WHO recommended first-line drug to treat HIV and has proven to be more effective, easier to take, shows fewer side effects than alternatives, and has a high genetic barrier to developing drug resistance [72]. However, the low HIV testing rates, high mortality, and increased prevalence of co-morbid mental health problems among ALHIV indicate that health service delivery is lagging behind and struggling to meet the needs of ALHIV, especially in LMICs. Addressing the diverse and unique needs of ALHIV requires integrated and comprehensive approaches which address behavioural, social, and psychological components to improve HIV-related health outcomes and overall wellbeing [11, 26, 73]. In recognition, the WHO published guidelines on providing Youth Friendly Services (YFS) in healthcare settings as an evidence-based intervention to provide accessible, appropriate and acceptable health services for adolescents and young people. In line with this, non-governmental organisations (NGOs) in South Africa, such as *loveLife*, collaborated to develop and implement the National Adolescent-Friendly Clinic Initiative (NAFCI) in 2009, which aimed to provide appropriate services for adolescents and address barriers to service uptake [74, 75]. Additionally, the South African Department of Health (DoH) developed the National Adolescent and Youth Health Policy in 2017 and highlighted the provision of quality YFS as a key strategy in its mission to improve the health

status of young people [74, 75].

Despite the availability of guidelines and evidence supporting the efficacy of YFS in public healthcare and buy-in from key stakeholders, evaluation reports indicate that health facilities experience challenges in implementing such services long term, which is related to a lack of resources, financial constraints and limited staff availability [74, 75]. Furthermore, existing YFS are often poorly integrated with services specifically for ALHIV, including mental health services [74, 75]. Compounding the challenges of service delivery for ALHIV is the lack of evidence to support the implementation, provision, and monitoring of YFS to ensure that ALHIV receives appropriate services that meet their unique needs [74, 75].

Providing appropriate YFS for perinatally infected ALHIV is critical to support their transition from paediatric to adult care, because a growing body of evidence has shown that this transition is a contributor to poor treatment outcomes for ALHIV on ART. Additionally, such services may also help older behaviourally infected ALHIV who are expected to enter adult HIV programme, which is often described as not being sensitive to the needs of adolescents [74, 75]. Transitioning ALHIV to adult care is beneficial because this provide access to ART regimens that are more effective and present with fewer side effects. However, as mentioned before, ALHIV face nuanced challenges related to HIV care and require relevant support, such as YFS, to help them adapt to the adult care environment and adopt appropriate health behaviours to self-manage their chronic condition.

There has been a proliferation of policies to guide adolescents from paediatric to adult care, such as the South African *National Consolidated Guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents, and adults* [13]. However, standardized definitions, measures of a successful transition, and tracking tools are lacking [76]. Furthermore, integrating mental health promotion services in YFS to support mental wellness among ALHIV is crucial as evidence has shown that mental wellness is a significant protective factor that can help to prevent the development of mental health problems and support long-term adherence. Emerging evidence suggests that mental wellness factors such as hope and resilience may help direct healthy behaviours among ALHIV and motivate them to stay on treatment [42, 77–79]. A key step towards integrating mental wellness services into care and improving YFS is the inclusion of routine mental wellness screening in public healthcare for ALHIV. However, few measures are available to provide much-needed evidence on what mental wellness means to ALHIV or which mental wellness

factors are most significant in supporting their well-being and health.

Additionally, one of the goals of the National Strategic Plan (NSP) for HIV, TB and STI 2017-2022 is to increase adherence and retention in care through a combination of approaches which includes: '*community education and awareness initiatives, patient tracking systems, routine patient counselling, the use of PLHIV and PTB to encourage adherence and access to services and age-appropriate psychosocial support'* [33]. Part of this strategy lies in the development of various differentiated HIV treatment and care models which operate parallel to mainstream ART care [15]. Studies have shown that these differentiated models can improve adherence and retention in care and may function to alleviate the burden of congestion in public healthcare facilities [15].

One such differentiated care model is the adherence club intervention, which aims to improve adherence by providing patient-friendly access to ART and peer support for clinically stable HIV patients [80]. Evidence from pilot studies suggests that the adherence club model improved retention in care and adherence and relieved clinic congestion [57, 81]. As an extension, the adherence club model has been modified to youth clubs to address the specific needs of ALHIV [57]. However, the role and influence of psychosocial support within such models are only partially understood and most often poorly implemented. Empirical evidence is needed to describe the interaction of differentiated models of care with other psychosocial support interventions and how this may improve mental wellness among ALHIV for improved adherence and retention in care.

To contribute to the body of evidence on understanding mental health among ALHIV and the role it plays in supporting adherence outcomes, we aimed to conceptualise mental wellness among ALHIV and develop an instrument to measure this in the South African context. Such an instrument is needed to build an evidence base of the critical mental wellness factors that should be prioritised in interventions and YFS for ALHIV. Additionally, this measure can screen and identify which ALHIV are at risk of developing mental health problems during any stage of the HIV care continuum so that they may receive adequate care.

Aims and objectives

The doctoral research project aimed to conceptualise mental wellness for ALHIV in the context of the HIV "test and treat" era and to develop a mental wellness instrument for ALHIV.

The two main objectives of the study were:

1. To conceptualise mental wellness amongst ALHIV and identify key mental wellness constructs. This objective was achieved through phases 1 and 2:

- **Phase 1**: To identify the gap(s) and establish the need for a mental health instrument for adolescents living with HIV through a systematic review.

- **Phase 2**: To establish the theoretical foundations of mental wellness through (1) conducting an exploratory photovoice study with ALHIV, which aided in describing the context of HIV service delivery for ALHIV and identifying the mental wellness discourses (concepts) that are relevant to ALHIV on ART; and (2) conducting an integrative review of mental wellness concepts for ALHIV to confirm the mental wellness concepts that were identified in the systematic review and photovoice studies.

2. To develop a mental wellness instrument for ALHIV. This objective was achieved through the third phase of the study, which included:

- **Phase 3:** To develop the instrument and establish content validity by conducting a Delphi Study with experts in the field; and to establish the face validity of the instrument through cognitive interviewing with ALHIV.

Project design and methodology

This doctoral study followed a multi-phased, mixed-methods exploratory sequential design. Cresswell [82] argues that a mixed-methods design is useful for developing an instrument or exploring a phenomenon in depth. A further strength of the experimental sequential design is that it can easily be applied to multiphase research studies.

As the study aims to develop an instrument to measure mental wellness, we utilized test construction theory design as a framework to guide the study and methodological choices. Test construction is not linear. Rather, it comprises multiple phases in developing and evaluating a test to measure a specific phenomenon [83]. While a substantial body of literature collectively outlines the instrument development process with various guidelines proposed, the guidelines proposed by DeVellis [83] and Boateng et al. [84] provide a comprehensive methodological overview of the test construction process. DeVellis [83] presents the fundamentals of social science scale development in a series of steps, while Boateng et al. [84] present the phases of

scale development as a primer for best practices in scale development in measuring complex social phenomena. DeVellis [83] provides complete detail of each of the steps and theory involved in scale development through the following steps:

1) determine what is measured,
2) generate an item pool,
3) determine the format of the measure,
4) expert review and revision, and
5) pilot testing and establishing psychometric properties.

Boateng et al. [81] provide clear and logical boundaries to indicate the differences in item- and scale- development and scale evaluation as three distinct phases, including nine steps:

1) Item development: Identification of domain, item generation and content validity
2) Scale development: Pre-testing questions, survey administration, item reduction, extraction of factors
3) Scale evaluation: Test reliability and validity.

In this PhD project, we report on the first four steps of DeVellis [83] and the 1st phase of Boateng et al. [84] to guide the development of a mental wellness measure for ALHIV in South Africa and inform the methodological choices. Based on these guidelines, we conceptualized the study over three phases:

(1) identifying the gap, (2) setting the theoretical foundations and (3) item development and initial validation (figure 1.1).

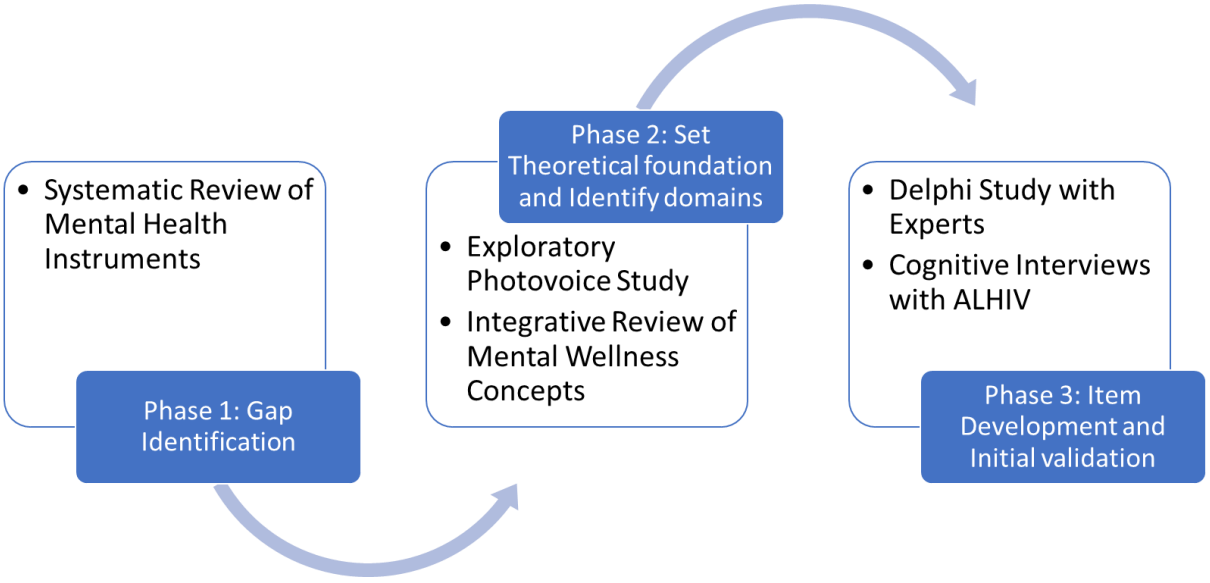

Figure 1.1: Process to develop the mental wellness measure for adolescents living with HIV

Phases 1 and 2 addressed the study's first objective and represented the first two steps of the DeVellis framework - which aimed to establish what is being measured. To this end, we first set out to identify the gaps and establish the need to develop an instrument through a systematic review of all instruments used to measure mental health among adolescent populations. The systematic review was chosen as an appropriate method to aid in identifying measures that already exist for adolescent populations and determine how adolescent mental health is being measured in research. Our interest wrested in developing an instrument to measure mental wellness specifically. However, as we identified early on in the study, there is a lack of agreement on how mental health is defined – therefore, it was decided that reviewing instruments which measure positive and negative aspects of mental health would help us to develop a comprehensive understanding of the concept in general. Additionally, we retained a broad scope of the review to include all adolescent populations between the ages of 10-19 years to be as inclusive as possible and to allow for comparisons between different groups of adolescents.

The second phase built on the findings from phase 1 to establish the theoretical foundations of mental wellness for ALHIV. We used photovoice methods with ALHIV and qualitative interviews with key healthcare workers to determine the most relevant mental wellness factors for ALHIV to be included in the instrument. Photovoice is a participatory method that allows participants to reflect creatively, talk freely and share their narratives of mental wellness. Therefore, this method was particularly useful in listening to the participants'

feelings and experiences, giving us an improved understanding of mental wellness from their perspective without imposing our own biases and assumptions.

Additionally, the qualitative interviews with the healthcare workers further contextualised the role of mental wellness and supporting adherence to ALHIV from the health systems perspective. According to Krause [85], utilising multiple qualitative methods is useful for triangulation and strengthening the item development strategy. As such, we set out to further refine the findings from phases 1 and 2 through an integrative review of mental wellness concepts identified in research with ALHIV in the African context. This review provided further clarity on what mental wellness concepts are salient for ALHIV in the African context and aided in establishing the concepts' operationalisation. The findings from phases 1 and 2 were used to develop a conceptual model of mental wellness for ALHIV in the African context, which served as a guide for the item writing phase.

Phase 3 of the study addressed the second objective of this study and represented the 3rd and 4th steps of DeVellis's [83] framework. In this phase, we generated items for each domain in the instrument using the findings from the previous phases. We developed a draft version of the instrument, including the operational definitions for all the included concepts, the measure format, and scaling decisions. To establish *content validity*, we conducted a Delphi Study with a panel of key experts in the fields of instrument design, adolescent mental health, and ALHIV. As highlighted in DeVellis' framework, consulting the experts is essential in the test construction process by providing consensus on the relevance of the domain how it is operationalised and verifying that the key dimensions of the domain are included [83]. Once the feedback from the Delphi study was integrated, we conducted cognitive interviews with a sample of ALHIV to establish *face validity*. These phases represent the completion of phase 1 of Boateng et al. [84] test construction framework and the first four steps outlined by DeVellis [83]. Phases 2 and 3 of Boateng et al. and step 5 of DeVellis' framework represent an ongoing process beyond the scope of the doctoral study.

Overview of the thesis

Section I presents an overview of the context of mental health and adherence among ALHIV, and the methodology used to carry out this doctoral study. In the following sections, I present the findings from the three phases and end with the conclusions and recommendations.

In **Section II**, we report on the first phase of the study. The findings from the systematic

review are presented and illustrate how the review provided a comprehensive view of the literature on measuring mental health in adolescents globally. The findings from this review provided the necessary justification to develop a measure of mental wellness for ALHIV in South Africa.

In Section **III**, we report on the findings from the study's second phase. The findings from the photovoice study and integrative review were used to establish the theoretical foundations of mental wellness for ALHIV and map the relevant mental wellness concepts, culminating in the development of the Salutogenic Model of Mental Wellness (SMoMW).

In Section **IV**, we report and present the findings of the third phase of the study. We describe how the SMoMW was used to guide the development of the instrument, which was then reviewed by a panel of experts and a sample of ALHIV to establish the content and face validity. We present the conclusion at the end of this section which states the contribution of this thesis and provides recommendations for future research.

References

[1] UNICEF. Adolescent health and well-being. 2022. Available from: https://www.unicef.org/health/adolescent- health-and-well-being.

[2] Health A, Sawyer SM, Afi RA, et al. Series Adolescence: A foundation for future health. Lancet. 2012; 379: 1630–1670. doi: 10.1016/S0140-6736(12)60072-5.

[3] Patton GC, Sawyer SM, Santelli JS, et al. Our future: a Lancet commission on adolescent health and wellbeing. Lancet. 2016; 387: 2423–2478. doi: 10.1016/S0140-6736(16)00579-1

[4] World Health Organization. Health for the world's adolescents: A second chance in the second decade. 2014. Available from: https://apps.who.int/iris/handle/10665/112750.

[5] UNICEF. Adolescent data portal. 2022. Available from: https://data.unicef.org/adp.

[6] UNICEF. Adolescents. 2022. Available from: https://data.unicef.org/topic/adolescents/overview/.

[7] World Health Organization. Health for all: Meeting the needs of children and adolescents through enabling policies. 2022. Available from: https://www.who.int/news/item/07-12-2022-health-for-all-meeting-the-needs-of-children-and-adolescents-through-enabling-policies.

[8] UNAIDS. AIDSinfo. 2022. Available from: https://aidsinfo.unaids.org.

[9] Bhana A, Abas MA, Kelly J, et al. Mental health interventions for adolescents living with HIV or affected by HIV in low- and middle-income countries: Systematic review. BJPsych Open. 2020; 6: 1- 15. doi: 10.1192/bjo.2020.67.

[10] Dambi JM, Cowan FM, Martin F, et al. Conceptualisation and psychometric evaluation of positive psychological outcome measures used in adolescents and young adults living with HIV: a mixed scoping and systematic review protocol. BMJ Open. 2022; 12: 1-8. doi: 10.1136/bmjopen-2022- 066129.

[11] Inbarani N, Sinovuyo T, Ronel S, et al. Past and current status of adolescents living with HIV in South Africa, 2005–2017. BMC Res Notes. 2022;15: 1-6. doi: 10.1186/s13104-022-06006-2.

[12] Sherr L, Cluver LD, Toska E, et al. Differing psychological vulnerabilities among behaviourally and perinatally HIV infected adolescents in South Africa–implications for targeted health service provision. AIDS Care. 2018; 30: 92–101. doi: 10.1080/09540121.2018.1476664.

[13] Sherman GG, Mazanderani AH, Barron P, et al. Toward elimination of mother-to-child transmission of HIV in South Africa: How best to monitor early infant infections within the Prevention of Mother- to-Child Transmission Program. J Glob Health. 2017; 7(1):1-8. doi: 10.7189/jogh.07.010701.

[14] Lowenthal ED, Marukutira TC, Chapman J, et al. Psychosocial assessments for HIV+ African adolescents: Establishing construct validity and exploring under-appreciated correlates of adherence. PLoS One. 2014; 9: 1–8. doi: 10.1371/journal.pone.0109302.

[15] Bhana A, Mellins CA, Small L, et al. Resilience in perinatal HIV+ adolescents in South Africa. AIDS Care. 2016; 28(2): 49–59. doi: 10.1080/09540121.2016.1176676.

[16] UNAIDS. The youth bulge and HIV. 2018. Available from: https://www.unaids.org/sites/default/files/media_asset/the-youth-bulge-and-hiv_en.pdf.

[17] UNAIDS. Ending the AIDS epidemic for adolescents, with adolescents A practical guide to meaningfully engage adolescents in the AIDS response. 2016. Available from: https://www.unaids.org/sites/default/files/media_asset/ending-AIDS-epidemic-adolescents_en.pdf.

[18] Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc. 2017; 20: 21497. doi: 10.7448/IAS.20.4.21497

[19] Zungu, N., Naidoo, I., Hodes, R., North, A., Mabaso, M., Skinner, D., Gittings, L., Sewpaul, R., Takatshana, S., Jooste, S., Moyo, S., Ramlagan, S., Cloete, A., Toska, E. & ALHIV, team. Adolescents living with HIV in South Africa. Pretoria: Human Sciences Research Council, 2021.

[20] Kim MH, Mazenga AC, Yu X, et al. High self-reported non-adherence to antiretroviral therapy amongst adolescents living with HIV in Malawi: Barriers and associated factors. J Int AIDS Soc .2017; 20: 1–12. doi: 10.7448/IAS.20.1.21437

[21] West N, Schwartz S, Mudavanhu M, et al. Mental health in South African adolescents living with HIV. AIDS Care. 2019; 31: 117–124. doi: 10.1080/09540121.2018.1524121

[22] UNICEF. HIV and AIDS in adolescents. 2021. Available from: https://data.unicef.org/topic/hiv-aids/.

[23] UNAIDS. Global HIV and AIDS statistics – Fact sheet.2020. 2021. Available from: https://www.unaids.org/en/resources/fact-sheet.

[24] World Health Organization. HIV and Adolescents: Guidance for HIV testing and counselling and care for adolescents living with HIV. Recommendations for a public

health approach and considerations for policy-makers and managers. 2013. Available from: https://apps.who.int/iris/handle/10665/94334.

[25] UNICEF. Adolescents living with HIV: Developing and strengthening care and support services. 2016. Available from: https://www.unicef.org/eca/sites/unicef.org.eca/files/2017-10/Adolescents_Living_with_HIV.pdf.

[26] Cluver LD, Sherr L, Toska E, et al. From surviving to thriving: Integrating mental health care into HIV, community, and family services for adolescents living with HIV. Lancet Child Adolesc Health. 2022; 6(8): 582-592. doi:10.1016/S2352-4642(22)00101-8

[27] Nachega JB, Hislop M, Nguyen H, et al. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in Southern Africa. J Acquir Immune Defic Syndr. 2009; 51: 65–71. doi: 10.1097/QAI.0b013e318199072e

[28] Enane LA, Vreeman RC, Foster C. Retention and adherence: Global challenges for the long-term care of adolescents and young adults living with HIV. Curr Opin HIV AIDS. 2018;13(3):212-219. doi:10.1097/COH.0000000000000459

[29] Clinical Info HIV.gov. Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV. 2022. Available from: https://clinicalinfo.hiv.gov/en/guidelines/hiv-clinical-guidelines-adult-and-adolescent-arv/plasma-hiv-1-rna-cd4-monitoring.

[30] World Health Organization. What's new in treatment monitoring: Viral load and CD4 testing. 2017. Available from: https://apps.who.int/iris/bitstream/handle/10665/255891/WHO-HIV-2017.22-eng.pdf.

[31] UNAIDS. Undetectable = Untransmittable: Public health and viral load suppression. 2018. Available from: https://www.unaids.org/en/resources/presscentre/featurestories/2018/july/undetectable- untransmittable.

[32] Zhou S, Cluver L, Shenderovich Y, et al. Uncovering ART adherence inconsistencies: An assessment of sustained adherence among adolescents in South Africa. J Int AIDS Soc. 2021; 24: 25832. doi: 0.1002/jia2.25832

[33] Okonji EF, Wyk B van, Mukumbang FC. Two-year retention in care for adolescents on antiretroviral therapy in Ehlanzeni district, South Africa: a baseline cohort analysis. AIDS Care. 2022: 1-11. doi: 10.1080/09540121.2022.2057409.

[34] Spaan, P.; Luenen, S.; Ganesfski, N.; and Kraaiji V. Psychosocial interventions enhance HIV medication adherence: A systematic review and meta-analysis. J Health Psychol. 2018; 25 1326–1340. doi: 10.1177/1359105318755545.

[35] Naidoo K, Munsami A, Archary M. Adolescent antiretroviral management: Understanding the complexity of non-adherence. SAMJ. 2015; 105(11): 1-3. doi: 10.7196/SAMJ.2015.v105i11.10150.

[36] Nguyen N, Lovero KL, Falcao J, et al. Mental health and ART adherence among adolescents living with HIV in Mozambique. AIDS Care. 2022: 1-9. doi: 10.1080/09540121.2022.2032574.

[37] Haberer JE, Sabin L, Amico KR, et al. Improving antiretroviral therapy adherence in resource-limited settings at scale: A discussion of interventions and recommendations. J Int AIDS Soc. 2017;20(1):2137. doi:10.7448/IAS.20.1.21371.

[38] Kim SH, Gerver SM, Fidler S, et al. Adherence to antiretroviral therapy in adolescents living with HIV: Systematic review and meta-analysis. AIDS. 2014; 28: 1945–1956. doi: 10.1097/QAD.0000000000000316.

[39] Sherr L. Comment Mental health—a bridge not so far. Lancet Glob Health. 2017; 5: e559–e560. doi: 10.1016/S2214-109X(17)30183-3.

[40] World Health Organization. Adolescent mental health. 2021. Available from: https://www.who.int/news- room/fact-sheets/detail/adolescent-mental-health.

[41] Dessauvagie AS, Jörns-Presentati A, Napp A-K, et al. The prevalence of mental health problems in sub-Saharan adolescents living with HIV: A systematic review. Global Mental Health. 2020;7: 1-13. doi: 10.1017/gmh.2020.18.

[42] Fabri M, Ingabire C, Cohen M, Donenberg G. The mental health of HIV-positive adolescents. Lancet Psychiatry. 2015;2(8): e21. doi: 10.1016/S2215-0366(15)00291-6.

[43] Haas A, Technau KG, Pahad S, et al. Mental health, substance use and viral load suppression in adolescents receiving ART at a large paediatric HIV clinic in South Africa. J Int AIDS Soc. 2020; 1– 26. doi: 10.1002/jia2.25644.

[44] Boyes ME, Cluver LD, Meinck F, et al. Mental health in South African adolescents living with HIV: Correlates of internalising and externalising symptoms. AIDS Care. 2019; 31: 95–104. doi: 10.1080/09540121.2018.1524121.

[45] Greifinger R & Dick B. Provision of psychosocial support for young people living with HIV: Voices from the field. SAHARA-J. 2011, 8;1: 33–41. doi: 10.1080/17290376.2011.9724982.

[46] Petersen I, Bhana A, Myeza N, et al. Psychosocial challenges and protective influences for socio- emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. AIDS Care. 2010; 8:970–978. doi: 10.1080/09540121003623693.

[47] Mavhu W, Berwick J, Chirawu P, et al. Enhancing psychosocial support for HIV positive adolescents in Harare, Zimbabwe. PLoS One. 2013; 8: 1-9. doi: 10.1371/journal.pone.0070254.

[48] Bhana A, Mellins CA, Petersen I, et al. The VUKA family program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV-infected early adolescents in South Africa. AIDS Care. 2014; 26: 1–11. doi: 10.1080/09540121.2013.806770.

[49] Chory A, Callen G, Nyandiko W, et al. A pilot study of a mobile intervention to support mental health and adherence among adolescents living with HIV in Western Kenya. AIDS Behav. 2022; 26: 232– 242. doi: 10.1007/s10461-021-03376-9.

[50] World Health Organization. Safeguarding the future: Giving priority to the needs of adolescents and young mothers living with HIV. 2021. Available from: https://apps.who.int/iris/bitstream/handle/10665/350035/9789240039896-eng.pdf?sequence=1&isAllowed=y.

[51] UNICEF, University of Cape Town & University of Oxford. Mental health and antiretroviral treatment adherence among adolescents living with HIV: Evidence on risk pathways and protective factors. 2021. Available from: https://www.unicef.org/esa/documents/mental-health-and-antiretroviral-treatment-adherence.

[52] South African National Department of Health. National adolescent & youth health policy 2017. 2017. Available from: https://www.uj.ac.za/wp-content/uploads/2021/10/key-doc-adolescent-and-youth-policy- 4-sept-2017.pdf.

[53] Hudelson C, Cluver L. Factors associated with adherence to antiretroviral therapy among adolescents living with HIV/AIDS in low- and middle-income countries: A systematic review. AIDS Care. 2015; 27(7): 805–816. doi: 10.1080/09540121.2015.1011073

[54] Crowley T, Rohwer A. Self-management interventions for adolescents living with HIV: A systematic review. BMC Infect Dis. 2021; 21: 1–29. doi: 10.1186/s12879-021-06072-0.

[55] World Health Organization. A qualitative review of psychosocial support interventions for young people living with HIV. 2009. Available from: https://apps.who.int/iris/handle/10665/70174.

[56] Mukumbang FC, van Belle S, Marchal B, et al. Exploring 'generative mechanisms' of the antiretroviral adherence club intervention using the realist approach: A scoping review of research- based antiretroviral treatment adherence theories. BMC Public Health. 2017; 17(1): 1–14. doi: 10.1186/s12961-019-0428-z.

[57] Mukumbang FC, Orth Z, van Wyk B. What do the implementation outcome variables tell us about the scaling-up of the antiretroviral treatment adherence clubs in South Africa? A document review. Health Res. Policy Syst. 2019; 17(28): 1-12. doi: 10.1186/s12961-019-0428-z.

[58] Okonji EF, Mukumbang F, Orth Z, et al. Psychosocial support interventions for improved adherence and retention in ART care for adolescents and young people living with HIV: A scoping review. BMC Public Health. 2020;20: 1–27. doi: 10.1186/s12889-020-09717-y

[59] Laurenzi C, Skeen S, Gordon S, et al. Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence. J Int AIDS Soc. 2020; 23:1-6. doi: 10.1002/jia2.25556.

[60] Manwell LA, Barbic SP, Roberts K, et al. What is mental health? Evidence towards a new definition from a mixed methods multidisciplinary, international survey. BMJ Open. 2015; 5: 1–11. doi: 10.1136/bmjopen-2014-007079.

[61] Eriksson C, Arnarsson ÁM, Damsgaard MT, et al. Towards enhancing research on adolescent positive mental health. Nordic Welfare Research. 2019; 4: 113–128. doi: https://doi.org/10.18261/issn.2464- 4161-2019-02-08.

[62] Roscoe LJ. Wellness: A review of theory and measurement for counselors. J Couns Dev. 2009; 87: 216–226. doi: 10.1002/j.1556-6678.2009.tb00570.x

[63] Bodeker G, Pecorelli S, Choy L, et al. Well-being and mental wellness. In: Oxford Research Encyclopaedia of Global Public Health. Oxford: Oxford University Press; 2020.

[64] Manderscheid RW, Ryff CD, Freeman EJ, et al. Evolving Definitions of Mental Illness and Wellness. Prev Chronic Dis. 2010; 7(1): 5–10. http://www.cdc.gov/pcd/issues/2010/jan/09_0124.htm.

[65] Ryan RM, Huta V. Wellness as healthy functioning or wellness as happiness: The importance of eudaimonic thinking (response to the Kashdan et al. and Waterman discussion). J Posit Psychol. 2009; 4(3): 202–204. doi: 10.1080/17439760902844285.

[66] Ryff CD, Singer BH, Love GD. Positive health: Connecting well-being with biology. Philos Trans R Soc Lond B Biol Sci. 2004; 359: 1383–1394. doi: 10.1098/rstb.2004.1521.

[67] Njau T, Ngakongwa F, Sunguya B, Kaaya S, Fekadu A. Development of a psychological intervention to improve depressive symptoms and enhance adherence to antiretroviral therapy among adolescents and young people living with HIV in Dar es Salaam Tanzania. Healthcare. 2022; 10(12):2491. doi: 10.3390/healthcare10122491

[68] Shoshani A, & Steinmetz S. Positive psychology at school: A school-based intervention to promote adolescents' mental health and well-being. Journal of Happiness Studies. 2014;15(6): 1289–1311. https://doi.org/10.1007/s10902-013-9476-1.

[69] Barry MM & Jenkins R. Implementing mental health promotion. Edinburgh: Churchill Livingstone Elsevier, 2007.

[70] Barry MM. Addressing the determinants of positive mental health: Concepts, evidence and practice. Int J Ment Health Promot. 2009; 11: 4–17. doi: 10.1080/14623730.2009.9%20721788.

[71] Jahoda M. Current concepts of positive mental health. New York, USA: Basic Books, 2006.

[72] World Health Organization. WHO recommends dolutegravir as the preferred HIV treatment option in all populations. 2019. Available from: https://www.who.int/news/item/22-07-2019-who-recommends- dolutegravir-as-preferred-hiv-treatment-option-in-all- populations.

[73] Robbins RN, Spector AY, Mellins CA, et al. Optimizing ART adherence: Update for HIV treatment and prevention. Curr HIV/AIDS Rep. 2014;11(4): 423–433. doi: 10.1007/s11904-014-0229-5.

[74] James S, Pisa PT, Imrie J, et al. Assessment of adolescent and youth-friendly services in primary healthcare facilities in two provinces in South Africa. BMC Health Serv Res. 2018; 18: 1–10. doi: 10.1186/s12913-018-3623-7

[75] Dahourou DL, Gautier-lafaye C, Teasdale CA, et al. Transition from paediatric to adult care of adolescents living with HIV in sub-Saharan Africa: Challenges, youth-friendly

models, and outcomes. J Int AIDS Soc. 2017: 16(20): 34-49. doi: 10.7448/IAS.20.4.21528.

[76] Mutabazi JC, Zarowsky C, Trottier H. The impact of programs for the prevention of mother-to-child transmission of HIV on health care services and systems in sub-Saharan Africa - A review. Public Health Reviews. 2017; 38: 1-28. doi: 10.1186/s40985-017-0072-5.

[77] Strasser S, Gibbons S. The development of HIV-related mental health and psychosocial services for children and adolescents in Zambia: The case for learning by doing. Child Youth Serv Rev. 2014; 45: 150–157. doi: 10.1016/j.childyouth.2014.03.032.

[78] Cavazos-Rehg P, Byansi W, Xu C, et al. The impact of a family-based economic intervention on the mental health of HIV-infected adolescents in Uganda: Results from Suubi + Adherence. J Adolesc Health. 2021;4: 742-749. doi: 10.1016/j.jadohealth.2020.07.022.

[79] Laurenzi CA, Melendez-Torres GJ, Page DT, et al. How do psychosocial interventions for adolescents and young people living with HIV improve adherence and viral load? A realist review. J Adolesc Health. 2022; 71: 254–269. doi: 10.1016/j.jadohealth.2022.03.020.

[80] Medecins Sans Frontieres. ART adherence club report and toolkit. 2014. Available from: https://www.msf.org.za/news-and-resources/publications/art-adherence-club-report-and-toolkit.

[81] Sharp J, Wilkinson L, Cox V, et al. Outcomes of patients enrolled in an antiretroviral adherence club with recent viral suppression after experiencing elevated viral loads. South Afr J HIV Med. 2019; 20(1): 1–7. doi: 10.4102/sajhivmed.v20i1.905

[82] Cresswell JohnW, Clark VP. Designing and conducting mixed methods research. Thousand Oaks, CA: Sage Publications Inc, 2007.

[83] DeVellis, RF. Scale development: Theory and applications 4th ed. Thousand Oaks, CA: Sage Publications Inc, 2016.

[84] Boateng GO, Neilands TB, Frongillo EA, et al. Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. Front Public Health. 2018; 6: 1-18. doi: 10.3389/fpubh.2018.00149.

[85] Krause N. A comprehensive strategy for developing closed-ended survey items for use in studies of older adults. J Gerontol B Psychol Sci Soc Sci. 2002; 57: 263–274. doi: 10.1093/geronb/57.5.s263.

SECTION II: IDENTIFYING THE GAP

This section is related to the aim of conceptualizing mental wellness for ALHIV. It addresses the first objective of the study – to identify gaps in the literature on measuring adolescent mental health and determine the need for an instrument to be developed by conducting a systematic review of mental health and mental wellness instruments used in research with adolescents aged 10-19 years. Three publications emanated from the systematic review.

In **Chapter 2,** the systematic review protocol is presented.

PAPER 1: Orth Z., & van Wyk B. Adolescent mental wellness: A systematic review protocol of instruments measuring general mental health and well-being. BMJ open. 2020;10(8): 1-6. doi: 10.1136/bmjopen-2020-037237.

Using the comprehensive search strategy outlined in the protocol, we identified 350 eligible articles related to measuring mental health and wellbeing in adolescent populations. Due to the large number of eligible studies identified, the analysis was done in two phases, resulting in two subsequent publications described in chapters 3 and 4.

In **Chapter 3,** I describe the mental health and mental wellness instruments used in research with adolescents with a chronic condition. The findings from this paper indicated that there is a lack of appropriate mental wellness measures for adolescents living with a chronic condition, especially in LMICS, thereby providing support for the need to develop a mental wellness measure for ALHIV in the South African context.

PAPER 2: Orth Z & van Wyk B. Measuring mental wellness among adolescents living with aphysical chronic condition: A systematic review of the mental health and mental well-being instruments. BMC Psychology. 2021;9(176): 1-17. doi: 10.1186/s40359-021-00680-w.

Chapter 4 describes the mental wellness instruments used with adolescents in general. We identified 13 mental wellness concepts, 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,* which comprised the preliminary mental wellness framework

PAPER 3: Orth Z, Moosajee F & van Wyk B. Measuring mental wellness of adolescents: A systematic review of instruments. Frontiers in Psychology. 2022; 13:1-14. doi: 10.3389/fpsyg.2022.835601.

CHAPTER 2

Paper 1: Orth, Z., & van Wyk, B. Adolescent mental wellness: A systematic review protocol of instruments measuring general mental health and well-being. BMJ open. 2020;10(8): 1-6. doi: 10.1136/bmjopen-2020-037237.

Abstract

Introduction: Promoting mental health well-being among global adolescent populations is of great public health and social significance. This is particularly true for adolescents with chronic illnesses, as studies have shown that these populations are at higher risk for developing mental health problems. There is vast recognition of the need for age and culturally appropriate interventions to promote mental well-being and prevent mental health problems. In stark contrast, there is a dearth of relevant measures of mental well-being for adolescents. Our proposed systematic review aims to identify mental well-being measures and to assess domain content, psychometric properties, and relevance to adolescent populations.

Methods and analysis: The systematic review methodology will be guided by the seven steps proposed by Eggar, Davey, and Smith. Documents will be sourced from electronic databases (Academic Search Complete, ERIC, Medline, CINAHL plus, PsyArticles, SocIndex, & Sabinet). All documents will be exported to Mendeley, and two reviewers will independently screen the titles, abstracts, and full texts for inclusion. A third party will resolve any discrepancies. We will include studies published in all languages from 2000-2020 that utilise an instrument(s) that measure mental well-being among adolescent populations. Studies reporting on clinically significant mental illnesses or disorders will be excluded. A descriptive meta-synthesis approach will be used to identify and describe adolescent populations' mental health instruments and report on the psychometric properties.

Ethics and dissemination: Ethical approval is not required. The results of this review will be disseminated through a peer-reviewed publication and conference presentations.

Introduction

In recent years, mental health has been a key public health concern, particularly for children and adolescents [1, 2]. According to the World Health Organisation (WHO) [3], mental health conditions account for 16% of the global burden of disease and injury for adolescents aged 10-19 years, with depression being identified as the leading cause of disability and illness

among this population. Evidence suggests that half of all lifetime mental disorders will start during adolescence, yet most of these will go unrecognised and untreated [4]. There are various factors which hinder the effective treatment of adolescent mental health. These include a lack of resources, a lack of communication between parents and health care practitioners, policies aimed at child and adolescent health, and how mental health problems are diagnosed. According to Wissow et al. [4], many children and adolescents have functional problems related to emotions or behaviour but do not meet the mental health disorder diagnosis criteria. It is critical that such at-risk children and adolescents be identified, so that appropriate prevention is implemented. This is concerning as adolescence represents a crucial period of development, where exposures, learnt behaviours, and experiences can set the trajectory for an individual's mental and physical health in adult life [3, 4]. The life-course approach advocates for effective interventions during adolescence to protect public health investments in child survival and early childhood development and to ensure the next generation's physical and mental health and development [6]. To this end, it is imperative to widen the focus from providing care and treatment for adolescents diagnosed with a mental health disorder to including those who are challenged with their mental health and well-being before diagnoses are reached.

Studies exploring mental health problems among children and adolescents have found various attitudinal, stigma-related, and structural barriers to accessing mental health services. Findings from a study suggested that 80 per cent of children and adolescents who require mental health services did not receive any [7]. These barriers are particularly apparent among adolescents living with chronic disorders or diseases. According to the WHO, the incidence and prevalence of chronic conditions are rising in most developed and developing countries and will constitute the main cause of death for children and adolescents by 2020 [8]. As such, it is necessary to consider mental health challenges in the context of adolescents living with chronic conditions.

Research has demonstrated that while children and adolescents with chronic health conditions are at increased risk for developing mental health problems, the overall mental well-being of chronically ill youth is largely determined by, among others, the severity of the disease, the amount of treatment required, and the psychological and social complications associated with such conditions [7, 8]. The variable nature of these factors has resulted in contradictory findings in different research studies. For example, studies have found gendered differences with chronically ill girls more likely to demonstrate emotional health problems than chronically

ill boys compared to healthy control groups [8].

Findings from a South African study comparing psychological vulnerabilities among perinatally- and behaviourally infected HIV-positive adolescents found that perinatally infected adolescents were more likely to be adherent to antiretroviral therapy (ART) and retained in care. In contrast, behaviourally infected adolescents were more likely to be depressed, report internalised stigma and express suicidal ideation [9]. These findings suggest that adherence, retention in care and mental health problems among adolescents living with HIV (ALHIV) are differentially influenced by the mode of infection [9]. As such, tailored interventions are recommended to address the differences between these groups to ensure optimal health outcomes. However, the differences between these two groups may also be influenced by external circumstances related to the care received rather than factors related to the disease. For example, perinatally infected adolescents receive support and build a trusting relationship with their healthcare worker while in paediatric care [9]. Behaviourally infected adolescents may not have similar experiences in the healthcare system.

In the context of prioritising adolescent mental health, prevention and health promotion programmes have been identified as key strategies to help adolescents thrive [3]. In line with the United Nations (UN) Sustainable Developmental Goal 3 (SDG 3) – which aims to promote well-being for all ages – many countries and organisations aim to improve the development of age-appropriate interventions to provide psychosocial support and services to adolescents. For example, the *Every Child Matters United Kingdom* government initiative increased investment in child and adolescent mental health services (CAHMS) to increase access to appropriate services [10]. Additionally, global, and local policies such as the Global Strategy for Women's, Children's and Adolescents' Health [11], the Global Accelerated Action for the Health of Adolescents [12], the Lancet Commission on Adolescent Health and Well-being [13], and the South African National Adolescent and Youth Policy 2017-2022 [14], have identified adolescent mental health as a priority area and has committed to developing specific programmes to promote mental health among adolescents.

Despite the increased focus on adolescent mental health on the global health agenda, there is a lack of evidence concerning mental health conditions among adolescents, especially in low- and middle- income countries (LMIC) [2]. According to Vreeman, McCoy and Lee [2], the lack of information about adolescent mental health in LMICs may be partially related to the lack of validated instruments for these contexts. To address this, UNICEF has launched a

project to develop a measure of mental health among adolescents at the population level [5]. This is of great significance as it will provide valuable evidence regarding the prevalence of mental disorders, inform policy makers and healthcare workers, and guide intervention and treatment programmes. However, the aim of this instrument is majorly focused on improving data on the prevalence and burden of mental illness, meaning that adolescents who experience challenges to their mental health and well-being but do not meet the characteristics for a mental diagnosis may be overlooked.

It is argued that the development of valid instruments to measure mental health depends on how mental health is conceptualised. However, there is currently little agreement on a general definition of 'mental health', which results in inconsistencies in how mental health is being measured and addressed in global health policies [15]. Traditionally, clinical psychologists focused more on the pathogenic side of mental health by describing and treating mental disorders. As such, mental health has popularly been used as a euphemism for 'mental illness' [15]. Consequently, the majority of the research focused on adolescent mental health adopts a pathological view by focusing on mental health disorders such as psychiatric disorders, general mental health disorders, emotional and behavioural problems, psychological distress and lower levels of illness symptoms as representative of mental well-being [2, 16].

However, this pathological view of mental health and human health, in general, is not without its critiques. According to the WHO defining human health as more than the absence of illness has been on ongoing and elusive objective [17]. As Ryff [18] argues, to advance our understanding of human health, we should also focus on the presence of wellness and what it means to flourish. In contrast to the pathological view of health, positive psychologists have focused on positive mental health or general mental health [15], which is defined as the absence of psychopathology and the presence of optimal wellbeing [19]. From this point, mental health is viewed as including both hedonic (feeling well) and eudemonic (functioning well) traditions of wellbeing.

The concept of wellbeing in mental health has gained significant interest as evidence has shown that positive mental health functions as a recovery factor and a protective factor against both physical and mental illness [13, 20, 21]. Studies have shown that high levels of wellbeing are associated with better health outcomes in general and chronic adult populations, while low levels of wellbeing were associated with poorer health outcomes [20]. For example, psychological factors, including well-being, have been associated with adjustment in patients

diagnosed with hypertension [22]. Additionally, research has shown that individuals who engage in diverse types of physical activity are more likely to report higher levels of psychological wellbeing than those who do not exercise, suggesting a link between physical outcomes and wellbeing [23].

There are fewer studies focused on adolescent health and psychological wellbeing. However, the available evidence shows that while adolescents may experience multiple physical, social and emotional changes which can negatively impact their mental well-being, providing psychosocial support and mental health promotion to support positive mental health can protect against psychopathology and support physical health [3, 19]. For example, a longitudinal study in Australia found that one-third of boys and nearly half of girls in a secondary school experienced an episode of depressive and anxiety symptoms. However, these episodes did not follow into their adult life, suggesting that interventions may prevent morbidity in later life [24]. Additionally, research on ALHIV suggests that mental health well-being may support adherence to ART. A randomised control trial conducted by Willis et al. [25] found that adolescents who received the community adolescent treatment support intervention were 3.9 times more likely to adhere to ART than those who only received a standard of care.

While there may be disputes regarding the definition of mental health, there is agreement that mental health should be viewed as more than the absence of mental illness. To this end, the WHO has adopted the complete state model to define mental health as 'a state of wellness in which every individual realizes his or her potential can cope with the normal stresses of life can work productively and fruitfully and can contribute to her or his community' [26]. While this is a step forward in advancing our understanding of mental health in general, considerations should be made that focus specifically on adolescent mental health and its association with physical health, especially given the rise of chronic conditions. Understanding how positive mental health can be used as a resilience resource to protect against psychopathology and poor physical health outcomes is necessary to develop appropriate health policies and interventions. Measures aimed at diagnosing or screening mental health problems are useful in contexts where CAMHS are well-developed and supported. However, LMICs like South Africa face challenges relating to a lack of policy development and implementation for CAMHs, a lack of resources and overburdened public healthcare facilities, which challenges the sustainability of adolescent mental health and healthcare in general [27].

Mental health measurements play a significant role in policy and intervention

development as these are used to provide empirical evidence regarding the effectiveness of programmes aimed at improving adolescent mental well-being. Focusing primarily on measuring low-level disorder symptoms may result in ceiling effects by limiting the range of scores in a positive direction. Consequently, this limits the opportunity to measure the full range of mental health well-being [16]. Additionally, evidence linking wellbeing and physical health outcomes make it important to consider these associations in adolescence. Measuring mental health among adolescents necessitates using age- appropriate and culturally valid instruments to capture improvements in mental well-being where variances in general mental health can be accurately measured [16, 28].

More research focused on emphasising the healthy psychosocial development of adolescents that moves beyond identifying and addressing social and psychological problem trajectories is needed to support the development of psychosocial support programmes and interventions for adolescents who do not qualify for a mental illness diagnosis yet experience challenges to their mental wellness [29]. These interventions should be theory-driven and accessible within the local culture without placing strain on healthcare systems, especially in resource-limited contexts [24, 30].

The rationale for the review

To identify currently available general mental health and well-being instruments for adolescents between the ages of 10-19 years to describe the content and review the psychometric properties of the instruments. For this study, general mental health and well-being instruments are those that measure 'generic' outcome measures that do not aim to diagnose and can be applied in a wide range of settings. In other words, these wellbeing and general mental health factors may include social and psychological functioning, relationships with others, social support, self-perception, quality of life etc. The findings of this review will provide evidence-based knowledge regarding what mental health instruments are used in research focused and adolescents and how reliable and valid these instruments are.

Methods and data analysis

This section describes the methods used in conducting the systematic review. The seven steps described by Eggar, Davey and Smith [31] will be used to guide the systematic review process. These steps are; 1) formulate the review question; 2) define the inclusion and exclusion criteria; 3) develop a search strategy; 4) study selection; 5) assess the quality of studies; 6)

extract data; and 7) analyse or synthesis the data.

Review question

The following question will guide the review;

1) What instruments are used to measure/describe adolescent mental health outcomes?
2) What are the psychometric properties of instruments used to measure/describe adolescent mental health outcomes?

Inclusion and exclusion criteria

The inclusion criteria for the search are as follows:

(1) Studies published in peer-reviewed journals or grey literature.
(2) The sample includes adolescents between the ages of 10-19.
(3) The measure used was a self-report measure of general mental health and well-being.
(4) Quantitative and mixed methods studies.
(5) Studies published in all languages
(6) Studies from all countries will be included; and
(7) Studies aimed at developing or validating instruments

Studies will be excluded based on the following criteria:

1) Review papers or case studies.
2) Screening tools for mental disorders or disorder/symptom-specific measures.

The decision to include studies with adolescent samples between the ages of 10-19 is based on the WHO definition of adolescence. However, not all studies focus specifically on adolescents between these age groups. Some studies may include samples of younger children (under ten years), while others may focus on older adolescents and young adults (older than 19 years). Additionally, other studies may focus on mental health for general populations and have adolescents included in the sample. This study aims to review instruments used with adolescents specifically that recognise adolescence as a unique developmental period. Therefore, studies on mental health in general populations or young adults (including 18–19-year-olds) will be excluded. Studies that include samples of children younger than ten may be included if there is a strong focus on adolescent mental health. Furthermore, studies with measures aimed at

diagnosing mental health disorders or specific to mental illness are excluded as measures for mental health conditions are well-known compared to general mental health and well- being measures. As previously mentioned, many adolescents are often overlooked in mental health policies as they do not meet the requirements for a mental disorder diagnosis. Therefore, we aim to review instruments that can provide a broad measure of general health and wellbeing that capture a range of common presenting difficulties and strengths.

Search strategy

The search strategy was developed after consultation with the faculty librarian. The broad search strategy includes all research articles that use a psychological or psychometric instrument to measure mental health outcomes among adolescents. A systematic database search will be performed using Ebscohost (Psycharticles, Academic Search Premier), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Educational Resource Information Center (ERIC), Medical Literature Analysis Retrieval System Online (MEDLINE) and Sabinet. Full texts will be searched using the list of key words for the search strategy; "((adolescent* OR teenage* OR young people OR youth) [AND] (psychological instrument OR measure* OR tool) [AND] (mental health OR mental well-being OR psychological well-being) [AND] {psychometri*; reliability*; validity*)).

Study selection

Studies were included in the systematic review using the PICOT mnemonics for reviews (Table 2.1). These included:

Table 2.1: PICOT

Patient population	Adolescents aged 10-19 years
Intervention or Interest	Reviewing the psychometric properties of psychological tools or instruments which measure general mental health and well-being among adolescents
Comparison interventions	Not applicable
Outcomes	
Primary outcomes	The definitions and/or concepts of mental health and psychological wellbeing
Secondary outcomes	Psychometric properties of instrument/measure
Time	2000–2020

Other considerations	Geographical area: Global
	Age limits: Adolescents or young adults aged 10 – 19 years.
	Language: All language.
	Study designs: Quantitative method or mixed methods.

The above criteria and search strategy will be used to search the databases. The search strategy's time period was chosen due to the paucity of research in this area [2, 12, 30]. Furthermore, the prioritization of adolescent health and the focus on adolescent-friendly services occurred after 2000 [32]. However, we recognise that studies published after 2000 may use already developed measures and established psychometric properties. In these cases, we will compare the psychometric data of the study included in the review with the psychometric data available from previous studies if those studies also focused on our population of interest. The review's screening and reporting will be conducted per the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. The number of hits for each database will be recorded, and the citations will be exported to Mendeley citation software. Following this, two reviewers will independently review all the titles and abstracts to assess which articles are appropriate for inclusion. The full-text articles of the included abstracts will be downloaded and independently reviewed to determine which articles should be included in the final assessment [31, 33].

Quality assessment

Evaluating the quality of a study is an essential step in systematic reviews as it ensures the validity and reliability of findings [33]. Therefore, each of the potentially relevant articles to be included in the review will be evaluated using the SFS scoring system (version D) [34]. Version D of the SFS is an appropriate tool to use for assessing the quality of studies in this review as it will allow the two reviewers to assess the appropriateness of the methodological elements of the included studies, such as the psychometric properties of the instruments and the theoretical and operational definitions used to define constructs. The SFS version D scoring system contains 29 questions covering the following sub- sections; 1) purpose of the measure, which includes questions regarding the purpose, target group and theoretical dimensions of the measure; 2) methodological rigour, which focuses on the design, sample, and data collection and analyses; 3) and general considerations which includes questions regarding the type of publication. The first reviewer will score each of the included studies using the scoring system and present them in tabular form to be reviewed by the second reviewer. The overall quality of

the study is based on the score it obtained and will be categorised as either weak (0-25%), moderate (26-50%), strong (51-75%), or excellent (76-100%). Only articles with a score of 51% and above will be included in the analysis.

Data extraction

Following the quality assessment, a data extraction sheet will be set up in excel. The two reviewers will then extract the sample characteristics (ages, gender, school grade, etc.), geographic location, mental health concepts, psychometric properties of the instrument, type of instrument and the instrument's format and the instrument's results. For the purpose of this study, only data presented in the articles will be used as we are interested in how the data is reported. Where needed, we will contact authors for original data.

Data synthesis

A descriptive meta-synthesis approach will be used to identify and describe adolescent populations' mental health instruments and report on the psychometric properties. The synthesis of information regarding each instrument will be presented in tabular form, in which the included articles will be ranked based on the methodological rigour scores of the quality assessment [35]. This will allow the reviewers to assess whether the research design reflects a particular study's aims and objectives and whether the conclusions are supported by the data [33, 35]. As part of the review's aims, we will focus on how mental health or concepts of mental health are defined in the studies and which theories are used (if any) to frame mental health. As we look at sample characteristics, we will consider if there are any notable differences in the studies based on sample characteristics. We would also be interested to see the differences across countries regarding the number of studies conducted in higher and LMICs, and how mental health is investigated in these contexts. The data extracted from each included article will be presented in the table to clearly summarise the core findings.

Patient and public involvement

As this is a protocol for a systematic review, no patients or the public were involved in the design or research of this study.

Ethics and dissemination

Ethics approval is not required as the systematic review does not involve the

participation of human subjects; rather, it involves reviewing and collecting data from publicly available sources. This review aims to contribute to research on adolescent mental health. Specifically, it aims to understand what measures are available to measure mental health and well-being to identify gaps and areas of improvement for future measures. There is an increasing need to develop instruments which can measure all aspects of adolescent mental health. These include instruments which can identify adolescents who may be experiencing challenges to their mental health yet do not qualify for a mental illness diagnosis. Measures of general mental health and well-being may provide useful information to inform intervention and policy. We plan to publish the results of this systematic review and present the findings to key stakeholders and colleagues on various platforms, such as webinars and conferences.

References

1. World Health Organization. Health for the world's adolescents: A second chance in the second decade. 2014. Available from: https://apps.who.int/iris/handle/10665/112750.
2. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc. 2017; 20: 21497. doi: 10.7448/IAS.20.4.21497
3. World Health Organization. Adolescent mental health. 2021. Available from: https://www.who.int/news- room/fact-sheets/detail/adolescent-mental-health.
4. UNICEF. Measurement of mental health among adolescents at the population level (MMAP): Conceptual framework and the roadmap to the measurement of mental health, 2018. Available from: https://data.unicef.org/resources/a-roadmap-to-measure-mental-health-among-adolescents/.
5. Wissow L, Anthony B, Brown J, et al. A common factors approach to improving the mental health capacity of pediatric primary care. Adm Policy Ment . 2008; 23:1–7. doi: 10.1007/s10488-008-0178-7.
6. World Health Organization. Mental health action plan 2013-2020. 2013. Available from: https://www.who.int/publications/i/item/9789241506021.
7. Delamater A, Delamater AM, Guzman A, Aparicio K. Mental health issues in children and adolescents with chronic illness. IJHR. 2017; 10(3): 163-173. doi: 10.1108/IJHRH-05-2017- 0020.
8. Michaud PA, Suris JC, Viner R. The adolescent with a chronic condition: Epidemiology, development issues and health care provision. World Health Organization. 2007. Available from https://apps.who.int/iris/handle/10665/43775.
9. Sherr L, Cluver LD, Toska E, He E. Differing psychological vulnerabilities among behaviourally and perinatally HIV infected adolescents in South Africa–implications for targeted health service provision. AIDS Care. 2018; 30:92–101. doi: 10.1080/09540121.2018.1476664.
10. Department for Education and Skills. Every Child Matters: Change for Children, Nottingham: DfES Publications, 2004.
11. Every Woman, Every Child. The global strategy for women's, children's and adolescents' health (2016-2030). 2015. Available from: https://globalstrategy.everywomaneverychild.org/.
12. World Health Organization. Global Accelerated Action for the Health of Adolescents (AA-HA!): Guidance to support country implementation. 2017. Available from:

https://www.who.int/publications/i/item/9789241512343.

13. Patton GC, Sawyer SM, Santelli JS, et al. Our future: A Lancet commission on adolescent health and wellbeing. Lancet. 2017; 387:2423–2478. doi: 10.1016/S0140-6736(16)00579-1.
14. National Department of Health. National adolescent & youth health policy 2017. Pretoria: National Department of Health Republic of South Africa, 2017.
15. Manwell LA, Barbic SP, Roberts K, Durisko Z, Lee C, Ware E, McKenzie K. What is mental health? Evidence towards a new definition from a mixed methods multidisciplinary international survey. BMJ Open 2015; 5:1–11. doi: 10.1136/bmjopen-2014-007079
16. Rose T, Joe S, Williams A, Harris R, Betz G, Stewart-brown S, Rose T. Measuring mental wellbeing among adolescents: A systematic review of instruments. J Child Fam Stud. 2017; 26:2349–2362. doi: 10.1007/s10826-017-0754-0.
17. Svalastog AL, Donev D, Jahren Kristoffersen N, Gajović S. Concepts and definitions of health and health-related values in the knowledge landscapes of the digital society. Croat Med J. 2017;58(6):431-435. doi:10.3325/cmj.2017.58.431.
18. Ryff CD (2013) Psychological well-being revisited: Advances in the science and practice of eudaimonia. Psychother Psychosom. 2014; 83:10–28. doi: 10.1159/000353263.
19. Keyes CLM. Promoting and protecting mental health as flourishing. Am Psychol. 2005;95– 108. doi: 10.1037/0003-066X.62.2.95
20. Trompetter HR, Ten Klooster PM, Schreurs KMG, Fledderus M, Westerhof GJ, Bohlmeijer ET. Measuring values and committed action with the Engaged Living Scale (ELS): psychometric evaluation in a nonclinical sample and a chronic pain sample. Psychol Assess. 2013;25(4):1235-1246. doi:10.1037/a0033813
21. Ryff CD, Singer BH, Love GD. Positive health: Connecting well-being with biology. Philos Trans R Soc B Biol Sci. 2004; 359:1383–1394. doi: 10.1098/rstb.2004.1521.
22. Rafanelli C, Offidani E, Gostoli S, Roncuzzi R. Psychological correlates in patients with different levels of hypertension. Psychiatry Res. 2012;198(1):154-160. doi:10.1016/j.psychres.2011.09.014
23. Edwards SD, Ngcobo HS, Edwards DJ, Palavar K. Exploring the relationship between physical activity, psychological well-being and physical self- perception in different exercise groups. South African J Res Sport Phys Educ Recreat. 2005;27(1):75-90. doi: 10.4314/sajrs.v27i1.25908

24. Sawyer MG, Arney FM, Baghurst PA, et al. The mental health of young people in Australia: key findings from the child and adolescent component of the national survey of mental health and well-being. Aus N Z J Psychiatry, 2001;35(6):806-814. doi: 10.1046/j.1440-1614.2001.00964.x

25. Willis N, Milanzi A, Mawodzeke M, et al. Effectiveness of community adolescent treatment supporters (CATS) interventions in improving linkage and retention in care, adherence to ART and psychosocial well-being: a randomised trial among adolescents living with HIV in rural Zimbabwe. BMC Public Health. 2019;19(1):117. doi:10.1186/s12889- 019-6447-4.

26. World Health Organisation. Mental health: a state of well-being, 2019. Available from: https://www.who.int/features/factfiles/mental_health/en/

27. Mokitimi S, Schneider M, de Vries PJ. Child and adolescent mental health policy in South Africa: History, current policy development and implementation, and policy analysis. Int J Ment Health Syst. 2008;12(36):1–15. doi: 10.1186/s13033-018-0213-3.

28. Bentley N, Hartley S, Bucci S. Systematic review of self-report measures of general mental health and wellbeing in adolescent mental health. Clin Child Fam Psychol. 2019; 22:225– 252. doi: 10.1007/s10567-018-00273-x.

29. Eriksson C, Arnarsson ÁM, Damsgaard MT, et al. Towards enhancing research on adolescent positive mental health. Nordic Welfare Research. 2019; 4: 113–128. doi: https://doi.org/10.18261/issn.2464- 4161-2019-02-08.

30. Sherr L. Comment Mental health—a bridge not so far. Lancet Glob Health. 2017; 5: e559–e560. doi: 10.1016/S2214-109X(17)30183-3.

31. Eggar M, Smith GD, Altman DG. Systematic reviews in health care: Meta analysis in context, 2nd ed. London: BMJ Publishing Group; 2001.

32. World Health Organization. Adolescent friendly health services: An agenda for change. 2003. Available from: https://apps.who.int/iris/handle/10665/67923

33. Gough D, Oliver S, Thomas J. An introduction to systematic reviews. Oakland: Sage Publications Inc; 2012.

34. Smith MR, Franciscus G, Swartbooi C, Munnik E, Jacobs W. The SFS scoring system. In MR Smith (Ed., Chair), Symposium on Methodological Rigour and Coherence: Deconstructing the Quality Appraisal Tool in Systematic Review Methodology, conducted at the 21st National Conference of the Psychological Association of South Africa, South Africa.

35. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in

systematic reviews. BMC Med Res Methodol. 2008; 8:1–10. Doi: 10.1186/1471-2288-8-45.

CHAPTER 3

Paper 2: Orth, Z., van Wyk, B. Measuring mental wellness among adolescents living with a physical chronic condition: A systematic review of the mental health and mental well-being instruments. BMC Psychology. 2021;9(176): 1- 17. doi: 10.1186/s40359-021-00680-w.

Abstract

Background: Globally, promoting mental health and well-being among adolescents has become a public health priority, especially for adolescents living with a chronic physical condition (CC), as research suggests they may be more at risk of developing mental health co-morbidities. Valid and reliable instruments are needed to measure and better understand mental health and well-being among adolescents living with a CC. To this end, we reviewed studies reporting on mental health and well- being instruments used in global adolescent populations living with a chronic physical condition/disease.

Methods: We used a systematic review method guided by PRISMA to identify and assess mental health and mental well-being instruments used in adolescents living with a CC. In this instance, mental health instruments were defined as those representing negative domains of mental health (i.e., depression and anxiety), while mental well-being instruments included positive aspects of mental health (i.e., self-concept and resilience).

Results: We identified 22 articles, which include 31 instruments that were used to measure either mental health (n= 8) or mental well-being (n= 15) or both (n=8) in adolescents living with a CC. Of these, thirteen studies used a Health-Related Quality of Life (HRQoL) scale to measure mental health and/or mental well-being; three were used. The KIDSCREEN and Strengths and Difficulties Questionnaire were identified as frequently used across the 22 studies. Additionally, 7 out of the 31 instruments were disease-specific, with three focusing on adolescents with diabetes. All the instruments were developed in high-income countries and adapted for use in lower- and middle- income countries (LMICs). Adolescents with Type 1 Diabetes (n=7) and HIV (n=4) were researched in 11 out of 22 studies. Only eight studies were conducted in LMIC, four in Africa.

Conclusions: HRQoL instruments are useful in measuring mental health and well-being in adolescents living with a CC. However, relatively few valid measures of mental health and mental well-being for adolescents living with CC exist, accentuating the paucity of research on

mental health and mental well-being of adolescents living with CC. Specific measures need to be developed in and for LMIC, where cultural contexts uniquely affect mental well-being.

Background

As of 2015, there were an estimated 1.2 billion adolescents (aged 10-19 years), representing 16 per cent of the global population – making them the largest group of adolescents in history [1,2]. In recent years, the global public health agenda has shifted to recognise the importance of adolescent mental health in achieving global development goals [1,2]. According to the World Health Organisation (WHO) [2], mental health conditions account for 16% of adolescents' global disease burden.

Depression, anxiety, self-harm, and childhood behavioural disorders have been reported as the leading causes of disability and illness [3]. It is further argued that half of all chronic mental disorders will start during adolescence, with approximately 75% of adults reporting the onset of a mental health problem before the age of 24 years [4]. However, most adolescent mental health problems often go undiagnosed and untreated [5]. Crenna-Jennings and Hutchinson (2020), for example, report that despite the increased investment in child and adolescent mental health services (CAHMS) in England, considerable treatment gaps persist, as evidenced in approximately one-quarter of children and adolescents referred to mental health specialists not receiving treatment [6]. This is concerning as adolescence represents a crucial period of development, where exposures, learnt behaviours, and experiences can set the trajectory for an individual's mental and physical health in adult life [5,7].

Concomitantly, children and adolescents with physical chronic conditions (CC) are at increased risk for developing mental health problems or co-morbidities [8, 9]. Alderman et al. [10] confirmed a global trend of an increasing number of paediatric patients living with chronic medical conditions. In 2017, Jin et al. [11] reported that the overall prevalence of CCs among child and adolescent populations is estimated at 15-20%. According to Sawyer [9], initial stresses associated with diagnosis, ongoing stresses from treatments, social disruption, perceived stigma, marginalisation, and changes in plans and expectations about the future present substantive challenges to the social and emotional well-being of adolescents living with a CC. While most child and adolescent CC are not preventable by lifestyle changes, it is possible to prevent or modify the socially mediated co- morbidities adolescents experience with CC [9]. However, there are various challenges, as reports indicate that adolescents living with CC

experience various attitudinal, stigma-related, and structural barriers to accessing mental health services and psycho-social support [12]. Furthermore, the overall mental well-being of chronically ill adolescents is largely determined by, among others, the severity of the disease, the amount of treatment required, and the psychological and social complications associated with such conditions [12, 13].

Given the link between adult and adolescent health, it is necessary to promote a life-course perspective in adolescent health which advocates for effective interventions during adolescence to protect public health investments in child survival and early childhood development and to ensure the physical and mental health and development of the next generation [14]. Glasner suggests that almost 70% of the disease burden in adults can be prevented through early interventions during adolescents [23]. However, it is argued that preventative strategies to reduce the effect of mental health problems need to go beyond the traditional disease model of mental health. To this end, it is imperative to widen the focus from providing care and treatment for adolescents diagnosed with a mental health disorder to include those who experience challenges to their mental health and well-being before diagnoses are made.

In line with the United Nations (UN) Sustainable Developmental Goal 3 (SDG 3) - which aims to promote well-being for all ages - many countries and organisations are aiming to improve the development of age-appropriate interventions to provide psychosocial support and services to adolescents [15, 16]. Despite the increased focus on adolescent mental health on the global health agenda, there is a lack of evidence concerning mental health conditions among adolescents, especially in LMICs [17]. To address this, UNICEF has launched a project to develop a measure to determine the prevalence of mental illness among adolescents at the population level to inform policy makers and healthcare workers and guide intervention and treatment programmes level [5]. Current instruments in use to measure mental health are based on the traditional clinical psychology definitions of mental health as a pathology, which focuses on psychiatric disorders, general mental health disorders, emotional and behavioural problems, psychological distress, and lower levels of illness symptoms as representative of mental well-being [2,18]. As such, mental health has popularly been used as a euphemism for ‘mental illness’ [19].

However, it has been argued that mental health is more than the absence of illness. Therefore, instruments measuring general mental health should also include a high degree of

psychological well- being [21, 22]. Mental health should then include a focus on the presence of wellness and what it means for an individual to flourish. In contrast to the pathological view of health, positive psychologists have shifted their views to focus on positive mental health or psychological well-being (mental wellness) [19]. From the perspective mentioned above, mental health is viewed as including both hedonic (feeling well) and eudemonic (functioning well) traditions of well-being [22].

Research on well-being in mental health has gained significant interest as evidence suggests that positive mental health aids as a recovery factor and a protective factor against pathology, including both physical and mental [16, 20, 21]. Measures of mental well-being are useful in assessing the strengths and resilience that adolescents possess, which is essential to promote positive mental health (wellness) and youth development [23]. However, there is a lack of studies focused on the effectiveness of such measures or on identifying which mental well-being domains are the most useful for screening and assessment [23]. Considerations should be made that focus specifically on adolescent mental health and its association with physical health, especially given the rise of CCs. This paper reports on a systematic review of mental health and well-being instruments used globally in adolescent populations living with chronic physical conditions/diseases.

Methods

The current review is based on a larger systematic review of mental health instruments for adolescents [3]. For this paper, we have chosen to focus on an instrument used specifically for adolescents living with a physical CC. For the purpose of this study, general mental health and well-being instruments are those that measure ‘generic’ outcomes that do no not intend to diagnose and can be applied in a wide range of settings [24]. In other words, these well-being and general mental health factors may include social and psychological functioning, relationships with others, social support, self- perception, and quality of life. The seven steps described by Eggar, Davey and Smith [25] were used to guide the review process, namely: 1) formulate the review question; 2) define the inclusion and exclusion criteria; 3) develop a search strategy; 4) study selection; 5) assess the quality of studies; 6) extract data; and 7) analyse or synthesis the data.

Review question

We identified the following research question:

1. What instruments are used to measure the mental health and well-being of adolescents living with a chronic physical condition/disease?

Inclusion and exclusion criteria

The inclusion criteria for the search are as follows:

(1) Published in peer-reviewed journals or grey literature.

(2) The sample includes adolescents between 10-19 years old.

(3) The measure used was a self-report measure of general mental health and/or well-being.

(4) Quantitative and mixed methods studies.

(5) Studies aimed at developing or validating instruments [3].

Studies will be excluded based on the following criteria:

1) Review papers or case studies.

2) Screening tools for mental disorders or disorder/symptom-specific measures [3].

The decision to include studies with adolescent samples between the ages of 10-19 years is based on the WHO definition of adolescents [3]. This study aims to review instruments used with adolescents specifically, that recognise adolescence as a unique developmental period. Studies that focused on adults or young adults, where 18–19-year-old adolescents were included in the sample, were therefore excluded [3]. Furthermore, studies with measures aimed at diagnosing mental health disorders or specific to mental illness were excluded [3]. As such, we do not consider adolescents diagnosed with a chronic mental illness/disorder. While studies indicate that adolescents with a physical CC may have mental illness diagnoses as co-morbidities, our interest lies in identifying instruments which may be used to measure general health among adolescents with a physical CC, which can be used to inform mental health services and intervention to prevent mental health problems from developing into mental illness co-morbidities.

Search strategy

The search strategy was developed in consultation with the university's community and

health sciences faculty librarian. The search strategy was broad to include all research articles that use a psychological or psychometric instrument to measure mental health outcomes among adolescents [3]. A systematic database search was performed using Ebscohost (Psycharticles, Academic Search Premier), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Educational Resource Information Center (ERIC), Medical Literature Analysis Retrieval System Online (MEDLINE) and Sabinet. Full-texts searches were done using the following key words for the search strategy; "((adolescen* OR teenage* OR young people OR youth) [AND] (psychological instrument OR measure* OR tool) [AND] (mental health OR mental well-being OR psychological well-being) [AND] {psychometri*; reliability*; validit*)) [3, 24].

Study selection

Studies were included in the systematic review using the PICOT mnemonics for reviews (Table 3.1).

Table 3.1. PICOT

Patient population	Adolescents aged 10-19 years
Intervention of Interest	Measure general mental health and/or well-being among adolescents living with a chronic physical condition/disease
Comparison interventions	Not applicable
Outcomes	Mental health and psychological well-being
Time	2000–2020
Other considerations	Study designs: Quantitative method or mixed methods. Language: All

The period of the search strategy was chosen due to the paucity of research in this area [2, 17, 26]. Furthermore, the prioritization of adolescent health and the focus on adolescent-friendly services occurred after 2000 [27]. The review's screening and reporting were conducted per the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. The number of hits for each database was recorded, and the citations were exported

to Mendeley citation software. Following this, two reviewers (ZO & FM) independently reviewed all the titles and abstracts to assess which articles were appropriate for inclusion. The full-text articles of the included abstracts were downloaded and independently reviewed to determine which articles should be included in the final assessment [25, 28].

Quality assessment

Each of the potentially relevant articles included in the review was evaluated using the SFS scoring system (version D), which is an appropriate tool to use for assessing the quality of studies in this review as it allowed the two reviewers to assess the appropriateness of the methodological elements of the included studies, such as the psychometric properties of the instruments and the theoretical and operational definitions used to define constructs [28]. The SFS version D scoring system contains 29 questions covering the following sub-sections, namely: 1) purpose of the measure, 2) methodological rigour, and 3) general considerations. The overall quality of the study is based on the score as weak (0- 25%), moderate (26-50%), strong (51-75%), or excellent (76-100%). Only articles with a score of 51% and above were included in the synthesis.

Data extraction and synthesis

A descriptive meta-synthesis approach was used to identify and describe the mental health instruments used among adolescent populations. The synthesis of information regarding each instrument was presented in tabular form to display relevant information [29]. The article information was entered into an excel sheet, and the sample characteristics (ages, gender, school grade, etc.) geographic location, physical health, mental health and well-being domains and purpose of the instrument were extracted. For the purpose of this study, only data presented in the articles will be used as we are interested in how the data is reported.

Ethics

Ethics approval is not required as the systematic review does not involve the participation of human subjects; rather, it involves reviewing and collecting data from publicly available sources. However, this review forms part of the first-author's doctoral research project, which received ethical clearance from the University of the Western Cape Biomedical Research Ethics committee (BM19/09/18).

Results

In accordance with PRISMA guidelines, we completed a flowchart detailing the selection process (Figure 3.1). Following the screening, we included 208 articles for the quality appraisal. From this, 20 articles scored below 51% on the SFS scoring system and were subsequently excluded, leaving a sample of 188 articles. We screened the full text of 188 eligible articles and identified 22 articles, including samples of adolescents living with a CC or disease.

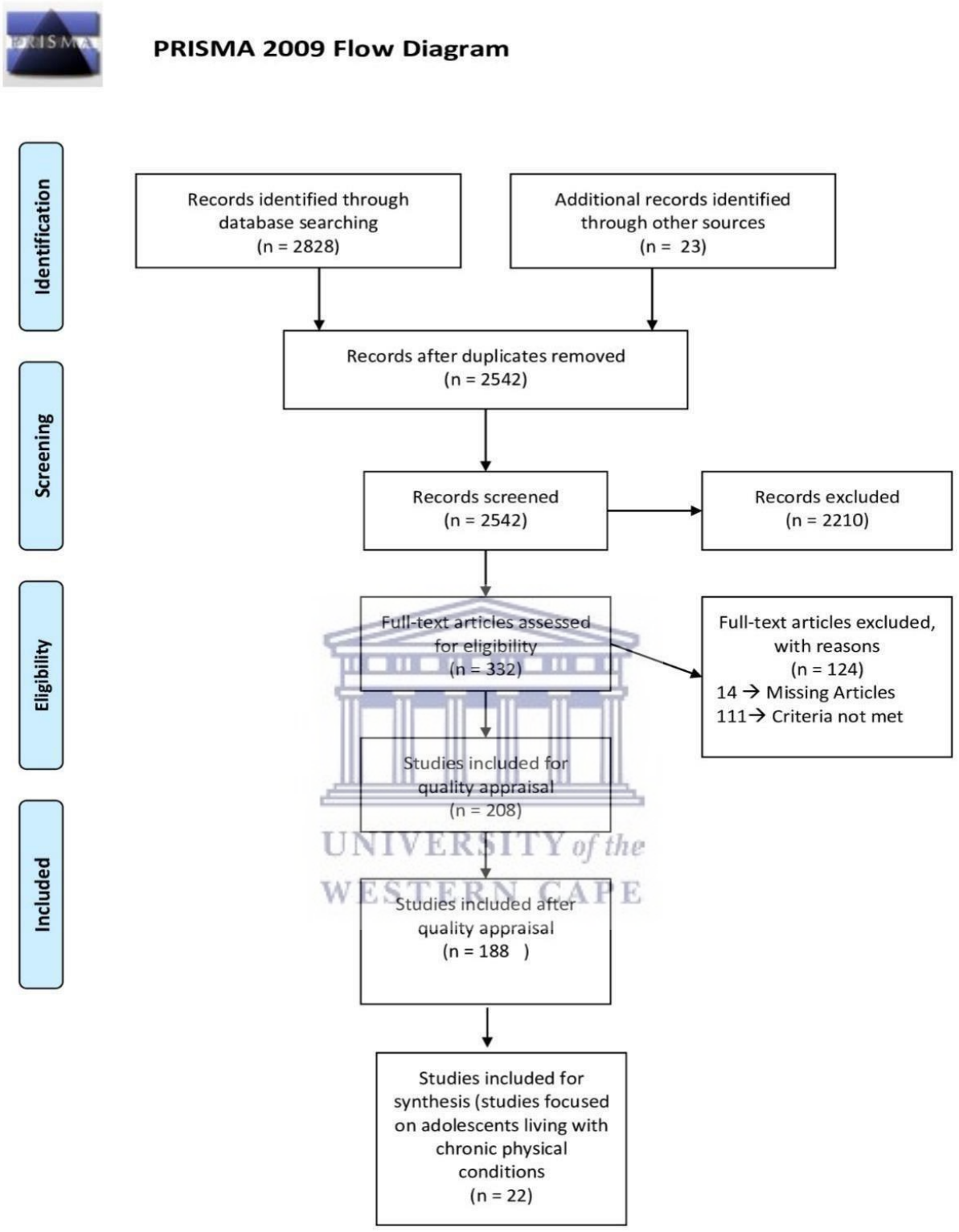

Figure 3.1: PRISMA Diagram

Study characteristics

An overview of the study characteristics is presented in Table 3.2. The study sample sizes ranged from 49 - 1,938, and the participants ranged from 8 to 19 years. More than half of

the studies were conducted in developed countries: three in the Netherlands, two each in Canada, the United States of America, Australia, and Poland, and one each in France, Taiwan, Spain, and Germany.

Most studies (n=18) were published after 2010, with only four studies published before 2010. Adolescents with Type 1 Diabetes (n=7) [33, 35 – 37, 42, 43, 49] and HIV (n=4) [30, 31, 38, 41] constituted half of the total number of studies. Other conditions were Asthma [33, 49], Cerebral Palsy [34, 46], Cystic Fibrosis [35, 40, 51]and Chronic Pain [45, 50] with two studies each: with single studies on Congenital Heart Disease [32], Sickle cell disease [33], Cancer [35], Adolescent Idiopathic Scoliosis [39], Juvenile Idiopathic Arthritis [44], Strabismus [47] and Short Stature [48]. Chronic Disease (unspecified by authors) [49]. Additionally, 3 of the studies [33, 35, 49] used samples of adolescents living with various chronic illnesses rather than looking at adolescents with a specific chronic illness, thereby suggesting that the instruments used in these studies were not symptom/disease specific. All four African studies involved ALHIV [30, 31, 38, 41], while studies involving adolescents living with type 1 diabetes are mostly from European and American countries [33, 36, 37, 42, 43, 49]. The KIDSCREEN [n=5] and Strengths and Difficulties Questionnaire [n=5] were the most frequently used measuring instruments.

Table 3.2: Characteristics of included studies (N=22)

First Author, Year	Country and setting	Sample size	Age Range (years)	Chronic condition	Instruments
Boyes et al., 2019 [30]	South Africa, Eastern Cape	1060	10-19	HIV	Child Depression Inventory – Short Form (translated to Xhosa) Revised Children's Manifest Anxiety Scale (translated to Xhosa)
Cavasos-Rehg et al., 2020 [31]	Uganda, Southwest Uganda	702	10-16	HIV	Beck Hopelessness scale Children's Depression Inventory Tennessee Self- Concept Scale (All three instruments were adapted to be culturally appropriate in the Ugandan context)
Chen, C-W., 2017 et al. [32]	Taiwan	500	15-20	Congenital Heart Disease	Healthcare Needs Scale for Youth with Congenital Heart Disease (Mandarin) The questionnaire on health needs for adolescents (Mandarin) WHO Quality of Life-BREF (Taiwan version)
Cox, E.D. et al., 2020 [33]	United States of America, Wisconsin	195	8-17	Asthma, Diabetes, Sickle cell disease	Patient-Reported Outcomes Measurement Information System (PROMIS)

Davis, E et al., 2013 [34]	Australia, Melbourne & Queensland	87	12-18	Cerebral Palsy	Cerebral Palsy Quality of Life Questionnaire- Teen KIDSCREEN-10 Paediatric Quality of Live Inventory
De Alvegera, W et al., 2019 [35]	Brazil, São Paulo	212	12-17	Chronic Illness (cancer, type 1 diabetes, cystic fibrosis)	The FACIT-Sp-12 Spiritual Well-Being Scale (Translated to Portuguese)
De Wit, M et al., 2012 [36]	Netherlands , Rotterdam & Amsterdam	84	8-18	Type 1 Diabetes	Monitoring Individual Needs in Diabetes Youth Questionnaire (MY-Q) (Dutch version) Paediatric Quality of Live Inventory (Dutch version) WHO-5 wellbeing index (Dutch version)
De Wit, M et al., 2007 [37]	Netherlands, North Holland	91	13-17	Type 1 Diabetes	WHO-5 wellbeing index (Dutch version) Center for Epidemiologic Studies Depression Scale (CES-D) (Dutch version) Child Health Questionnaire (CHQ-CF87) (Dutch version)s
Gentz, S et al., 2018 [38]	Namibia, Windhoek	99	12-18	HIV	Strengths and Difficulties Questionnaire (Oshimwaba and English versions)

Glowacki, M et al., 2013 [39]	Poland, Poznan	36	10-17	Adolescent Idiopathic Scoliosis	Strengths and Difficulties Questionnaire (Polish version)
Goldbeck, L et al., 2001 [40]	Germany, Southern Germany	70	16-38	Cystic Fibrosis	The Short Form 36 Health Survey (SF-36) (German version) The Quality of Life Profile for Chronic Diseases (PLC) (German) The Questions on Life Satisfaction (FLZ) (German)
Kaunda-Khangamwa et al., 2020 [41]	Malawi, Blantyre	406	15-19	HIV	Child Youth Resilience Measurement (CYRM-28) (translated to Chicewa)
Klages, K et al., 2019 [42]	United States of America, Tennesee	181	12-18	Diabetes	Diabetes Stress Questionnaire The Paediatric Quality of Life Inventory 3.2 Diabetes module

Mayoral, K et al., 2019 [43]	Spain, Barcelona	136	8-19	Type 1 Diabetes	EQ-5D-Y (Spanish version) KIDSCREEN-27 (Spanish version) Strengths and Difficulties Questionnaire (Spanish version)
Misterka, E et al., 2017 [44]	Poland, Poznan	52	11-18	Juvenile Idiopathic Arthritis	Strength and Difficulties Questionnaire (Polish version)
Pavlova, M et al., 2017 [45]	Canada, Alberta	147	8-18	Chronic Pain	Patient-Reported Outcomes Measurement Information System (PROMIS)
Power R et al., 2019 [46]	Bangladesh, Sirajganj district	154	10-18	Cerebral Palsy	Cerebral Palsy Quality of Life Questionnaire- Teen (translated to Bengali) Bengali version Kidscreen-27 Bengali version Strengths and difficulties questionnaire
Ramirez-Hernandez, A et al., 2018 [47]	Mexico, Mexico City	71	8-18	Strabismus	Kidscreen-52 Spanish version

Rohenkal, A et al., 2016 [48]	Netherlands, Hilversum	49	8-18	Short Stature	Quality of Life in Short Stature Youth (QoLISSY) (translated to Dutch) KIDSCREEN-52 (Dutch version)
Sapin, C et al., 2005 [49]	France	1938	10-17	180 inpatient youth (asthma & diabetes) 254 chronic disease	Vécu et Santé Perçue des Adolescents (VSP-A) (French).
Soltani, S et al., 2018 [50]	Canada, Alberta	145	8-18	Chronic Pain	Patient-Reported Outcomes Measurement Information System (PROMIS) The Paediatric Quality of Life Inventory (Peds- QL)
Szyndler et al., 2005 [51]	Australia, Sydney	52	12-18	Cystic Fibrosis	The Cystic Fibrosis Questionnaire (CFQ) The Hunter's Opinions and Personal Expectations Scale (HOPES).

Measuring instruments of mental health and mental well-being in adolescents

From the 22 articles, we identified a total of 31 instruments that were used to measure either mental health (n= 8) or mental well-being (n= 15) or in combination (n=8) (Table 3.3). We categorised the mental health instruments as those that measure symptoms or aspects related to a specific mental illness (i.e., symptoms of depression) and mental well-being instruments as those that measure aspects related to [over-all] mental wellness or positive mental health (i.e., resilience, hopefulness).

Measuring constructs of mental health and mental well-being

With the exception of the WHO-5 well-being index [36, 37], all instruments measured domains associated with either mental health, mental well-being or both. For example, five of the mental well-being instruments are aimed at measuring different constructs related to mental well-being, such as resilience [41], hopefulness [51], self-esteem or sense of coherence [31] and spirituality [35]. These concepts refer to hedonic dimensions of mental well-being, i.e., are associated with 'feeling well'. The exception is measuring *resilience* as a concept, which related to function or eudemonic well-being. This suggests that studies using instruments which measure singular constructs of mental well-being may be interested in understanding how hedonic (feeling well) indicators influence the general mental health and well-being of adolescents with a physical CC. On the other hand, it may be that eudemonic (functioning well) measures are being underrepresented or that these indicators are subsumed as subscales in HRQoL measures. However, each of these instruments was used only once, whereas the WHO-5 Well-being Index was used twice, indicating that instruments which include multiple domains of mental health and well-being may be preferable to instruments which measure singular constructs.

Additionally, seven of the instruments measured constructs that are detriments to mental health, such as emotional and behavioural problems [38, 39, 43, 44, 46], symptoms of depression [30, 31, 37], symptoms of anxiety [30], and hopelessness [31]. These instruments measure negative feelings, except for the SDQ, which also measures behaviours that can negatively affect mental health. The SDQ measure was used frequently across the studies suggesting that bothemotional and behavioural risks to mental health are important considerations among adolescents living with a physical CC. Additionally, measures screening for depression among adolescents with a CC were used frequently. This is not

surprising as adolescents with a physical CC are at risk of developing depression as a co-morbidity. The CESD scale is the only measure of depression in this review which measures a positive aspect of mental health (positive affect). Screening for depressive symptoms may help prevent the onset of disorders.

The Diabetes Stress questionnaire is a disease-specific instrument measuring mental health and well-being in adolescents living with diabetes. It is included in this category as it measures specific stressors related to living with diabetes, which may negatively impact mental health. Additionally, it includes the subscale of 'self-care', which is related to the eudemonic well-being construct of self-efficacy.

Health-related quality of life and quality of life

The review identified various HRQoL and QoL instruments used as mental health and well-being measures. HRQoL and QoL are often related to mental well-being measures as the social indicator's movement in the 1950s, which pertained to quality of life, gave rise to the development of theoretically based and validated instruments of positive psychological functioning, including a sense of well-being and hope [52]. This may explain why none of the HRQoL or QoL instruments can be categorised as having only mental health subscales. HRQoL has been developed into a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death and focuses on the impact health status has on quality of life [53].

From Table 3.3, seven of the HRQoL include both mental health and mental well-being subscales, namely: Patient-Reported Outcomes Measurement Information System (PROMIS) paediatric profile -25 [33, 46, 50]; Child Health Questionnaire [37]; EQ-5D-Y [43]; Monitoring Individual Needs in Diabetes Youth Questionnaire (MY-Q) [36]; Quality of Life Profile for Chronic Diseases (PLC) [40]; Paediatric Quality of Life Inventory Diabetes Module (PedsQL-DMTM) [42]; and the Short Form 36 Health Survey (SF-36) [40]. The Questions on Life Satisfaction (FLZ) was also identified as a QoL measure [40].

In this category, the PROMIS instrument paediatric profile-25 [30, 31, 37] was used frequently. Additionally, PROMIS, EQ-5D-Y and CHQ are the only instruments in this category designed to measure HRQoL in general child and adolescent populations and those living with a physical CC or illness. This may allow for comparisons between general

child/adolescent populations and those living with a CC. In comparison to the CHQ, thePROMIS measure has fewer subscales. However, in these subscales' mental health (anxiety, depression) and physical well-being are emphasized, whereas the CHQ seem to emphasize the mental well-being subscales. Similarly, the EQ-5D-Y focuses more on the physical aspects of well-being. The PROMIS may be used more frequently to provide information regarding the prevalence of depressive and anxiety symptoms concerning physical functioning.

Similarly, the MY-Q and PedsQL-DMTM are disease-specific measures designed for children and adolescents living with diabetes. The four subscales of the MY-Q mostly emphasize both hedonic and eudemonic mental well-being concepts such as social and emotional well-being, self-efficacy satisfaction and general QoL. However, the 'diabetes management' subscale includes aspects related to mental health (worries) and physical well-being (problematic eating and treatment barriers). The PedsQL-DMTM also has four subscales which represent mental health, well-being and physical well-being as it relates to living with diabetes specifically.

The SF-36 is a validated and well-researched measure of QoL in adult populations. This review was used in a comparison study with the PLC and FLZ instruments on a sample of adolescents and adults living with cystic fibrosis. Both the PLC and FLZ instruments were developed in Germany to measure QoL in the general population, with the PLC being designed specifically for those with a chronic disease. Compared to the other instruments in this review, these may be less suited for adolescent populations.

Additionally, six HRQoL and three QoL measures are categorized as mental well- being measures. These are the Paediatric Quality of Life Inventory (PedsQL) [34, 36, 50], The KIDSREEN questionnaires [34, 43, 46–48], the Cystic Fibrosis Questionnaire (CFQ) [51],Vécu et Santé Perçue des Adolescents (VSP-A) [49], WHO Quality of Life BREF [32]; Cerebral Palsy Quality of Life Questionnaire-Teen [34, 46]; and the Quality of Life in Short Stature Youth (QoLiSSY) [48].

The KIDSCREEN questionnaires, PedsQL and VSP-A, were specifically developed to measure HRQoL in adolescent populations. The three versions of the KIDSCREEN questionnaires provide some flexibility for researchers who may choose to use the questionnaire based on completion time. For example, for younger adolescents, it may be more appropriate to use the KIDSCREEN-10 (5 minutes) or KIDSCREEN-27 (10-15 minutes) to

ensure they do not get fatigued while filling out the questionnaire. The KIDSCREEN-52 (15-25 minutes) may be more appropriate for older adolescents. Additionally, the KIDSCREEN questionnaires were designed to measure physical well-being and emphasized both hedonic and eudemonic dimensions of mental well-being. Similarly, the Peds-QL measures physical well-being and hedonic and eudemonic well-being. The VSP-A is a French instrument with similar well-being subscales to the KIDSCREEN and Peds-QL. However, it also includes 'vitality' and 'relationship with medical staff', which may be useful to assess in adolescents living with chronic conditions.

The CFQ is a disease-specific instrument that can measure mental well-being among adolescent and adult populations diagnosed with cystic fibrosis. The Cerebral Palsy Quality of Life Questionnaire-Teen and QoLiSSY instruments are age- and disease-specific measures of well-being. Unlike other instruments in this review, the QoLiSSY includes a specific 'coping' subscale. Coping is often listed as an important indicator of eudemonic well-being as it speaks to one's ability to overcome challenges and improve resilience. It may be that 'coping' items are included within other subscales in the instruments, such as the 'individual' subscale in the CYRM-28 measure or the 'psychological well-being' scale in the KIDSCREEN.

Healthcare needs instruments

The Healthcare Needs Scale for Youth with Congenital Heart Disease (HNS-CHD) measures the transitional healthcare needs of adolescents living with congenital heart disease. The questionnaire on health needs for adolescents [32] measured the healthcare needs of adolescents and was used to establish the concurrent validity of the HNS-CHD [41]. These instruments measure mental health and well-being by looking at adolescents' healthcare needs, which allows for early identification of mental health problems. However, not much information about these instruments is available outside this initial study [41].

Physical well-being subscales

We found that 21 instruments included one or more subscales related to physical well-being. As shown in Table 3.3, some physical well-being subscales may overlap with the mental health and mental well-being subscales. For example, the Center for Epidemiological Studies Depression (CESD) questionnaire includes four subscales aimed at measuring symptoms of depression. One of the subscales, 'somatic complaints,' relates to physical symptoms of depression. However, it is also related to the individual's physical well-being.

Similarly, the Short Form Health 36 Survey (SF-36) includes subscales like ‘Limitations in social activities because of physical or emotional problems’, which relates to both physical well-being and mental health (i.e., the emotional state has a negative effect on functioning). This is not surprising as mental health, as it relates to mental illness, considers somatic symptoms or functioning capabilities as an indicator to diagnose and assess the severity of an individual’s mental illness.

Table 3.3: Characteristics of the included instruments

Instrument	Aim of the Instrument	Subscales in the instrument	# Subscales	Mental health subscales	Mental wellbeing subscales	Physical wellbeing	Studies
Beck Hopelessness scale	Hopelessness	Feelings about the future Loss of motivation Expectations	3	□ (n=3)			[83]
Cerebral Palsy Quality of Life Questionnaire- Teen	QoL in adolescents living with Cerebral Palsy	global QoL, social wellbeing, emotional wellbeing, school wellbeing, physical wellbeing, participation, communication, pain	8		□ (n=5)	□ (n=3)	[34, 36]
Child Youth Resilience Measurement (CYRM-	Measures resilience	Individual, relational, community, cultural	4		□ (n=4)		[41]

28)							

Cystic Fibrosis Questionnaire (CFQ)	Measures HRQoL in patients with Cystic Fibrosis	Physical, role limitations/ school performance, energy/wellbeing, emotional state, social limitations	5		□ (n=2)	□ (n=3)	[51]
EQ-5D-Y	Measure HRQoL	mobility, looking after myself, doing usual activities, having pain or discomfort and feeling worried, sad or unhappy	5	□ (n=1)	□ (n=1)	□ (n=3)	[43]
FACIT-Sp-12 Spiritual Well- Being Scale	Measure Spiritual Wellbeing	Spiritual Well-Being, Meaning, Peace, Faith	4		□ (n=4)		[35]
Healthcare Needs Scale for Youth with Congenital Heart Disease (HNS-CHD)	Measure Healthcare Needs	health, family, individual, interpersonal and policy needs	5		□ (n=2)	□ (n=1)	[32]

Hunter's Opinions and	Measure hope and despair for	Hope, despair, global personal happiness	3	□ (n=1)	□ (n=2)		[51]

Personal Expectations Scale (HOPES).	adolescents and adults						
KIDSCREEN-10	Measure HRQoL in children and adolescents	unidimensional construct of HRQOL	1		□ (n=1)	□ (n=1)	[34]
KIDSCREEN-27	Measure HRQoL in children and adolescents	Physical Well-Being, Psychological Well-Being, Autonomy & Parents, Peers & Social Support and School Environment.	5		□ (n=4)	□ (n=1)	[43, 36]
KIDSCREEN-52	Measure HRQoL in children and adolescents	Physical, Psychological Wellbeing, Moods and Emotions, Self-Perception, Autonomy, Parent Relations and Home Life, Social Support and	10		□ (n=8)	□ (n=1)	[47, 48]

		Peers, School Environment (6 items), Social					

		Acceptance (Bullying), Financial Resources					
Paediatric Quality of Life Inventory (Peds- QL)	Measure HRQoL	Physical Functioning (8 items) Emotional Functioning (5 items) Social Functioning (5 items) School Functioning (5 items)	4		□ (n=3)	□ (n=1)	[34, 36, 50]
Quality of Life in Short Stature Youth (QoLISSY	Measures QoL	Physical, Social, Emotional, Coping, Treatment, Beliefs	6		□ (n=4)	□ (n=2)	[48]
Tennessee Self- Concept Scale	Measures self- concept	Physical, moral, personal, family, social, academic	6		□ (n=5)	□ (n=1)	[31]
Vécu et Santé Perçue des Adolescents (VSP-A)	Measure HRQoL	Vitality, Psychological Well-being, Relationships with Friends, Leisure Activities, Relationships with	10		□ (n=8)	□ (n=2)	[49]

		Parents, Physical Well-being, Relationships with Teachers, School					

		Performance, Body Image and Relationships with Medical Staff					
WHO-5 wellbeing index	Measures current mental wellbeing	Mental /Emotional wellbeing (unidimensional)	1		□ (n=1)		[36, 37]
WHO Quality of Life-BREF	Measures QoL	physical health, psychological health, social relationship and environment.	4		□ (n=3)	□ (n=1)	[32]
Center for Epidemiological Studies Depression	Symptoms of depression	Depressive affect Somatic complaints Positive affect Interpersonal activity	4	□ (n=4)		□ (n=1)	[37]
Child Depression Inventory (CDI)	Symptoms of depression	Anhedonia, negative mood/physical symptoms, negative self-esteem, interpersonal problems,	5	□ (n=5)			[31]

		Ineffectiveness					

Child Depression Inventory – Short Form	Symptoms of depression	Negative mood/physical symptoms, negative self-esteem, interpersonal problems, ineffectiveness	4	□ (n=4)			[30]
Paediatric Quality of Life Inventory Diabetes Module (PedsQL-DMTM)	Measure HRQoL in adolescents with Diabetes	general concerns about diabetes, treatment, worry, and communication	4	□ (n=1)	□ (n=1)	□ (n=2)	[42]
Revised Children's Manifest Anxiety Scale	Measures symptoms of anxiety in children and adolescents	Psychological anxiety, worry/oversensitivity, social concerns/concentration	3	□ (n=3)			[30]

Strengths and Difficulties Questionnaire (SDQ)	Emotional and Behavioural Screening Questionnaire	Emotional symptoms subscale Conduct problems subscale Hyperactivity/inattention	5	□ (n=5)			[38, 39, 43, 44, 46]

		subscale Peer relationships problem subscale Prosocial behaviour subscale					
The questionnaire on health needs for adolescents	Measure of Healthcare Needs	physical health, reproductive health, mental health, interpersonal concerns and behavioural concerns	5	□ (n=3)		□ (n=2)	[32]
Child Health Questionnaire (CHQ)	Measure HRQoL	General health perceptions, physical functioning, role/social physical functioning, bodily pain, role/social emotional functioning, role/social behavioural functioning, parent impact-time, parent impact-emotion, self-esteem, mental health, behaviour, family activities, family	14	□ (n=1)	□ (n=7)	□ (n=3)	[37]

		cohesion, change in health					

Diabetes Stress Questionnaire	Measures Diabetes stressors	Distress-Worry, Peer Stress, Adverse-Personal Effects, Parental Stress, Hyperglycemia, Self-Care, Diet, and Hypoglycemia	8	□ (n=5)	□ (n=1)	□ (n=3)	[42]
Monitoring Individual Needs in Diabetes Youth Questionnaire (MY-Q)	Measure HRQoL in adolescents with Diabetes	General QoL, the teenagers' social life (friends, family, and school), diabetes management (worries, treatment barriers, self-efficacy and satisfaction, and problematic eating), and emotional well-being	4	□ (n=1)	□ (n=4)	□ (n=1)	[36]

Patient-Reported Outcomes Measurement Information System	Measure that evaluates and monitors physical, mental, and	anxiety, depressive symptoms, fatigue, pain interference, physical function-mobility, peer	7	□ (n=2)	□ (n=1)	□ (n=4)	[33, 45, 50]

(PROMIS) paediatric profile -25	social health in adolescents and children (HRQoL)	relationships, and a single pain intensity item.					
Quality of Life Profile for Chronic Diseases (PLC)	Measures HRQoL in chronic patients	Capacity, positive mood, negative mood, ability to relax and enjoy, sense of belonging to others, contact ability	6	□ (n=1)	□ (n=4)	□ (n=2)	[40]
Questions on Life Satisfaction (FLZ)	Measures subjective QoL	Friends/acquaintances, leisure, general health, income, occupation, housing, family life, partner relationship/sexuality, physical, ability to relax, energy, mobility, vision & hearing, freedom from anxiety, freedom from pain, independence from help	16	□ (n=1)	□ (n=7)	□ (n=5)	[40]

Short Form 36 Health Survey (SF-36)	Measure HRQoL	Limitations in physical activities because of health problems. Limitations in social activities because of physical or emotional problems Limitations in usual role activities because of physical health problems Bodily pain General mental health (psychological distress and well-being) Limitations in usual role activities because of emotional problems Vitality (energy and fatigue) General health perceptions	8	□ (n=3)	□ (n=1)	□ (n=5)	[40]

Discussion

The increase in HRQoL studies on people living with a CC indicates a shift to include social and psychological dimensions of health in biomedical research [9]. Our review confirmed that HRQoL is useful for assessing physical and psychosocial well-being among adolescents living with a CC. However, there are concerns that measures of HRQoL may focus more on physical health domains and, therefore, may not be appropriate for measuring HRQoL in people with mental health problems [54]. However, as shown in Table 3.3 and confirmed by Bech et al. [19], HRQoL instruments have more domains relating to mental well-being than physical well-being. Indeed, we found that many *other* instruments measuring mental well-being also included measures of HRQoL or QoL.

Additionally, adolescents in these studies were not diagnosed with any mental health problems. Therefore, it may be that these HRQoL instruments are useful for assessing the mental well-being of adolescents with a CC before they develop or are diagnosed with mental health problems. The PedsQL-DMTM was the only HRQoL instrument which measured a mental health domain (worry). This suggests that while mental well-being may be a key and necessary feature in HRQoL research, it may be that mental health is either underrepresented, as Connel et al. [56] argue, or it may be that measuring mental health is not considered useful in certain contexts. According to Bech [55], the mixture of distress and well-being items has become increasingly problematic as well-being is an important aspect of HRQoL, while mental health measures are related to the stipulations of diagnostic manuals such as the DSM V and ICD-10. However, as seen in Table 3.3, instruments often include both mental health (distress) and mental well-being domains to decrease floor and ceiling effects. In their study, Bech et al. [55] show that despite containing 'pure' well-being items, the WHO-Five measure was more sensitive and had lower ceiling effects compared to the SF-36 mental health (distress) scales. This reflects a conceptual problem related to the psychometrics of measuring mental health –to what extent is the absence of mental disorder symptoms equal to a high degree of psychological well-being? Nevertheless, this highlights the importance of conceptualising mental health and well-being as it will determine which instruments are most appropriate.

Sawyer et al. discussed issues relating to HRQoL measures as there are discrepancies between parental proxy reports and adolescent self-reports [9]. We found that ten of the included studies used self-report measures to measure HRQoL, while five included both parent and adolescent reports. This suggests that self-report measures with adolescents living with a

CC may be preferred to measure HRQoL. Of the five studies using HRQoL self- and parent reports, three [33, 34, 46] reported discrepancies between the adolescents and parents, which were discussed as being consistent with previous studies. According to the KIDSCREEN group [57], there are issues regarding discrepancies between parent and adolescent reports, yet sometimes proxy reports are necessary for additional information or when the adolescent is unable to respond. Additionally, parent perspectives are important as they contribute to healthcare decision-making [57]. However, if there are discrepancies between the child/adolescent report, the adolescent should be considered the preferred respondent [9, 37, 42].

Additionally, the choice of disease-specific or generic instruments should be considered as generic instruments facilitate comparisons between adolescents with different conditions and population norms, whereas disease-specific instruments can measure differential effects related to a specific disorder [56]. Our findings show that of the 31 instruments, 7 were disease-specific (of which three focused on diabetes). Previously only a few studies have compared HRQoL across adolescents with different disorders, as most focus on adolescent populations with a specific disorder. In our review, we found three studies which involved samples of adolescents with different disorders. While disease-specific studies are useful in describing the psychological effects (i.e., coping, adjustment, mental health problems) of individual diseases and conditions on adolescents and their families, research on the similarities and differences between disorders or diseases could inform practice and policy [56]. Additionally, measures that transcend specific diseases and conditions may help us better understand how structural elements of paediatric and mainstream healthcare systems can facilitate or hinder transitions of care [56]. Furthermore, considering the context of resource-limited countries, it may be more practical to compare features of different disorders or conditions to understand how best to maximise health resources, design sustainable intervention programmes and establish adolescent- friendly services for adolescents living with a CC.

The KIDSCREEN, SDQ, Paediatric Quality of Life and PROMIS instruments were repeatedly used across the 22 studies and proven to be reliable and valid instruments. Unlike the other instruments mentioned here, the SDQ is the only ‘mental health’ measure as it is often used as an emotional and behavioural screening tool rather than a measure of HRQoL or QoL. This is not to say that the SDQ is the only mental health/mental well-being measure to use among adolescents living with a CC. Indeed, there are a variety of reliable and valid measures

of mental well-being and mental health to be used in adolescent populations, such as the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) or the Beck Youth Inventory. However, as shown in this review, it may be that HRQoL instruments are preferable for use in adolescent populations with a CC, as Sawyer et al. [9] argued. Additionally, instruments such as the SDQ and KIDSCREEN were specifically developed for adolescent populations, whereas the WEMWBS is designed for all ages.

Limitations and future research

We conducted a comprehensive and systematic review of the literature using broad search terms and criteria to ensure the inclusion of all relevant articles. Unlike previous studies in this field [18, 24], our review included general mental health and well-being measures. However, some limitations are noted. While we tried to keep the criteria as broad as possible, we acknowledge that there are inherent issues related to the databases we have chosen, which may have restricted our access to certain articles. For example, the chosen databases may have restricted access to psychological journals. Additionally, we gained access to these databases via our institution. As such, we only had access to articles based on our institutional access.

Additionally, it should be noted that this review forms part of a larger review focused on assessing mental health measures used among adolescents [3]. Therefore, this review represents a snapshot of our main review. Assessing general mental health and well-being among adolescents living with a CC is important for clinicians and policy makers. However, future research should focus on clearly conceptualising what mental health and well-being mean to adolescents, especially those living with a CC. This is relevant as we previously mentioned that there is currently no agreed-upon definition of mental health, and how a concept is defined has implications for how it is measured. This study shows that many mental health/well-being instruments were HRQoL instruments. Future research should also establish the validity of HRQoL instruments as measures of mental health/well-being by comparing the convergent validity of mental health/well-being instruments.

Conclusions

Many adolescent CCs are not preventable. However, the potential mental co-morbidities resulting from living with a life-long condition can be prevented or modified to ensure optimal quality of life. As such, the findings from our review reflect previous research trends suggesting that HRQoL measures seem to be more useful in measuring mental health and/or mental well-

being among adolescents living with a CC as this allows for an all-round assessment of both physical, psychological and social outcomes. Measures such as the KIDSCREEN, SDQ and Paediatric Quality of Life scales are useful and valid measures to assess mental health and well-being among adolescents living with a CC in developed and developing countries. However, all the instruments included in this study were developed in high-income countries and then adapted for use in LMICs. While these instruments were useful, we would suggest that more instruments be developed in LMICs as this may provide us with more insight into which constructs of mental health/mental well-being and health are important to adolescents living in this context. Furthermore, such assessments may help researchers, policy makers, and health professionals better understand the complex issues experienced by adolescents living with a CC in resource-limited settings. We recommend more research to compare adolescents with different CC, especially in LMICs, which will inform the development of new frameworks for healthcare systems that will [better] support the healthy development of adolescents living with a CC as they transition to adult life.

References

1. World Health Organization. Health for the world's adolescents: A second chance in the second decade. 2014. Available from: https://apps.who.int/iris/handle/10665/112750.
2. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc. 2017; 20: 21497. doi: 10.7448/IAS.20.4.21497
3. Orth Z, Van Wyk B. Adolescent mental wellness: A systematic review protocol of instruments measuring general mental health and wellbeing. BMJ Open. 2020; 10:37237. doi: 10. 1136/ bmjop en- 2020- 037237.
4. O'Brien D, Harvey K, Howse J, Reardon T, Creswell C. Barriers to managing child and adolescent mental health problems: A systematic review of primary care practitioners' perceptions. Br J Gen Pract. 2016;66:e693-707. doi: 10. 3399/ bjgp1 6X687 061.
5. UNICEF. Measurement of mental health among adolescents at the population level (MMAP): Conceptual framework and the roadmap to the measurement of mental health, 2018. Available from: https://data.unicef.org/topic/child-health/mental-health/mmap/
6. Crenna-Jennings W, Hutchinson J. Access to child and adolescent mental health services in 2019. The Education Policy Institute. 2020. Available from: https:// epi. org. uk/ wp- conte nt/ uploa ds/ 2020/ 01/ Access- to- CAMHS- in- 2019_ EPI. pdf.
7. World Health Organization. Adolescent mental health. 2018. Available from: https:// www. who. int/ news- room/ fact- sheets/ detail/ adolescent- mental- health.
8. Santos T, De Matos MG, Simões C, Machado MDC. Psychological wellbeing and chronic condition in Portuguese adolescents. Int J Adolesc Youth. 2015; 20:334–45. https:// doi. org/ 10. 1080/ 02673 843. 2015. 10078 80.
9. Sawyer MG, Arney FM, Baghurst PA, et al. The mental health of young people in Australia: key findings from the child and adolescent component of the national survey of mental health and well-being. Aus N Z Psychiatry. 2001;35(6):806–14. doi: 10.1046/j.1440-1614.2001.00964.x.
10. Alderman EM, Breuner CC. Unique needs of the adolescent. Pediatrics. 2019;144: e20193150. doi: 10.1542/peds.2019-3150.
11. Jin M, An Q, Wang L. Chronic conditions in adolescents. Exp Ther Med. 2017; 14:478–

82. doi: 10.3892/etm.2017.4526.

12. Delamater A, Delamater AM, Guzman A, Aparicio K. Mental health issues in children and adolescents with chronic illness. IJHR. 2017;10(3):163–73. doi:10. 1108/ IJHRH-05- 2017- 0020.

13. Michaud PA, Suris JC, Viner R. The adolescent with a chronic condition: Epidemiology, development issues and health care provision. World Health Organization. 2007. Available from https://apps.who.int/iris/handle/10665/43775.

14. World Health Organization. Mental health action plan 2013-2020. 2013. Available from: https://www.who.int/publications/i/item/9789241506021.

15. Thornton H. Every child matters. J Diabetes Nurs. 2007; 11(6):222–3. https://www.woundsme.com/resources/details/every-child-matters.

16. Patton GC, Sawyer SM, Santelli JS, et al. Our future: A Lancet commission on adolescent health and wellbeing. Lancet. 2017; 387:2423–78. doi: 10. 1016/ S0140-6736(16) 00579- 1.

17. World Health Organization. Global Accelerated Action for the Health of Adolescents (AA-HA!): Guidance to support country implementation. 2017. Available from: https://www.who.int/publications/i/item/9789241512343.

18. Rose T, Joe S, Williams A, Harris R, Betz G, Stewart-brown S, Rose T. Measuring mental wellbeing among adolescents: A systematic review of instruments. J Child Fam Stud. 2017; 26:2349–62. doi: 10. 1007/s10826- 017- 0754-0.

19. Manwell LA, Barbic SP, Roberts K, Durisko Z, Lee C, Ware E, McKenzie K. What is mental health? Evidence towards a new definition from a mixed methods multidisciplinary international survey. BMJ Open. 2015; 5:1–11. doi: 10.1136/ bmjop en- 2014- 007079.

20. Trompetter HR, Ten Klooster PM, Schreurs KMG, Fledderus M, Westerhof GJ, Bohlmeijer ET. Measuring values and committed action with the Engaged Living Scale (ELS): psychometric evaluation in a nonclinical sample and a chronic pain sample. Psychol Assess. 2013;25(4):1235-1246. doi:10.1037/a0033813

21. Ryff CD, Singer BH, Love GD. Positive health: connecting well-being with biology. Philos Trans R Soc B Biol Sci. 2004; 359:1383–94. doi: 10.1098/rstb.2004.1521.

22. Svalastog AL, Donev D, Kristoffersen NJ, Gajović S. Concepts and definitions of health and health-related values in the knowledge landscapes of the digital society. Croat Med J. 2017; 58:431–5. doi: 10. 3325/cmj. 2017. 58. 431.

23. Glasner J, Baltag V, Ambresin AE. Previsit multidomain psychosocial screening tools for adolescents and young adults: A systematic review. J Adolesc Health. 2021;68(3):449-459. doi:10.1016/j.jadohealth.2020.10.003

24. Bentley N, Hartley S, Bucci S. Systematic review of self-report measures of general mental health and wellbeing in adolescent mental health. Clin Child Fam Psychol. 2019; 22:225–52. doi: 10. 1007/s10567- 018- 00273-x.

25. Eggar M, Smith GD, Altman DG. Systematic reviews in health care: Meta analysis in context. 2nd ed. London: BMJ Publishing Group; 2001.

26. Sherr L. Comment Mental health—a bridge not so far. Lancet Glob Health. 2017; 5: e559–e560. doi: 10.1016/S2214-109X(17)30183-3.

27. World Health Organization. Adolescent friendly health services: An agenda for change. 2003. Available from: https://apps.who.int/iris/handle/10665/67923

28. Smith MR, Franciscus G, Swartbooi C, Munnik E, Jacobs W. The SFS scoring system. In: Smith MR, editor. Symposium on Methodological Rigour and Coherence: Deconstructing the Quality Appraisal Tool in Systematic Review Methodology, conducted at the 21st National Conference of the Psychological Association of South Africa, South Africa.

29. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol. 2008; 8:1–10. Doi: 10.1186/1471-2288-8-45

30. Boyes ME, Cluver LD, Meinck F, et al. Mental health in South African adolescents living with HIV: Correlates of internalising and externalising symptoms. AIDS Care. 2019; 31: 95–104. doi: 10.1080/09540121.2018.1524121.

31. Cavazos-Rehg P, Byansi W, Xu C, Nabunya P, Sensoy Bahar O, Borodovsky J, et al. The impact of a family-based economic intervention on the mental health of HIV-infected adolescents in Uganda: results from Suubi+ Adherence. J Adolesc Heal. 2020;68(4):742–9. doi: 10.1016/j.jadohealth.2020.07.022.

32. Chen CW, Ho CL, Su WJ, Wang JK, Chung HT, Lee PC, et al. Initial validation of a

healthcare needs scale for young people with congenital heart disease. J Adv Nurs. 2018; 74:223–31. doi: 10. 1111/ jan.13390.

33. Cox ED, Connolly JR, Palta M, Rajamanickam VP, Flynn KE. Reliability and validity of PROMIS® pediatric family relationships short form in children 8–17 years of age with chronic disease. Qual Life Res. 2020; 29:191–9. doi: 10. 1007/ s11136- 019- 02266-x.

34. Davis E, Mackinnon A, Davern M, Boyd R, Bohanna I, Waters E, et al. Description and psychometric properties of the CP QOL-Teen: A quality-of-life questionnaire for adolescents with cerebral palsy. Res Dev Disabil. 2013; 34:344–52. doi: 10. 1016/j. ridd. 2012. 08. 018.

35. de Alvarenga WA, Nascimento LC, dos Santos CB, Leite ACAB, Mühlan H, Schmidt S, et al. Measuring spiritual well-being in Brazilian adolescents with chronic illness using the FACIT- Sp-12: Age adaptation of the self-report version, development of the parental-report version, and validation. J Relig Heal. 2019; 58:2219–40. doi: 10. 1007/s10943- 019- 00901- y.

36. De Wit M, Winterdijk P, Aanstoot HJ, Anderson B, Danne T, Deeb L, et al. Assessing diabetes- related quality of life of youth with type 1 diabetes in routine clinical care: the MIND Youth Questionnaire (MY-Q). Pediatr Diabetes. 2012; 13:638–46. doi: 10. 1111/j. 1399- 5448. 2012. 00872.x.

37. De Wit M, Pouwer F, Gemke RJBJ, Delemarre-Van De Waal HA, Snoek FJ. Validation of the WHO-5 well-being index in adolescents with type 1 diabetes. Diabetes Care. 2007; 30:2003–6. doi:10. 2337/ dc07- 0447.

38. Gentz SG, Calonge-Romano I, Martínez-Arias R, Zeng C, Ruiz-Casares M. Mental health among adolescents living with HIV in Namibia: the role of poverty, orphanhood and social support. AIDS Care. 2018; 30:83–91. doi: 10. 1080/ 09540 121. 2018. 14697 27.

39. Glowacki M, Misterska E, Adamczyk K, Latuszewska J. Changes in scoliosis patient and parental assessment of mental health in the course of cheneau brace treatment based on the strengths and difficulties questionnaire. J Dev Phys Disabil. 2013; 25:325–42. doi: 10. 1007/s10882- 012- 9310-4.

40. Goldbeck L, Schmitz TG. Comparison of three generic questionnaires measuring

quality of life in adolescents and adults with cystic fibrosis: the 36-item short form health survey, the quality-of-life profile for chronic diseases, and the questions on life satisfaction. Qual Life Res. 2001; 10:23–36. doi: 10. 1023/a: 10167 11704 283.

41. Kaunda-Khangamwa BN, Maposa I, Dambe R, Malisita K, Mtagalume E, Chigaru L, et al. Validating a child youth resilience measurement (CYRM-28) for adolescents living with HIV (ALHIV) in Urban Malawi. Front Psychol. 2020; 11:1–13. doi:10. 3389/ fpsyg. 2020. 01896.

42. Klages KL, Ankney RL, Berlin KS, Keenan ME, Wood NR, Semenkovich K, et al. Validity, reliability, and measurement invariance of the diabetes stress questionnaire-short form. J Pediatr Psychol. 2019; 44:442–52. doi:10. 1093/ jpepsy/ jsy078.

43. Mayoral K, Rajmil L, Murillo M, Garin O, Pont A, Alonso J, et al. Measurement properties of the online EuroQol-5D-youth instrument in children and adolescents with type 1 diabetes mellitus: questionnaire study. J Med Internet Res. 2019;21: e14947–e14947. doi: 10. 2196/14947.

44. Misterska E, Kaminiarczyk-Pyzałka D, Adamczak K, Adamczyk KA, Niedziela M, Głowacki M, et al. Mental health and adjustment to juvenile idiopathic arthritis: Level of agreement between parent and adolescent reports according to Strengths and Difficulties Questionnaire and Adolescent Outcomes Questionnaire. PLoS ONE. 2017; 12:1–16. doi: 10. 1371/ journ al. pone. 01737 68.

45. Pavlova M, Ference J, Hancock M, Noel M. Disentangling the sleep-pain relationship in pediatric chronic pain: the mediating role of internalizing mental health symptoms. Pain Res Manag. 2017; 2017:1586921. doi:10. 1155/ 2017/ 15869 21.

46. Power R, Akhter R, Muhit M, Wadud S, Heanoy E, Karim T, et al. A quality-of-life questionnaire for adolescents with cerebral palsy: Psychometric properties of the Bengali CPQoL-teens. Heal Qual Life Outcomes. 2019. doi:10. 1186/ s12955- 019-1206- x.

47. Leticia A, Hernández R, Quiroz EM, Córdova VF. Kidscreen52 questionnaire for measuring health-related quality of life in children with strabismus. Rev Cuba Oftal. 2018; 31(3):1-5.

48. Rohenkohl A, Stalman S, Kamp G, Bullinger M, Quitmann J. Psychometric performance of the Quality of Life in Short Stature Youth (QoLISSY) questionnaire in

the Netherlands. Eur J Pediatr. 2016; 175:347–54. doi:10. 1007/ s00431- 015- 2656-8.

49. Sapin C, Simeoni M, El Khammar M, Antoniotti S, Auquier P. Reliability and validity of the VSP-A, a health-related quality of life instrument for ill and healthy adolescents. J Adolesc Health. 2005; 36:327–36. doi:10.1016/j. jadoh ealth. 2004. 01. 016.

50. Soltani S, Neville A, Hurtubise K, Hildenbrand A, Noel M. Finding silver linings: a preliminary examination of benefit finding in youth with chronic pain. J Pediatr Psychol. 2018; 43:285–93. doi:10. 1093/ jpepsy/jsx126.

51. Szyndler JE, Towns SJ, van Asperen PP, McKay KO. Psychological and family functioning and quality of life in adolescents with cystic fibrosis. J Cyst Fibros. 2005; 4:135–44. doi:10. 1016/j. jcf. 2005. 02. 004.

52. Manderscheid RW, Ryff CD, Freeman EJ, et al. Evolving Definitions of Mental Illness and Wellness. Prev Chronic Dis. 2010; 7(1): 5–10. http://www.cdc.gov/pcd/issues/2010/jan/09_0124.htm.

53. Karimi M, Brazier J. Health, health-related quality of life, and quality of life: What is the difference? Pharmacoeconomics. 2016; 34:645–9. doi:10. 1007/ s40273- 016-0389-9.

54. Connell J, Cathain AO, Brazier J. Measuring quality of life in mental health: Are we asking the right questions? Soc Sci Med. 2014; 120:12–20. 10.1016/j.socscimed.2014.08.026.

55. Bech P, Olsen LR, Kjoller M, Rasmussen NK. Measuring well-being rather than the absence of distress symptoms: A comparison of the SF-36 mental health subscale and the WHO-five well- being scale. Int J Methods Psychiatr Res. 2003; 12:85–91. doi:10. 1002/ mpr. 145.

56. Sawyer SM, Drew S, Yeo MS, Britto MT. Adolescents with a chronic condition: Challenges living, challenges treating. Lancet. 2007; 28:1481–9. doi:10. 1016/ S0140-6736(07) 60370-5 (PMID: 17467519).

57. Ravens-Sieberer U, Gosch A, Rajmil L, Erhart M, Bruil J, Duer W, Auquier P, Power M, Abel T, Czemy L, Mazur J. The KIDSCREEN questionnaires: quality of life instruments for children and adolescents. Lengerich: Pabst Science Publishers; 2006.

CHAPTER 4

Paper 3: Orth, Z., Moosajee, F., & van Wyk. B. Measuring mental wellness of adolescents: A systematic review of instruments. Frontiers in Psychology. 2022; 13:1-14. doi: 10.3389/fpsyg.2022.835601.

Abstract

Objective: Mental health is critical to the healthy development of adolescents. However, mental health encompasses more than the absence of mental illness; and should include indicators of mental wellness. A critical review of available mental wellness instruments for adolescents was conducted to identify operational definitions of mental wellness concepts for this population group.

Method: A systematic review of the literature published between 2000-2020 was done to identify mental wellness instruments for adolescent populations. The review followed the PRISMA operational steps.

Results: We identified 2,543 articles from the search strategy and screened titles and abstracts for eligibility. After the appraisal, 97 studies were included in the qualitative synthesis; 79 mental wellness instruments were identified. Most studies did not define mental wellness. We identified thirteen mental wellness concepts from 97 studies, namely: life satisfaction, mental well-being [general], resilience, self-efficacy, self-esteem, connectedness, coping, self-control, mindfulness/spirituality, hope, sense of coherence, happiness, and life purpose.

Conclusion: The review reflected previous research identifying a lack of consensus around mental health, mental wellness, and mental well-being definitions. This has implications for developing instruments for adolescents that adequately measure these constructs. Most of the instruments identified in the review were predominantly English and from developed countries. This indicates a need for explicitly conceptualised and operationalised instruments for adolescents in all their varied contexts.

Background

Adolescents are prioritized in the global public health agenda because they play a central role in achieving the 2030 Sustainable Development Goals (SDGs) [1–3]. In 2019 UNICEF estimated that there were 1.2 billion adolescents (aged 10-19 years), representing approximately 16% of the global population [4]. It is further estimated that approximately 50% of all mental

disorders have their onset during adolescence [1,5,6]. According to the World Health Organization (WHO) [7], one in seven adolescents experienced a mental health condition in 2019. Poor mental health hinders healthy adolescent development and is associated with poorer health and social and economic outcomes across their lifetime [1,5]. Adolescent mental disorders represent a significant disease burden on health systems, particularly in low- and middle-income countries (LMICs), where mental health services and resources are lacking [5,7,8].

Early intervention and prevention programs are critical for the healthy development of adolescents. The SDGs, the Global Strategy for Women's, Children's and Adolescent's Health, the Global Accelerated Action for the Health of Adolescents, and the Lancet Commission on Adolescent Health and Well-Being highlight the gaps in research on adolescent mental health and argue for the need for valid high-quality data across different contexts to identify priorities and monitor progress in adolescent health [3,9,10]. A notable exception is UNICEF's Measurement of Mental Health among Adolescents at the Population Level (MMAP) programme, which aims to measure the prevalence of mental health disorders globally [6]. However, mental health is more than the absence of [mental] illness symptoms and should include wellness measures [11–14]. Research on positive mental health or mental wellness among adolescents is largely underdeveloped [11]. To stimulate more research on mental well-being among adolescents, measures of mental wellness are needed [15]. To this end, we systematically reviewed mental wellness instruments used in research with adolescents and reported on the mental wellness concepts that emerge from the identified instruments.

Methods

The review was registered with PROSPERO (CRD42020186707), and the methods for this review have been explained in detail in the published protocol [16].

Review question

We identified the following research questions:

What instruments are used to measure mental wellness in adolescents?

What dimensions of mental wellness were measured? What indicators were used? How is mental wellness conceptualized in the studies?

Search strategy

The search strategy was developed in consultation with the faculty librarian. The databases searched included Ebscohost (Psycharticles, Academic Search Premier), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Educational Resource Information Center (ERIC), Medical Literature Analysis Retrieval System Online (MEDLINE), Google scholar and Sabinet. The following search terms were used: "((adolescen* OR teenage* OR young people OR youth) [AND] (psychological instrument OR measure* OR tool) [AND] (mental health OR mental well-being OR psychological well-being OR mental wellness) [AND] {psychometri*; reliability*; validit*)). The search was concluded in December 2020.

Inclusion and exclusion criteria

Our study selection was guided by the Population, Intervention, Comparison, Outcome and Time (PICOT) criteria (see Table 4.1.). To be included in the review, studies had to include adolescents aged 10-19 years, and the instruments used focused on general mental wellness [relating to positive mental health]. Instruments measuring mental illness symptoms or aiding clinical diagnoses were excluded. Studies that included samples of people outside our age criteria were only included if the study had a clear focus on discussing adolescent mental wellness.

The period of the search strategy was chosen due to the paucity of research in this area [6,17,18]. Furthermore, the prioritization of adolescent health and the focus on adolescent-friendly services occurred after 2000 [19].

Table 4.1: PICOT

Population of interest	Adolescents aged 10-19 years
Intervention of Interest	Use a validated measuring instrument for mental wellness
Comparison interventions	Not applicable
Outcomes	Mental wellness
Time	2000–2020
Other considerations	Study designs: Quantitative method or mixed methods. Language: All

Review procedure

We follow the preferred reporting item for systematic reviews and meta-analysis (PRISMA statement) results in the conduct of this review. The number of hits for each database was recorded, and the citations were exported to Mendeley citation software. Following this, two reviewers (ZO & FI) independently reviewed all the titles and abstracts to assess which articles were appropriate for inclusion. The full-text articles of the included abstracts were downloaded and independently reviewed to determine which articles should be included in the final assessment. Conflicts were discussed and arbitrated by third reviewer (BVW) where necessary.

Quality appraisal

Articles remaining after abstract screening were critically appraised using the SFS scoring system version D [20]. This tool was developed to evaluate full-text studies' methodological coherence and rigour by providing scores on a generic set of categories. The SFS scoring system contains 29 questions covering the following sub-sections, namely: 1) purpose of the measure, 2) methodological rigour, and 3) general considerations. The overall quality of the study is scored as weak (0-25%), moderate (26-50%), strong (51-75%), or excellent (76-100%). Only articles that scored 51% and above in each of the abovementioned sub-sections were included in the final synthesis, which indicated that the articles were of good quality.

Data extraction and synthesis

A descriptive meta-synthesis approach was used to identify and describe the mental wellness instruments used among adolescent populations. The synthesis of information regarding each instrument was presented in tabular form to display relevant information [21]. The article information was entered into an excel sheet, and the sample characteristics, ages, sample size, distinctive population, languages of studies, and geographic location and purpose of the instrument were extracted.

Ethics

This review, a sub-study 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).

Results

The screening and selection process results are presented in the PRISMA diagram (Figure 4.1). We found 2,543 articles from the search strategy and screened titles and abstracts for eligibility; 326 full-text articles were screened for possible inclusion. We excluded 196 articles because the measures used in the study focused on measures for mental illness or were conducted with general population samples rather than adolescents specifically. Furthermore, 14 articles could not be accessed due to payment and were excluded. After conducting a quality appraisal, a further 19 articles were excluded leaving a total of 97 studies to be included in the qualitative synthesis.

As shown in Figure 4.2, most studies were conducted in Europe (36%) or North America (23%) and in English (n = 48), followed by Spanish (n = 18), Chinese (n = 8) and Portuguese language (n = 7). All instruments were originally developed in English, with some (n = 75) translated and adapted for use in a different cultural/language context.

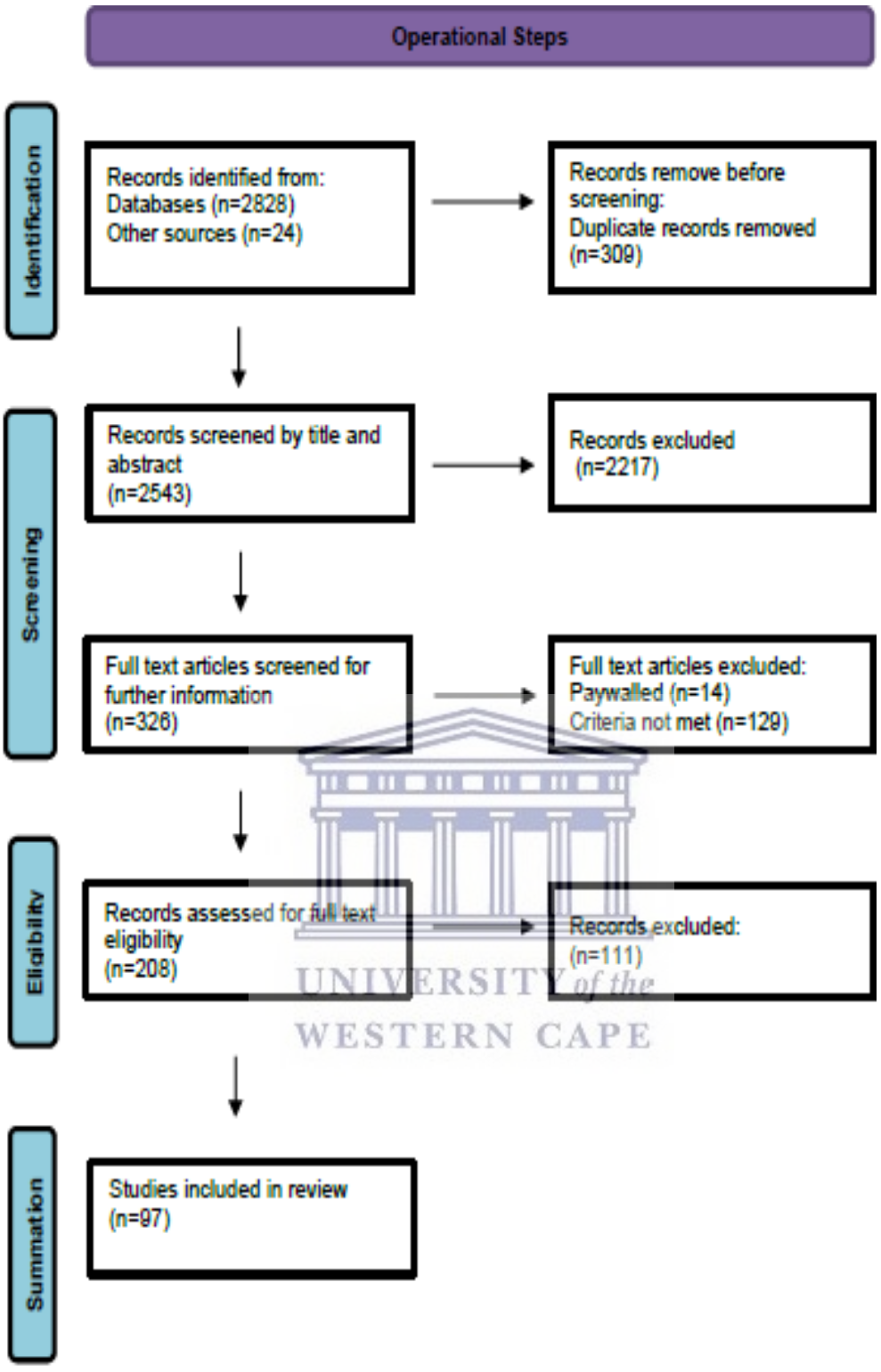

Figure 4.1: Prisma flowchart for selection of studies

Table 4.2 summarises the characteristics of 79 mental wellness instruments identified from the 97 studies. The instruments were categorised into 13 broad themes representing indicators of mental wellness, namely, life satisfaction (n = 12), mental wellbeing [general] (n = 7), resilience (n = 7), self- efficacy (n = 7), self-esteem (n = 7), connectedness (n = 6), coping (n = 6), self-control (n = 6), mindfulness/spiritual (n = 6), hope (n = 5), sense of coherence (n = 4), happiness (n = 3), and life purpose/goal (n = 3).

Table 4.3 provides an overview of the summary characteristics of all the mental wellness instruments included in the qualitative synthesis.

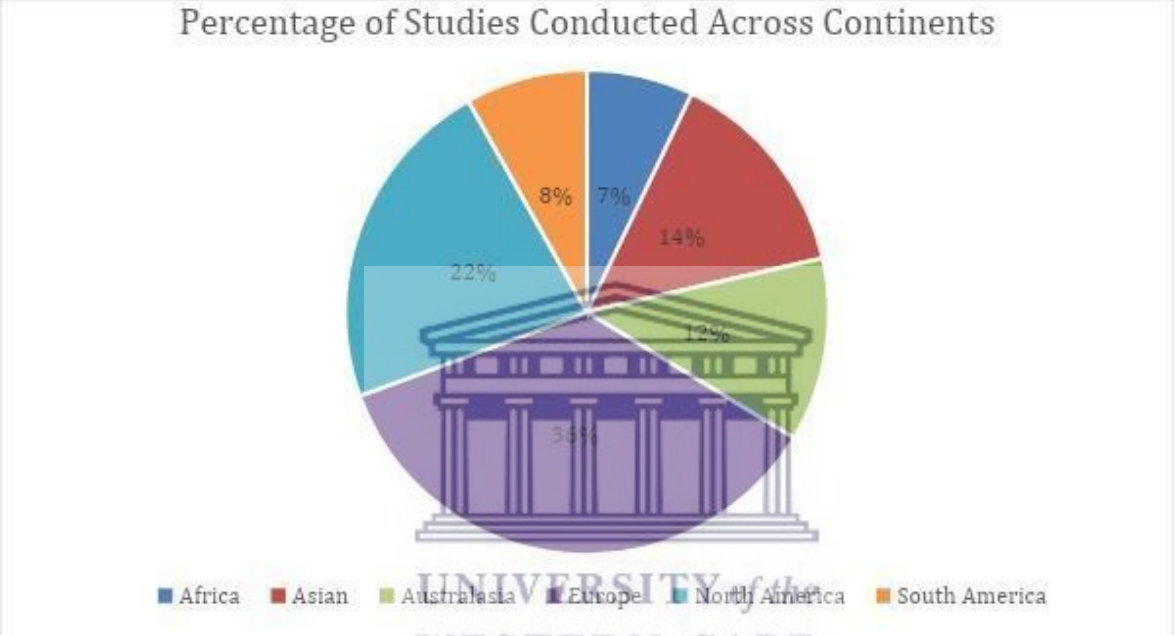

Figure 4.2: Pie chart depicting the percentages of studies conducted across continents

Table 4.2: Summary of mental wellness concepts (n = 13) and mental wellness instruments (n-79)

Mental wellness concept	Definition of mental wellness	Title of Instrument	Frequency of use; [Study references]
Mental well-being [general]	Experience of positive mental and physical health	Mental Health Continuum-Short Form	5; [22–26]
		Ryff Psychological Wellbeing Scale	5; [27–31]
		Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)	6; [25,32–36]
		WHO-5 Wellbeing Index	5; [25,37–40]
		Warwick-Edinburgh Mental Well-Being Scale short (SWEMWBS)	1; 30,36
		EPOCH Measure (Engagement, Perseverance, Optimism, Connectedness, and Happiness)	1; [42]
		QEWB Eudemonic Well-being Questionnaire	1; [43]
Connectedness	Refers to the supportive and caring relationships of the child	Hemingway Measure of Adolescent Connectedness–Short Version	1; [44]
		Awareness of Connectedness Scale	1; [45]

	in relation to groups and other people	Cultural Connectedness Scale-Short Version (CSS-S)	1; [44]
		Milwaukee Youth Belongingness Scale (MYBS	1; [46]
		Social Support Appraisals	1; [46]
		Social Support Scale (Cluver)	1; [47]
Coping	Ability to employ strategies to handle adverse or stressful events	A-COPE	1; [48]
		COPE	1; [49]
		KIDCOPE	1; [50]
		The Coping Response Inventory-Youth (CRI-Y)	1; [51]
		The Schoolagers' Coping Strategies Inventory (SCSI)	1; [52]
		Utrechtse Coping List	1; [53]
Self-control	Ability to control and regulate their emotions and thoughts	Difficulties in Emotion Regulation Scale (DERS)	2; [54,55]
		Trait Meta-Mood Scale (TMMS)	2;[56,57]
		Weinberger Adjustment Inventory	2; [46,58]
		Brief control scale	1; [59]
		Self-Control Scale (SCS)	1; [60]

		Psychological Empowerment	1; [61]
Happiness	Emotional state of mind or mood that determines satisfaction with life, flourishing and overall, well being	Oxford happiness questionnaire	2; [62,63]
		Adolescent Happiness Scale	1; [64]
		The Subjective Happiness Scale (SHS)	1; [65]
Hope	Belief in the future and that hopes, and goals will be met	(FESA Scale) Children Future Expectation Scale	1; [66]
		Children's Hope Scale	2; [67,68]
		The Children's dispositional hope scale	1; [49]
		The Hopefulness about Future (Hope) scale	2; [66,69]
		Urban Adolescent Hope Scale	1; [69]
Life purpose/goal	Feeling that one's life is significant, comprehensible, or purposeful	Adolescent Life Goal Profile Scale (ALGPS)	1; [65]
		Meaning in life questionnaire	1; [70]
		The Purpose in Life Test-10 Items	1; [55]
Life Satisfaction		Students' Life Satisfaction Scale (SLSS)	5; [52,71–74]
		The Personal Well-Being Index	4; [75–78]
		The Personal Well-Being Index School Children (PWI-SC)	4; [52,79–81]
		The Satisfaction with Life Scale (SWLS)	6; [32,44,65,82–84]

	Overall quality of life rather than current feelings	Single Item on Overall Life Satisfaction	4; [76–78,85]
		Huebner's Multidimensional Students' Life Satisfaction Scale (MSLSS)	3; [86–88]
		Cantril's self-anchoring ladder	3; [35,71,86]
		Overall Life Satisfaction (OLS)	1; [74]
		Affect Balance Scale (ABS)	1; [54]
		Multidimensional Student Life Satisfaction Questionnaire Short Form (MDAS-SF)	1; [89]
		The Children's Intrinsic Needs Satisfaction Scale (CINSS)	1; [90]
		The Satisfaction with Life Scale for Children	1; [44]
Mindfulness/ Spiritual	Ability to be present in life and the multidimensional concept that nurtures and celebrates wholeness through attention and awareness	Child and Adolescent Mindfulness Measure (CAMM)	3; [30,91,92]
		Mindful Attention Awareness Scale	1; [60]
		Spiritual well-being scale shortened version	2; [93,94]
		Newly developed strong souls	1; [95]
		Spiritual Well-being Questionnaire (SWBQ)	1; [96]
		The FACIT-Sp-12 Spiritual Well-Being Scale	1; [97]

Resilience	Ability to cope with and recover from adverse situations or stress	Child and Youth Resilience Measure (CYRM-28)	5; [46,82,98–100]
		Resilience Scale for Adolescents (READ)	4; [101–104]
		Chinese version of the resilience scale	1; [70]
		GMSR measure- gender minority stress and resilience scale	1; [105]
		Modified Connor Davidson Resilience Scale	1; [75]
		Student Resilience Scale	1; [106]
		Student Resilience Survey	1; [107]
Self-efficacy	Personal judgement on how well they will be able to cope in situations given the skills they possess	General Perceived Self-Efficacy Scale (GSE)	4; [32,65,84,108]
		Adolescent self-consciousness questionnaire	1; [59]
		Emotional Self-Efficacy Instrumentation	1; [109]
		Mandala Model of Self Scale (MMSS)	1; [70]
		Perceived Social Self-Efficacy (PSSE)	1; [60]
		Research and action self-efficacy	1; [61]
		Self-Efficacy Scale	1; [70]
Self-esteem	Confidence in own abilities and worth	Rosenberg Self-esteem Scale (RSE)	15; [32,33,62,66,68,69,84,89, 104,108,110–114]

		Self-Compassion Scale (SCS)	2; [30,115]
		The Self-Esteem Questionnaire (SEQ)	2; [61,116]
		Self-Perception Profile for children	1; [117]
		Harter Self-Perception Profile for children	1; [67]
		Self-Compassion Scale- Short Form	1; [83]
		Tennessee self-concept scale	1; [118]
Sense of Coherence	Ability to manage and cope with everyday life stressors due to their confidence and resources. A mixture of optimism and control	Sense of Coherence Scale (SOC-13)	1; [65]
		Orientation to Life Questionnaire	1; [104]
		The Life Orientation Test-Revised (LOT-R)	1; [84]
		The Social Capital and Cohesion Scale (SCCS)	1; [119]

Mental wellness concepts from the general mental wellbeing instruments

In line with the aims of this study, we examined each mental well-being [general] instrument to explore what mental wellness concepts are utilised to represent overall mental well-being. Through this process, we extracted the individual mental wellness concepts within each of the seven mental well-being [general] instruments – which brought the total amount of mental wellness concepts to 24. In Table 4.3, we rank the 24 mental wellness concepts in order of frequency of use in the identified instruments.

Table 4.3: Mental wellness concepts by frequency of use and definitions

Mental wellness concept	Frequency	Definition or Interpretation
Connectedness	7	A sense that one has satisfying relationships with others, believing that one is cared for, loved, esteemed, and valued, and providing friendship or support to others
Happiness	5	Steady states of positive mood and feeling content with one life rather than a momentary emotion.
Hope	4	An emotion characterized by positive feelings about the immediate or long-term future.
Life purpose/goal	4	You have goals in life and a sense of directedness; feel there is meaning to your present and past life; hold beliefs that give life purpose; and have aims and objectives for living.
Self-efficacy	4	A person's particular set of beliefs that determine how well one can execute a plan of action in prospective situations. Self-efficacy is a person's belief in their ability to succeed in a particular situation.
Personal expressiveness	4	Personal expressiveness and self-realization are thus linked to eudaimonia, where what is considered worth desiring and having in life is the best within us or personal excellence. Experiences of an activity as personally expressive occur when there is (a) an unusually intense involvement in an undertaking, (b) a feeling of a special fit or

		meshing with an activity that is not characteristic of most daily tasks, (c) a feeling of intensely being alive, (d) a feeling of being complete or fulfilled while engaged in an activity, (e) an impression that this is what the person was meant to do, and (f) a feeling that this is who one really is
Life satisfaction	3	A person's cognitive and affective evaluations of his or her life
Personal growth	3	You have a feeling of continued development; see yourself growing and expanding; are open to new experiences; have the sense of realizing your potential; see improvement in yourself and your behaviour over time; are changing in ways that reflect more self-knowledge and effectiveness.
Autonomy	3	You are self-determining and independent; you can resist social pressures to think and act in certain ways, regulate behaviour from within, and evaluate yourself by personal standards.
Physical functioning (feeling relaxed/energy)	3	Related to physical well-being, i.e. feeling relaxed, energy
Self-esteem	2	A person's overall subjective sense of personal worth or value
Coping	2	Coping refers to cognitive and behavioural efforts to manage (master, reduce, or tolerate) a troubled person-environment relationship
Self-acceptance	2	A positive attitude toward yourself; acknowledge and accept multiple aspects of yourself, including both good and bad qualities; and feel positive about your past life.

Environmental mastery	2	You have a sense of mastery and competence in managing the environment; controlling a complex array of external activities; making effective use of surrounding opportunities; and can choose or create contexts suitable to your personal needs and values.
Engagement	2	Capacity to become absorbed in and focused on what one is doing, as well as involvement and interest in life activities and tasks
Mindfulness/spiritual	1	The psychological process of bringing one's attention to the internal and external experiences occurring in the present moment; concern for or sensitivity to things of the spirit or soul.
Sense of coherence	1	Degree of meaningfulness, comprehensibility, and manageability that people feel in their life
Self-control	1	The ability to control behaviours in order to avoid temptations and achieve goals
Resilience	1	The ability to mentally withstand or adapt to uncertainty, challenges, and adversity.
Social contribution	1	A belief that one is a vital member of society with something of value to give to the world. It includes the extent to which individuals believe that whatever they do in the world is valued by society and contributes to the commonwealth
Social coherence	1	Concern for knowing about the world and constitutes the perception of the social world's quality, organisation and operation. Social coherence involves appraisals that society is discernible, sensible and predictable.

Social actualization	1	Similar to the themes of self-realisation and personal growth. Individuals with a high degree of social actualisation are hopeful about the condition and future of society, and they recognise the potential that re- sides in a collective and believe that the world can change and improve for people like themselves
Social acceptance	1	The social counterpart to self-acceptance indicates that people hold favourable views of human nature, expect others to be capable of kindness and consequently feel comfortable with others
Perseverance	1	Ability to pursue one's goals to completion, even in the face of obstacles.

Discussion

Definition of mental wellness concepts

From our review, few authors (38%) explicitly defined the concepts of mental health, mental wellness or well-being as used in their study. This finding follows the trend in literature where mental wellness is not clearly or adequately defined and used interchangeably with mental health and mental well-being concepts [12,120–124]. The observed absence of clear definitions or concepts of mental wellness perpetuates the lethargy in adolescent research on mental wellness. This is an important point of consideration as the way in which concepts are defined affect the ways in which concepts are measured. Careful consideration should be taken on theory development and conceptualizing mental wellness, given the need for valid and reliable instruments specifically for adolescent populations. While instruments providing data on symptom and problem-oriented analyses are needed to improve our understanding of the mental health challenges adolescents face, there is a simultaneous need to examine positive aspects of mental wellness to enhance our understanding of the different mental health-related dimensions [11,17]. This, in turn, will be beneficial in aiding the development of theories and policies to guide sustainable health programmes which can address adolescent mental health on multiple levels of intervention and prevention.

The mental wellness concepts identified in this review are consistent with definitions of mental wellness in studies with adult populations [120-121]. However, the same fault line in interchanging mental wellness with mental well-being concepts is perpetuated. For example, Adams et al. [125] identified six dimensions of wellness - spiritual, physical, intellectual, emotional, psychological, and social – which provide a fitting categorization for the wellness concepts identified from our review of mental wellness instruments for adolescents. Similarly, Ryff [126] based her model of psychological well-being on concepts of self-acceptance, quality ties to others, a sense of autonomy, the ability to manage complex environments to suit personal needs and values, the pursuit of meaningful goals and purpose in life, and continued growth and development, - which are synonymous with our mental wellness concepts for adolescents. This may suggest that frameworks for mental wellness developed for adult populations may be fitting for adolescents. However, this also indicates that the constraints encountered in the

conceptualisation and operationalisation of mental wellness for research with adults are equally present in research with adolescents. Thus, the shortcomings in adolescent mental wellness research require critical conceptual development of mental wellness in general, with particular emphasis on reaching a consensus on the definition of mental wellness and the concomitant development of mental wellness indicators and measuring instruments. The mental wellness concepts identified from the instruments in this review may provide building blocks to conceptualise and guide theory development around adolescent mental wellness, which can aid in the development of valid and reliable instruments.

Although definitions of mental wellness vary, the concepts of eudaimonia and hedonia are commonly agreed-upon facets of mental wellness [121,123]. From a eudemonic perspective, mental wellness is associated with an individual's ability to function well and reach their full potential/purpose in life, while the hedonic perspective associates mental wellness with positive affects (feeling well) in the present [11,123,127]. Research on eudemonic and hedonic concepts have been well-documented for adult populations, indicating that both serve as protective factors against mental illness while promoting overall mental wellness [121,123]. Witten et al. [121] comment that research on hedonic mental wellness concepts in adolescents is well established, while less attention has been paid to eudemonic concepts. To explore this, we categorised 12 of the 13 types of mental wellness concepts to reflect eudemonic (functioning well) and hedonic (feeling well) mental wellness.

Our review identified six eudemonic concepts: coping, self-control, life purpose/goal, resilience, self-efficacy, and sense of coherence from the existing mental wellness instruments. This review also identified five hedonic concepts of connectedness, happiness, hope, life satisfaction, and self-esteem. We argue that mindfulness/spirituality can be considered a eudemonic and hedonic concept depending on the context. Additionally, the seven Mental well-being [general] instruments measured multiple mental wellness concepts and therefore included both hedonic (n=7) and eudomonic concepts (n=17). This suggests that instruments aimed at measuring general well-being as an indicator of adolescent mental wellness may reflect more comprehensive dimensions of mental wellness. In comparison to instruments which measure single concepts of mental wellness (i.e., self-esteem, resilience etc.), we found that the general well-being instruments in this review provided a better representation of overall mental wellness.

In this review, we see that hedonic mental wellness in adolescents goes beyond subjective feelings related to the self (i.e., happiness, hope, and life satisfaction) but also includes social aspects centred on the adolescents' connections to others and their sense of spirituality. While hedonic mental wellness is valuable, prioritising only happiness or life satisfaction may have unintended negative outcomes in adolescents. Therefore, a balance between eudemonic and hedonic concepts is necessary to promote mental wellness. For example, research has shown that adolescents have less impulse control than adults and show heightened activation in brain regions associated with reward processing, meaning they tend to engage in reward-seeking behaviours and pursue hedonic pleasures more frequently, resulting in an imbalance in their mental wellness [123].

Additionally, self-focused hedonic behaviours (i.e., partying, self-indulgence) are related to negative affect, lower life satisfaction, and more depressive symptoms [123]. Therefore, exclusive emphasis on hedonic wellness may influence adolescents' resilience and make them more vulnerable to social hardships and other challenges in life. In support of this, hedonic behaviours are considered less predictive of mental wellness than eudemonic behaviours. As an illustration, one longitudinal study of 15–17-year-olds found that hedonic decisions (gaining money for themselves) predicted greater depressive symptoms as opposed to eudemonic behaviours (donating money) [123]. Furthermore, emerging research suggests that globally subjective well-being tends to decrease in young people between the ages of 13-24 years [121]. The challenges related to the conceptualisation of mental wellness and related concepts and the lack of research on both eudomonic, and hedonic mental wellness simultaneously make it difficult to pinpoint the mechanism contributing to this phenomenon [121].

We argue that this decrease-with-age tendency may occur when adolescents only focus on pursuing hedonic mental wellness without developing eudemonic mental wellness, as the former is associated with lower levels of meaning in life [121]. Therefore, while adolescents may experience happiness or life satisfaction, their overall subjective well-being may decline as they come to terms with getting older, increasing responsibilities, and making sense of the changing world around them. Without the balance of eudemonic wellness, adolescents may struggle to cope with challenges and life demands associated with their development which could increase their engagement in risky behaviour as they try to stimulate the reward centre of their brains to maintain their hedonic wellness. On the other hand, adolescents who pursue both hedonic and eudemonic

mental wellness are more likely to adopt a balanced and realistic stance towards life by accepting that challenges are a part of life while maintaining the belief that these are manageable and that they are capable of working towards a better life. In such cases, the presence of eudemonic wellness may act as a buffer against risks associated with hedonic pursuits. To support this, longitudinal studies have shown that a stabilizing effect occurs as subjective well-being (SWB) scores stop decreasing over time [128]. This stabilizing effect may be influenced by the socio-political and cultural context in which adolescents develop – data shows that Australian adolescents' SWB scores start increasing at age 17/18, and Brazilian adolescents' SWB scores stop decreasing at 16, while data from Romania suggests SWB may continue decreasing after 20 years of age [128]. Some cultures may provide more opportunities for adolescents to develop both hedonic and eudomonic mental wellness, allowing them to regain a sense of SWB.

Additionally, due to the proliferation of quantitative studies aimed at measuring SWB in adolescents – we argue that more qualitative research is needed to explore why SWB decreases during these years and which eudemonic and hedonic factors may act as a buffer to promote enduring mental wellness. Therefore, our review supports previous research indicating that both hedonic and eudemonic indicators should be represented in instruments aimed at measuring mental wellness in adolescents – these indicators can be useful to track intervention and policy outcomes related to increasing adolescent mental wellness as it allows us to focus on gaining a better understanding of how they balance the desire to feel good and pursue a meaningful life, and under what conditions mental wellness is maintained.

Furthermore, while mental wellness instruments were originally developed for adult populations and adapted to demonstrate good reliability and validity scores among adolescents, it may be that these measures do not capture aspects of mental wellness that may be unique to adolescents [129]. As the decreasing-with-age tendency shows, some concepts related to mental wellness may be influenced by factors related to the developmental stage. This brings into question the extent to which research with adults can be generalised and adapted to adolescent populations. For example, the WEMWBS was originally developed to support work to develop Scottish mental health indicators for adults. This indicates that the identification and development of important mental wellness domains were derived from research focusing on aspects significant to adult mental wellness.

Similarities between adult and adolescent mental health exist. For example, research on mental health in adolescents living with HIV suggests that they experience similar challenges as adults living with HIV [129]. However, even in such cases, there is a call to recognise the unique developmental stage adolescents are in as they experience significant mental and physical changes. Studies have shown that, unlike adults, the adolescent brain is still developing and is more susceptible to changes caused by stress [130]. Additionally, evidence shows that individual factors such as age, sex, and gender present complex interactions with mental wellness among adolescents [130]. Therefore, there is a need to conduct more research with adolescents so that they may participate and contribute to the conceptualisation and operationalisation of mental wellness, which suits their needs.

Additionally, we found that all the instruments were originally developed in English, with many of these being developed with participants from a western context (see figure 4.2). The exceptions are the Urban Adolescent Hope Scale and the Strong Souls instruments which were developed with indigenous Australian Youth. While many of these instruments have been translated into other languages and validated in different cultural contexts, it raises questions which align with debates around decolonising mental health, such as what constitutes knowledge and 'evidence' of global mental health and who decides what counts as 'evidence' [131–133].

Mental wellness measures developed in western contexts are often translated and validated in other cultural settings as new measures are seen as involving costly and time-consuming processes [134]. However, do these validated measures accurately capture the evidence related to mental wellness experiences and challenges of youth living in cultural and religious contexts that differ from the west, or are they perpetuating definitions based on Western Psychology? According to Zaretsky [135], mental healthcare systems continue to be shaped by colonial policies and practices rooted in racism which consequently results in the perpetuation of mental wellness services that are not culturally appropriate.

Research shows that mental health disparities between indigenous and non-indigenous youth result from centuries of racism and colonial practices [131,135,136]. Indigenous youth are more likely to experience trauma, suicide attempts, substance use, HIV, homelessness, and mental health problems than non-indigenous youth [131,136]. Furthermore, treating mental health from a

western perspective can perpetuate colonial and oppressive practices [136]. Indigenous youth are hospitalized at a higher rate than non-indigenous youth, and the treatment involved may increase their chances of developing substance dependence [131]. Studies like these suggest that indigenous adolescents and those living outside of the western context may experience challenges to their mental health, which differ from non-indigenous youth. This also means that the strategies they need to improve and maintain their mental wellness could take on forms which are generally not considered in the western context. Therefore, understanding what mental wellness is from a decolonised perspective is necessary to increase the recognition of indigenous approaches to healing which should be incorporated into mental health services.

Study limitations and future research

There are a few limits to note regarding this study. Firstly, the databases we used to search may not have accessed psychology-relevant databases. As mentioned previously, some of the articles were excluded from this review because we did not access those via the university databases. Based on the results of our review and the global advocacy around adolescents' rights, we argue that there is a need for more qualitative research to explore how adolescents experience and understand mental wellness. This research can be used to address questions around how adolescents make sense of mental wellness, their experiences, and interpretations of wellness, and what they need to improve and maintain mental wellness. These critical questions require further investigation as adolescents' understanding of the concept during this unique developmental period may influence their lifestyle choices and behaviours, which may be carried into adulthood. This information is vital to support the development of mental health services which are accessible and valuable to adolescents. Most instruments in this review were designed in developed countries. Cross-cultural qualitative studies may help us explore how adolescents from different cultures experience mental wellness, which may help us better understand the need to develop instruments in developing countries. Additionally, qualitative research exploring adolescents' views of mental wellness may provide further insights into the similarities or differences between adolescent and adult populations, which can facilitate the development of instruments that specifically measure

adolescent mental wellness.

Conclusion

The review confirms a growing body of literature on adolescents' mental health. However, there is no consensus on an explicit definition of the concept of mental wellness. A clear definition is needed to improve our understanding of adolescent mental wellness, which can aid the development, monitoring, and evaluation of interventions and programmes aimed at improving adolescent mental wellness. Our findings indicate that the general mental wellbeing instruments reflected a more comprehensive measure of mental wellness, highlighting the need to include both hedonic and eudemonic indicators in mental wellness measures for adolescents. A key finding is the adaptation of the instruments to adolescent populations, as most instruments were developed for adults in the English language and a developed context. This indicates a need for adolescents to be involved in conceptualising and operationalising mental wellness. Mental wellness instruments should allow for the varied presentation of mental wellness evident amongst youth in different cultural contexts.

References

1. Patalay P, & Gage SH. Changes in millennial adolescent mental health and health- related behaviours over 10 years: A population cohort comparison study. Int J Epidemiol. 2019;48(5): 1650–1664. https://doi.org/10.1093/ije/dyz006.
2. Guthold R, Moller AB, Azzopardi P, et al. The Global Action for Measurement of Adolescent health (GAMA) Initiative—Rethinking adolescent metrics. J Adolesc Health. 2019; 64(6): 697–699. https://doi.org/10.1016/j.jadohealth.2019.03.008
3. World Health Organization. Global Accelerated Action for the Health of Adolescents (AA-HA!): Guidance to support country implementation. 2017. Available from: https://www.who.int/publications/i/item/9789241512343.
4. UNICEF. Adolescent health and well-being. 2020. Available from https://www.unicef.org/health/adolescent-health-and-well-being
5. Peters I, Handley T, Oakley K, Lutkin S, & Perkins D. Social determinants of psychological wellness for children and adolescents in rural NSW. BMC Public Health. 2019;19(1): 1– 11. https://doi.org/10.1186/s12889-019-7961-0.
6. UNICEF. Measurement of mental health among adolescents at the population level (MMAP). 2020. Available from https://data.unicef.org/topic/child-health/mental-health/mmap/
7. World Health Organization. Adolescent mental health. 2020. Available from https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health
8. Sorsdahl K, van der Westhuizen C, Neuman M, Weiss HA, & Myers B. Addressing the mental health needs of adolescents in South African communities: A protocol for a feasibility randomized controlled trial. Pilot Feasibility Stud. 2021;7(1): 1–14. https://doi.org/10.1186/s40814-021-00803-5
9. Every Woman, Every Child. The global strategy for women's, children's, and adolescents' health (2016-2030). 2015. Available from: https://globalstrategy.everywomaneverychild.org/.
10. Patton GC, Sawyer SM, Santelli JS, et al. Our future: A Lancet commission on adolescent health and wellbeing. Lancet. 2016; 387: 2423–2478. doi: 10.1016/S0140-6736(16)00579-1

11. Eriksson C, Arnarsson ÁM, Damsgaard MT, et al. Towards enhancing research on adolescent positive mental health. Nordic Welfare Research. 2019; 4: 113–128. doi: https://doi.org/10.18261/issn.2464- 4161-2019-02-08.
12. Manderscheid RW, Ryff CD, Freeman EJ, et al. Evolving Definitions of Mental Illness and Wellness. Prev Chronic Dis. 2010; 7(1): 5–10. http://www.cdc.gov/pcd/issues/2010/jan/09_0124.htm.
13. Manwell LA, Barbic SP, Roberts K, et al. What is mental health? Evidence towards a new definition from a mixed methods multidisciplinary, international survey. BMJ Open. 2015; 5: 1–11. doi: 10.1136/bmjopen-2014-007079.
14. Ryff CD (2013) Psychological well-being revisited: Advances in the science and practice of eudaimonia. Psychother Psychosom. 2014; 83:10–28. doi: 10.1159/000353263.
15. Glasner J, Baltag V, Ambresin AE. Previsit multidomain psychosocial screening tools for adolescents and young adults: A systematic review. J Adolesc Health. 2021;68(3):449-459. doi:10.1016/j.jadohealth.2020.10.003
16. Orth Z, Van Wyk B. Adolescent mental wellness: A systematic review protocol of instruments measuring general mental health and wellbeing. BMJ Open. 2020; 10:37237. doi: 10. 1136/ bmjop en- 2020- 037237.
17. Rose T, Joe S, Williams A, Harris R, Betz G, Stewart-brown S, Rose T. Measuring mental wellbeing among adolescents: A systematic review of instruments. J Child Fam Stud. 2017; 26:2349–2362. doi: 10.1007/s10826-017-0754-0.
18. Bentley N, Hartley S, Bucci S. Systematic review of self-report measures of general mental health and wellbeing in adolescent mental health. Clin Child Fam Psychol. 2019; 22:225–252. doi: 10.1007/s10567-018-00273-x.
19. World Health Organization. Making health services adolescent friendly. 2012. Available from: https://apps.who.int/iris/bitstream/handle/10665/75217/9789241503594_eng.pdf;jsessionid=63D 28258463D67FC5F8592E6D13162C6?sequence=1
20. Smith MR, Franciscus G, Swartbooi C, Munnik E, Jacobs W. The SFS scoring system. In MR Smith (Ed., Chair), Symposium on Methodological Rigour and Coherence: Deconstructing the Quality Appraisal Tool in Systematic Review Methodology, conducted

at the 21st National Conference of the Psychological Association of South Africa, South Africa.

21. Gough D, Oliver S, Thomas J. An introduction to systematic reviews. Oakland: Sage Publications Inc; 2012.
22. Guo C, Tomson G, Guo J, Li X, Keller C, et al. Psychometric evaluation of the Mental Health Continuum-Short Form (MHC-SF) in Chinese adolescents - a methodological study. Health Qual Life Outcomes. 2015; 13:1–9. https://doi.org/10.1186/s12955-015-0394-2
23. Piqueras JA, Rodriguez-Jimenez T, Marzo JC, Rivera-Riquelme M, Martinez- Gonzalez E, Falco R & Furlong MJ. Social Emotional Health Survey- Secondary (SEHS- S): A universal screening measure of social-emotional strengths for Spanish-speaking adolescents. International Journal of Environmental Research and Public Health. 2019; 16(24): 4982-4998. https://doi.org/10.3390/ijerph16244982.
24. Carvalho J, Pereira N, Pinto A, & Marôco J. Psychometric properties of the Mental Health Continuum-Short Form: A study of Portuguese speaking children/youths. Journal of Child & Family Studies. 2016;25(7): 2141–2154. http://10.0.3.239/s10826-016-0396-7.
25. Clarke A, Friede T, Putz R, Ashdown J, et al. Warwick-Edinburgh Mental Well-being Scale (WEMWBS): Validated for teenage school students in England and Scotland. A mixed methods assessment. BMC Public Health. 2011;11: 1-9. https://doi.org/10.1186/1471-2458-11-487.
26. Reinhardt M, Horváth Z, Morgan A, & Kökönyei G. Well-being profiles in adolescence: Psychometric properties and latent profile analysis of the mental health continuum model - a methodological study. Health Qual Life Outcomes. 2020;18(1): 1–10. https://doi.org/10.1186/s12955-020-01332-0
27. Karen Meier L., & Beatriz Oros L. Adaptation and psychometric analysis of Ryff's Scales of Psychological Well-Being in Argentinean adolescents. Psykhe. 2019;28(1): 1–16. https://doi.org/10.7764/psykhe.28.1.1169.
28. Kiang L, & Ip E. Longitudinal profiles of eudaimonic well-being in Asian American adolescents. Cultural Diversity & Ethnic Minority Psychology. 2018;24(1): 62– 74. https://doi.org/10.1037/cdp0000156.

29. Sirigatti S, Penzoa I, Giannetti E, & Stefanile C. The Humor Styles Questionnaire in Italy: Psychometric properties and relationships with psychological well-being. Europe's Journal of Psychology. 2014;10(3): 429–450. https://doi.org/http://10.0.23.76/ejop.v10i3.682.

30. Шульга ТИ. Mindfulness in orphan and parentless adolescents as a factor of psychological Well-Being. Psychological Science and Education. 2019;24(4): 36–50. https://doi.org/10.17759/pse.2019240403.

31. Gallardo Cuadra I, & Moyano-Diaz E. Análisis psicométrico de las escalas Ryff (versión española) en una muestra de adolescentes chilenos. Universitas Psychologica. 2012;11(3): 931–939.

32. Ringdal, R., Bradley Eilertsen, M.-E., Bjørnsen, H. N., Espnes, G. A., & Moksnes, U. K. (2018). Validation of two versions of the Warwick-Edinburgh Mental Well-Being Scale among Norwegian adolescents. Scandinavian Journal of Public Health. 2018;46(7), 718–725. https://doi.org/http://10.0.4.153/1403494817735391.

33. St Clair, M. C., Neufeld, S., Jones, P. B. et al. Characterising the latent structure and organisation of self- reported thoughts, feelings and behaviours in adolescents and young adults. Plos One. 2017;12(4): e0175381–e0175381. https://doi.org/10.1371/journal.pone.017538.

34. Hunter SC, Houghton S, & Wood L. Positive mental well-being in Australian adolescents: Evaluating the Warwick-Edinburgh Mental Well-Being Scale. Australian Educational and Developmental Psychologist. 2015;32(2): 93–104. https://doi.org/10.1017/edp.2015.12.

35. Melendez-Torres G J, Hewitt G, Hallingberg, B. et al. Measurement invariance properties and external construct validity of the short Warwick-Edinburgh mental wellbeing scale in a large national sample of secondary school students in Wales. Health And Quality of Life Outcomes. 2019; 17(1): 1-9. https://doi.org/10.1186/s12955-019-1204-z.

36. McKay MT, & Andretta JR. Evidence for the Psychometric Validity, Internal Consistency and Measurement Invariance of Warwick Edinburgh Mental Well-being Scale Scores in Scottish and Irish Adolescents. Psychiatry Research. 2017; 255: 382–386. https://doi.org/https://doi.org/10.1016/j.psychres.2017.06.071.

37. Stiglbauer B, Gnambs T, Gamsjager M, & Batinic B. The Upward Spiral of Adolescents' Positive School Experiences and Happiness: Investigating Reciprocal Effects over Time.

Journal of School Psychology. 2013;51(2): 231–242. https://doi.org/10.1016/j.jsp.2012.12.002.

38. Carli V, Wasserman C, Wasserman D et al. The saving and empowering young lives in Europe (SEYLE) randomized controlled trial (RCT): Methodological issues and participant characteristics. BMC Public Health. 2013;13(1): 479. https://doi.org/10.1186/1471-2458- 13-479.

39. de Wit M, Pouwer F, Gemke RJ, et al. Validation of the WHO-5 well-being index in adolescents with type 1 diabetes. Diabetes Care. 2007; 30(8): 2003–2006. https://doi.org/10.2337/dc07-044.

40. de Wit M, Winterdijk P, Aanstoot HJ, et al. Assessing diabetes-related quality of life of youth with type 1 diabetes in routine clinical care: The MIND Youth Questionnaire (MY-Q). Pediatric Diabetes. 2012;13(8): 638–646. https://doi.org/10.1111/j.1399-5448.2012.00872.x.

41. Bjørnsen HN, Eilertsen MEB, Ringdal R., Espnes GA, & Moksnes UK. Positive mental health literacy: development and validation of a measure among Norwegian adolescents. BMC Public Health. 2017;17(1): 1-10. https://doi.org/10.1186/s12889-017-4733-6.

42. Kern ML, Steinberg EA, Benson L, & Steinberg L. The EPOCH Measure of Adolescent Well-Being. Psychological Assessment. 2016;28(5): 586–597. https://doi.org/http://10.0.4.13/pas0000201.

43. Salavera C, & Usán P. Psychometric properties of the QEWB questionnaire on eudaimonic well-being in teenagers. Psicología Educativa. 2019;25(2): 139–146. https://doi.org/https://doi.org/10.5093/psed2019a3.

44. Snowshoe A, Crooks C, Tremblay P, Hinson R, Crooks C, et al. Cultural connectedness and its relation to mental wellness for First Nations Youth. Journal of Primary Prevention. 2017;38(1): 67–86. https://doi.org/10.1007/s10935- 016-0454-3.

45. Peters HJ, & Peterson TR. Developing an indigenous measure of overall health and well-being: The Wicozani Instrument. American Indian and Alaska Native Mental Health Research. 2019;26(2): 96–122. https://doi.org/https://doi.org/10.5820/aian.2602.2019.96.

46. Slaten CD, Rose CA, Bonifay W, & Ferguson JK. The Milwaukee Youth Belongingness Scale (MYBS): Development and validation of the scale utilizing item response theory. School Psychology. 2019; 34(3): 296–306. https://doi.org/10.1037/spq0000299.

47. Gentz SG, Calonge-Romano I, Martínez-Arias R, Zeng C, & Ruiz-Casares M. Mental health among adolescents living with HIV in Namibia: the role of poverty, orphanhood and social support. AIDS Care. 2018;30(0): 83–91. https://doi.org/10.1080/09540121.2018.1469727.

48. Forns M, Kirchner T, Pero M, Pont E, Abad J, Soler L, & Paretilla C. Factor structure of the adolescent coping orientation for problem experiences in Spanish adolescents. Psychological Reports. 2013;112(3): 845–871. https://doi.org/http://10.0.9.162/03.20.PR0.112.3.845- 871

49. Vaughn AA, Roesch SC, & Aldridge AA. Stress-related growth in racial/ethnic minority adolescents: Measurement structure and validity. Educational and Psychological Measurement. 2009;69(1): 131–145. http://dx.doi.org/10.1177/0013164408318775.

50. Powell TM, Wegmann KM, & Overstreet S. Measuring adolescent coping styles following a natural disaster: An ESEM analysis of the Kidcope. School Mental Health. 2019; 11(2):335–344. doi: 10.1007/s12310-018-9288-x.

51. Erickson SJ, & Feldstein SW. Adolescent humor and its relationship to coping, defence strategies, psychological distress, and well-being. Child Psychiatry and Human Development. 2007;37(3): 255–271. https://doi.org/10.1007/s10578-006-0034- 5.

52. Viñas F, Casas F, Abreu DP, Alcantara SC, & Montserrat C. Social disadvantage, subjective well-being and coping strategies in childhood: The case of northeastern Brazil. Children & Youth Services Review. 2019;97: 14–21. https://doi.org/http://10.0.3.248/j.childyouth.2017.06.012

53. Mavroveli S, Petrides K, Rieffe C, & Bakker F. Trait emotional intelligence, psychological well-being and peer-rated social competence in adolescence. British Journal of Developmental Psychology. 2007;25(2): 263–275. https://doi.org/10.1348/026151006X118577.

54. Wang Y, & Hawk ST. Development and validation of the Child and Adolescent Flexible Expressiveness (CAFE) Scale. Psychological Assessment. 2020;32(4): 358–373. https://doi.org/10.1037/pas0000795.

55. García-Alandete J, Gallego Hernández de Tejada B, Pérez Rodríguez S, & Marco-Salvador JH. Meaning in life among adolescents: Factorial invariance of the purpose in life test and buffering effect on the relationship between emotional dysregulation and

hopelessness. Clinical Psychology & Psychotherapy. 2019;26(1): 24–34. https://doi.org/http://10.0.3.234/cpp.2327.

56. Ballespí S, Vives J, Alonso N, Sharp C, Ramírez, et al. To know or not to know? Mentalization as protection from somatic complaints. PLoS ONE. 2019;14(5): 1–20. https://doi.org/http://10.0.5.91/journal.pone.0215308.

57. Salguero JM, Palomera R, & Fernández-Berrocal P. Perceived emotional intelligence as predictor of psychological adjustment in adolescents: A 1-year prospective study. European Journal of Psychology of Education. 2012;27(1): 21–34. https://doi.org/10.1007/s10212- 011-0063-8.

58. Vazsonyi AT, Ksinan A, Mikuška J, & Jiskrova G. The Big Five and adolescent adjustment: An empirical test across six cultures. Personality & Individual Differences. 2015;83: 234– 244. https://doi.org/http://10.0.3.248/j.paid.2015.03.049.

59. Espada JP, Rodríguez-Menchón M, Morales A, Hoerger M, & Orgilés M. Spanish validation of the Delaying Gratification Inventory in adolescents. Psicothema, 2019;31(3): 327–334. https://doi.org/10.7334/psicothema2019.17.

60. Black DS, Sussman S, Johnson CA, & Milam J. Psychometric assessment of the Mindful Attention Awareness Scale (MAAS) among Chinese adolescents. Assessment. 2012;19(1): 42–52. https://doi.org/10.1177/1073191111415365.

61. Ozer EJ, & Schotland M. Psychological empowerment among urban youth: Measure development and relationship to psychosocial functioning. Health Education & Behavior. 2011;38(4): 348–356. https://doi.org/10.1177/1090198110373734.

62. Meleddu M, Guicciardi M, Scalas LF, & Fadda D. Validation of an Italian version of the Oxford happiness inventory in adolescence. Journal Of Personality Assessment. 2012;94(2): 175–185. https://doi.org/10.1080/00223891.2011.645931.

63. Lung FW, & Shu BC. The psychometric properties of the Chinese Oxford Happiness Questionnaire in Taiwanese adolescents: Taiwan birth cohort study. Community Mental Health Journal. 2020;56(1): 135–138. https://doi.org/http://10.0.3.239/s10597-019-00472-y.

64. Isik S, & Üzbe Atalay N. Developing the Adolescent Happiness Scale: Validity and reliability study. Pegem Journal of Education and Instruction. 2019;9(3): 673–696. https://doi.org/10.14527/pegegog.2019.022.

65. Gabrielsen L, Ulleberg P, & Watten R. The Adolescent Life Goal Profile Scale: Development of a new scale for measurements of life goals among young people. Journal of Happiness Studies. 2012;13(6): 1053–1072. http://10.0.3.239/s10902- 011-9306-2.

66. Zhao J, Li X, Barnett D, Lin X, et al. Parental loss, trusting relationship with current caregivers, and psychosocial adjustment among children affected by AIDS in China. Psychology, Health & Medicine. 2011;16(4): 437–449. https://doi.org/10.1080/13548506.2011.554569.

67. Ey S, Hadley W, Allen DN, et al. A new measure of children's optimism and pessimism: The Youth Life Orientation Test. Journal of Child Psychology and Psychiatry. 2005;46(5): 548–558. https://doi.org/10.1111/j.1469- 7610.2004.00372.x

68. Ciarrochi J, Heaven PCL, & Davies F. The impact of hope, self-esteem, and attributional style on adolescents' school grades and emotional well-being: A longitudinal study. Journal of Research in Personality. 2007;41(6): 1161–1178. https://doi.org/10.1016/j.jrp.2007.02.001.

69. Canfield JP, Harley D, Hunn V, Haddad KL, Kim SH, Elliott W, & Mangan L. Development and initial validation of the urban adolescent hope scale. Journal of Evidence-Informed Social Work. 2018;15(3): 243–257. http://10.0.4.56/23761407.2018.1431576.

70. Shiah Y, & Hwang K. Socialized reflexivity and self-exertion: Mandala Model of Self and its role in mental health. Asian Journal of Social Psychology. 2019;22(1): 47– 58. http://10.0.4.87/ajsp.12344.

71. Levin K, & Currie C. Reliability and validity of an adapted version of the Cantril Ladder for use with adolescent samples. Social Indicators Research. 2014;119(2): 1047–1063. http://10.0.3.239/s11205-013-0507-4.

72. Furlong M, You S, Renshaw T, Smith D, & O'Malley M. Preliminary development and validation of the social and emotional health survey for secondary school students. Social Indicators Research. 2014;117(3): 1011–1032. https://doi.org/http://10.0.3.239/s11205-013-0373-0.

73. Burns JR, & Rapee RM. School-based assessment of mental health risk in children: The preliminary development of the Child RADAR. Child & Adolescent Mental Health. 2019;24(1): 66–75. https://doi.org/10.1111/camh.12258.

74. Savahl S, Tiliouine H, Casas F, et al. Children's subjective well-being in Africa: A comparative analysis across three countries. Children & Youth Services Review. 2017;80(C): 31–40. https://doi.org/10.1016/j.childyouth.2017.06.063

75. Tomyn, AJ, & Weinberg MK. Resilience and subjective wellbeing: A Psychometric evaluation in young Australian adults. Australian Psychologist. 2018;53(1): 68–76. https://doi.org/http://10.0.4.87/ap.12251.

76. Casas F, Baltatescu S, Bertran I, Gonzalez M, & Hatos A. School satisfaction among adolescents: Testing different indicators for its measurement and its relationship with overall life satisfaction and subjective well-being in Romania and Spain. Social Indicators Research. 2013;111(3): 665–681. http://dx.doi.org/10.1007/s11205-012-0025-9.

77. Sarriera JC, Casas F, Alfaro J, et al. Psychometric properties of the Personal Wellbeing Index in Brazilian and Chilean adolescents including spirituality and religion. Psychological Assessment. 2014;27(4): 710–719. https://doi.org/https://doi.org/10.1590/1678- 7153.201427411.

78. Casas F, Sarriera J, Alfaro J. et al. Testing the Personal Wellbeing Index on 12–16-year-old adolescents in 3 different countries with 2 new items. Social Indicators Research. 2012;105(3), 461–482. http://10.0.3.239/s11205-011- 9781-1.

79. Tomyn A, Fuller TM, & Norrish J. The psychometric equivalence of the Personal Wellbeing Index School-Children for indigenous and non-indigenous Australian adolescents. Journal of Happiness Studies. 2014;15(1): 43–56. https://doi.org/http://10.0.3.239/s10902-013-9415-1.

80. Tomyn A, Norrish JM, & Cummins RA. The subjective wellbeing of indigenous Australian adolescents: Validating the Personal Wellbeing Index-School Children. Social Indicators Research. 2013;110(3): 1013–1031. https://doi.org/10.1007/s11205-011-9970-y.

81. Tomyn AJ, Tyszkiewicz MDF, & Cummins RA. The Personal Wellbeing Index: Psychometric equivalence for adults and school children. Social Indicators Research. 2013;110(3): 913–924. http://dx.doi.org/10.1007/s11205-011-9964-9.

82. Sanders J, Munford R, Thimasarn-Anwar T, & Liebenberg L. Validation of the Child and Youth Resilience Measure (CYRM-28) on a sample of at-risk New Zealand youth. Research on Social Work Practice. 2017;27(7): 827–840. https://doi.org/10.1177/1049731515614102.

83. Abujaradeh H, Colaianne BA, Roeser RW, Tsukayama E & Galla M. Evaluating a short-form Five Facet Mindfulness Questionnaire in adolescents: Evidence for a four-factor structure and invariance by time, age, and gender. International Journal of Behavioral Development. 2020;44(1): 20–30. https://doi.org/https://doi.org/10.1177/0165025419873039.

84. Shoshani A, & Steinmetz S. Positive psychology at school: A school-based intervention to promote adolescents' mental health and well-being. Journal of Happiness Studies. 2014;15(6): 1289–1311. https://doi.org/10.1007/s10902-013-9476-1.

85. Casas F, Sarrier JC, Alfaro, J, et al. Subjective Well-Being and School Satisfaction in Adolescence: Putting Indicators for Their Measurement to the Test in Brazil, Chile and Spain. Social Indicators Research. 2014;21(2): 70– 80. https://doi.org/http://10.0.3.248/S0121- 4381(14)70009-8.

86. Sawatzky RA, Ratner P, Johnson J L, Kopec JA, & Zumbo BD. Self- reported physical and mental health status and quality of life in adolescents: A latent variable mediation model. Health & Quality of Life Outcomes. 2010;8: 17–27. https://doi.org/http://10.0.3.248/j.childyouth.2017.06.063.

87. Hatami G, Motamed N, & Ashrafzadeh M. Confirmatory Factor Analysis of Persian Adaptation of Multidimensional Students' Life Satisfaction Scale (MSLSS). Social Indicators Research. 2010;98(2): 265–271. https://doi.org/http://10.0.3.239/s11205- 009-9538-2.

88. Zeng Y, Ling Y, Huebner ES, He Y, & Lei X. The psychometric properties of the 5-item gratitude questionnaire in Chinese adolescents. Journal of Psychiatric & Mental Health Nursing. 2017; 24(4): 203–210. https://doi.org/http://10.0.4.87/jpm.12372.

89. Duy B, & Yildiz MA. Adaptation of the Regulation of Emotions Questionnaire (REQ) for Adolescents. Turkish Psychological Counseling and Guidance Journal. 2014; 5(41): 23–33.

90. Orpana H, Pearson C, Dopko R., & Kocum L. Validation of the Children's Intrinsic Needs Satisfaction Scale among Canadian youth: Psychometric properties, criterion- related validity and multitrait multimethod confirmatory factor analysis. Health Promotion and Chronic Disease Prevention. 2019; 39(1): 25–32. https://doi.org/10.24095/hpcdp.39.1.03.

91. Guerra J, García-Gómez M, Turanzas J, Cordón JR, Suárez-Jurado C, & Mestre JM. A Brief Spanish Version of the Child and Adolescent Mindfulness Measure (CAMM). A Dispositional Mindfulness Measure. International Journal of Environmental Research and Public Health. 2019; 16(8): 1335. https://doi.org/10.3390/ijerph16081355.

92. Prenoveau JM, Papadakis AA, Schmitz JCS, Hirsch EL, Dariotis JK, & Mendelson T. Psychometric properties of the Child and Adolescent Mindfulness Measure (CAMM) in racial minority adolescents from low-income environments. Psychological Assessment. 2018; 30(10): 1395–1400. https://doi.org/10.1037/pas0000630.

93. Malinakova K, Kopcakova J, Kolarcik P, et al. The Spiritual Well-Being Scale: Psychometric Evaluation of the Shortened Version in Czech Adolescents. Journal of Religion & Health. 2017; 56(2): 697– 705. https://doi.org/http://10.0.3.239/s10943-016-0318-4

94. Cotton S, Larkin E, Hoopes A, et al. The impact of adolescent spirituality on depressive symptoms and health risk behaviors. Journal of Adolescent Health. 2005; 36(6): 529.e7-14. https://doi.org/10.1016/j.jadohealth.2004.07.017.

95. Thomas A, Cairney S, Gunthorpe W, Paradies Y, & Sayers S. Strong Souls: development and validation of a culturally appropriate tool for assessment of social and emotional well-being in Indigenous youth. The Australian and New Zealand Journal of Psychiatry. 2010; 44(1): 40–48. https://doi.org/10.3109/00048670903393589.

96. Moodley T, Esterhuyse KGF, & Beukes RBI. Factor Analysis of the Spiritual Well-being Questionnaire Using a Sample of South African Adolescents. Religion & Theology. 2012; 19(1/2): 122–151. https://doi.org/http://10.0.4.139/157430112X650339.

97. de Alvarenga WA, Nascimento LC, dos Santos CB, et al. Measuring Spiritual Well-Being in Brazilian Adolescents with Chronic Illness Using the FACIT-Sp-12: Age Adaptation of the Self-Report Version, Development of the Parental-Report Version, and Validation. Journal of Religion and Health. 2019; 58(6): 2219–2240. https://doi.org/10.1007/s10943-019-00901-y.

98. van Rensburg AC, Theron LC, & Ungar M. Using the CYRM-28 With South African Young People: A Factor Structure Analysis. Research on Social Work Practice. 2019; 29(1): 93–102. https://doi.org/10.1177/1049731517710326.

99. Kaunda-Khangamwa BN, Maposa I, Dambe R, et al. Validating a Child Youth Resilience Measurement (CYRM-28) for Adolescents Living with HIV (ALHIV) in Urban Malawi. Frontiers in Psychology. 2020; 11: 1–13. https://doi.org/10.3389/fpsyg.2020.01896.

100. Panter-Brick C, Hadfield K, Dajani R, Eggerman M. Ager A, Ungar M, & Panter- Brick C. Resilience in Context: A Brief and Culturally Grounded Measure for Syrian Refugee and Jordanian Host-Community Adolescents. Child Development. 2018; 89(5): 1803–1820. http://10.0.4.87/cdev.12868.

101. Stratta P, Riccardi I, di Cosimo A, et al. A validation study of the Italian version of the Resilience Scale for Adolescents (READ) Journal of Community Psychology. 2012; 40(4): 479–485. https://doi.org/https://doi.org/10.1002/jcop.20518.

102. Hjemdal O, Friborg O, Stiles TC, Martinussen M, & Rosenvinge JH. A New Scale for Adolescent Resilience: Grasping the Central Protective Resources Behind Healthy Development. Measurement & Evaluation in Counseling & Development. 2006; 39(2): 84–96. https://doi.org/http://10.0.4.56/07481756.2006.11909791.

103. Kelly Y, Fitzgerald A, & Dooley B. Validation of the Resilience Scale for Adolescents (READ) in Ireland: a multi-group analysis. International Journal of Methods in Psychiatric Research. 2017; 26(2): e1506. https://doi.org/10.1002/mpr.1506.

104. Moksnes UK, & Haugan G. Validation of the Resilience Scale for Adolescents in Norwegian adolescents 13–18 years. Scandinavian Journal of Caring Sciences. 2018; 32(1): 430–440. https://doi.org/https://doi.org/10.1111/scs.12444.

105. Hidalgo MA, Petras H, Chen D, & Chodzen G. The Gender Minority Stress and Resilience Measure: Psychometric validity of an adolescent extension. Clinical Practice in Pediatric Psychology. 2019; 7(3): 278–290. https://doi.org/10.1037/cpp0000297.

106. Casey P, Patalay P, Deighton J, Miller SD, & Wolpert M. The Child Outcome Rating Scale: validating a four-item measure of psychosocial functioning in community and clinic samples of children aged 10-15. European Child & Adolescent Psychiatry. 2019; 29: 1089-1102. https://doi.org/10.1007/s00787-019-01423-4.

107. Lereya ST, Humphrey N, Patalay P, Wolpert M, Böhnke JR, Macdougall A, & Deighton J. The student resilience survey: psychometric validation and associations with mental health. Child & Adolescent Psychiatry & Mental Health. 2016; 10: 1–15. https://doi.org/https://doi.org/10.1186/s13034-016-0132-5.

108. Royer-Gagnier K, Skilling TA, Brown SL, Moore TE, & Rawana JS. The Strengths Assessment Inventory–Youth Version: An evaluation of the psychometric properties with male and female justice-involved youth. Psychological Assessment. 2016; 28(5): 563–574. https://doi.org/10.1037/pas0000199.

109. Valois RF, & Zullig KJ. Psychometrics of a Brief Measure of Emotional Self- Efficacy Among Adolescents from the United States. Journal of School Health. 2013; 83(10): 704–711. https://doi.org/https://doi.org/10.1111/josh.12084.

110. Toomey RB, Umana-Taylor AJ, Jahromi LB, & Updegraff KA. Measuring Social Support from Mother Figures in the Transition from Pregnancy to Parenthood among Mexican-Origin Adolescent Mothers. Hispanic Journal of Behavioral Sciences. 2013; 35(2): 194-212. http://dx.doi.org/10.1177/0739986312470636.

111. Hyun MS, Nam KA, Kang HS, & Reynolds WM. Reynolds Adolescent Depression Scale – Second Edition: initial validation of the Korean version. Journal of Advanced Nursing. 2009; 65(3): 642–651. https://doi.org/http://10.0.4.87/j.1365- 2648.2008.04913.x

112. Armstrong L. Initial development and validation of the checklist of risk behaviours for youth (CORBY). Psychology, Health & Medicine. 2012; 17(1): 116–124. https://doi.org/10.1080/13548506.2011.592842.

113. Eisman AB, Zimmerman MA, Kruger D, et al. Psychological Empowerment Among Urban Youth: Measurement Model and Associations with Youth Outcomes. American Journal of Community Psychology. 2016; 58(3/4): 410–421. http://10.0.3.234/ajcp.12094.

114. García – Álvarez D, & José Soler M. Growing up Strong Program, positive youth development and education: A healthy framework. Revista Mexicana de Orientación Educativa. 2019; 16(36): 1–19. https://doi.org/10.31206/rmdo132019.

115. Gouveia J, Xavier A, & Cunha M. Assessing Early Memories of Threat and Subordination: Confirmatory Factor Analysis of the Early Life Experiences Scale for Adolescents. Journal of Child & Family Studies. 2016; 25(1): 54–64. https://doi.org/http://10.0.3.239/s10826-015-0202-y.

116. Wild LG, Flisher AJ, Bhana A, & Lombard C. Psychometric properties of the Self-Esteem Questionnaire for South African adolescents. South African Journal of Psychology. 2005; 35(2): 195–208. https://doi.org/http://10.0.4.153/008124630503500203.

117. Donaldson SJ, & Ronan KR. The effect of sports participation on young adolescents' emotional well-being. Adolescence. 2006; 41(162): 369-389.

118. Cavazos-Rehg P, Byansi W, Xu C, Nabunya P, Sensoy Bahar O, Borodovsky J, Ssewamala FM. The Impact of a Family-Based Economic Intervention on the Mental Health of HIV-Infected Adolescents in Uganda: Results from Suubi + Adherence. Journal of Adolescent Health. 2020; 6(4): 742-749. https://doi.org/10.1016/j.jadohealth.2020.07.022.

119. Magson NR, Craven RG, & Bodkin-Andrews GH. Measuring Social Capital: The Development of the Social Capital and Cohesion Scale and the Associations between Social Capital and Mental Health. Australian Journal of Educational & Developmental Psychology. 2015; 14: 202–216.

120. Ryan RM, & Huta V. Wellness as healthy functioning or wellness as happiness: The importance of eudaimonic thinking (response to the Kashdan et al. and Waterman discussion). Journal of Positive Psychology. 2009; 4(3): 202–204. https://doi.org/10.1080/17439760902844285

121. Witten H, Savahl S, & Adams S. Adolescent flourishing: A systematic review. Cogent Psychology. 2019; 6(1):1640341. https://doi.org/10.1080/23311908.2019.1640341.

122. Fort Drum Regional Health Planning Organization. Regional Health in Focus: Child & Adolescent Mental Wellness. 2018. Available from https://fdrhpo.org/tag/wellness/

123. Gentzler AL, DeLong KL, Palmer CA, & Huta V. Hedonic and eudaimonic motives to pursue well-being in three samples of youth. Motivation and Emotion. 2021; 45(3): 312–326. https://doi.org/10.1007/s11031-021-09882-6.

124. Ahanonu EL, & Jooste K. Adolescents' Interpretation of the Concept of Wellness: A Qualitative Study. Journal of Caring Sciences. 2016; 5(4): 337–345. https://doi.org/10.15171/jcs.2016.035.

125. Adam T, Bezner J, & Steinhardt M. The conceptualization and measurement of perceived wellness: integrating balance across and within dimensions. American Journal of Health Promotion. 1997; 11(3): 208–218. https://doi.org/https://doi.org/10.4278/0890-1171-11.3.20.

126. Ryff CD, Singer BH, & Love GD. Positive health: Connecting well-being with biology. Philosophical Transactions of the Royal Society B: Biological Sciences. 2004; 359(1449): 1383–1394. https://doi.org/10.1098/rstb.2004.1521.

127. Ryan RM, & Deci EL. On Happiness and Human Potentials: A Review of Research on Hedonic and Eudaimonic Well-Being. Annual Review of Psychology. 2000; 52(1): 141–166. https://doi.org/https://doi.org/10.1146/annurev.psych.52.1.141.

128. Casas F, & González-Carrasco M. Subjective Well-Being Decreasing with Age: New Research on Children Over 8. Child development. 2019; 90(2): 375–394. https://doi.org/10.1111/cdev.13133.

129. Laurenzi C, Skeen S, Gordon S, et al. Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence. Journal of the International AIDS Society. 2020; 23(S5): e2556. https://doi.org/10.1002/jia2.25556.

130. Bodeker G, Pecorelli S, Choy L, Guerra R, & Kariippanon K. Well-Being and Mental Wellness. In Oxford Research Encyclopedia of Global Public Health. Oxford University Press, 2020.

131. Ninomiya M, George N, George J, et al. A community-driven and evidence-based approach to developing mental wellness strategies in First Nations: A program protocol. Research Involvement and Engagement. 2020; 6(1): 1-12. https://doi.org/10.1186/s40900-020-0176-9.

132. Fernando S, & Moodley R. Global Psychologies: Mental Health and the Global South. London: Palgrave Macmillan. 2019.

133. Horn J. Decolonising emotional well-being and mental health in development: African feminist innovations. Gender and Development. 2020; 28(1): 85–98. https://doi.org/10.1080/13552074.2020.1717177.

134. Mills C. Decolonizing Global Mental Health: The Psychiatrization of the Majority World. Sussex: Routledge, 2014.

135. Zaretsky L. Centering Indigenous Voices to Inform the Delivery of Culturally Appropriate Mental Wellness Services [dissertation]. Canada: Cumming School of Medicine, 2021.

136. Gould B, MacQuarrie C, O'Connell ME, & Bourassa C. Mental wellness needs of two Indigenous communities: Bases for culturally competent clinical services. Canadian Psychology. 2020; 62(3): 213–226. https://doi.org/10.1037/cap0000247.

SECTION III: SETTING THE THEORETICAL FOUNDATION AND IDENTIFYING THE DOMAINS

In this section, we report on the findings from (1) the exploratory photovoice study with ALHIV (aged 10-19 years) accessing treatment at three public primary healthcare facilities in the Cape Town Metropole district of South Africa as well as (2) findings from an integrative review of mental wellness concepts identified in literature focused on ALHIV in the African context. The current section consists of 4 publications.

The findings from phase 1 supported arguments that there is a lack of consensus on the definition of concepts such as mental health and mental wellness, which has implications for research, policy and, in this case, the measurement of mental wellness [1–3]. Additionally, many instruments identified through the systematic review were developed with adult populations in the global north and subsequently adapted and validated with adolescent populations. While this is a common strategy (as scale development can be a lengthy and costly process); findings from social desirability studies indicate that the items or domains from such instruments may not always accurately represent the context of the adolescent. For example, the nature and meaning of a construct like a self-esteem change as we get older – or adolescents from different cultures and different parts of the world may experience and interpret self-esteem differently. For these reasons, qualitative studies are considered especially useful in developing items for psychological instruments [4].

Building on the findings from the systematic review, we constructed a preliminary framework of the mental wellness constructs we extracted from the identified instruments. Following this, we conducted an exploratory photovoice study at three public healthcare facilities in the Cape Metropole District of South Africa to engage with ALHIV and learn how they talk about mental wellness and what it means from their perspective and how it shapes their experiences of being on treatment.

In **Chapter 5,** we present a case study of one of the facilities. By engaging with the adolescent participants through photovoice and conducting interviews with key healthcare workers, we developed an understanding of the context in which ALHIV live, the challenges they experience in adhering to treatment, how the presence of mental wellness can support their

treatment outcomes and what is being done, at the facility level, to provide support to ALHIV.

Paper 4: Orth Z & van Wyk B. A facility-based family support intervention to improve treatment outcomes for adolescents on antiretroviral therapy in the Cape Metropole, South Africa. Journal of the International Association of Providers of AIDS Care. 2021; 20:1-11. doi:10.1177/23259582211059289.

In **Chapter 6,** we present the findings from the photovoice study across the three facilities. The photovoice study gave participant the opportunity to create a narrative of what mental wellness means in their own words. Through discourse analysis, we uncovered the broad themes and constructs that more accurately reflect the ways that ALHIV think about and experience mental wellness and how this influences their adherence to ART. Thus, the findings from the photovoice study confirmed some of the mental wellness constructs identified in the systematic review and aided in refining the preliminary framework. Using the framework, we proposed a tentative model of mental wellness to guide the next part of the study.

Paper 5: Orth Z & van Wyk B. Discourses of mental wellness among adolescents living with HIV in Cape Town, South Africa. Psychology Research and Behavior Management. 2022; 15:1435-1450. doi: 10.2147/PRBM.S360145.

As Krause [4] mentions, using multiple qualitative methods as a way of triangulation is preferable as this results in more valid results. Therefore, to further test and unpack the mental wellness concepts and refine the model of mental wellness, we conducted an integrative review of mental wellness concepts in research with ALHIV in the African context.

In **Chapter 7,** we present the study's protocol, which was submitted for peer review in October 2020. Due to the COVID-19 pandemic, there were considerable delays – we received notice from the journal editor to confirm that the protocol was accepted with revision in May 2021. Following the revisions, the protocol was published in April 2022. The protocol acted as a tool for critical reflection on the lessons learned from the systematic review and photovoice study. Thus, these findings formed part of the 'problem identification' phase, which is the 1st step in the integrative review and subsequently informed the search strategy. When we initially conceptualised the protocol, we aimed to focus on research with general adolescent populations.

However, the findings from the systematic review were useful in helping us to identify the mental wellness concepts in research with general populations and those with a chronic physical illness. Subsequently, the photovoice study provided insight into the mental wellness concepts relevant to ALHIV on treatment in the South African context. Therefore, we shifted the focus of the integrative review to ALHIV in the African context to confirm and refine the mental wellness concepts already identified.

Paper 6: Orth Z & van Wyk B. Rethinking mental wellness among adolescents: An integrative review protocol of mental health components. Systematic Reviews. 2022;11(83): 1-7. doi: 10.1186/s13643-022-01961-0.

In **Chapter 8,** we present the findings of the integrative review. We identified 17 articles and from these we identified six mental wellness concepts: Connectedness, Sense of Coherence (SOC), Self-esteem, Self-acceptance, Hope for the Future and Spirituality, as well as six behaviours facilitating mental wellness: Coping, Resilience, Purpose in Life (goals), Self- efficacy, Adherence Self-efficacy, and Leisure Activities. The mental wellness concepts identified in the integrative review were used to triangulate our previous studies' findings and aided in the operationalisation of each concept. Additionally, the findings from the integrative review provided a better understanding of SOC, a central concept in Antonovsky's [5] Salutogenic model of health.

Paper 7: Orth Z & van Wyk B. Rethinking mental health wellness among adolescents living with HIV in the African context: An integrative review of mental wellness components. Frontiers in Psychology. 2022; 13:1-13. doi: 10.3389/fpsyg.2022.955869.

As such, we were able to develop the Salutogenic Model of Mental Wellness [SMoMW] (adapted from Antonovsky) which emphasises the role of the mental wellness concepts as a healing resource to help overcome daily stressors and challenges ALHIV and achieve overall mental wellness which can act as a buffer against illness and pathology. The SMoMW can be used to guide the development of an instrument to measure mental wellness among ALHIV in the South African context.

References

1. Orth Z, van Wyk B. Measuring mental wellness among adolescents living with a physical chronic condition: A systematic review of the mental health and mental well-being instruments. BMC Psychol. 2021;9(1): 1-17. doi:10.1186/s40359-021-00680-w.
2. Orth Z, Moosajee F, van Wyk B. Measuring mental wellness of adolescents: A systematic review of instruments. Front Psychol. 2022; 13:1-14. doi:10.3389/fpsyg.2022.835601.
3. Manwell LA, Barbic SP, Roberts K, Durisko Z, Lee C, Ware E, et al. What is mental health? Evidence towards a new definition from a mixed methods multidisciplinary international survey. BMJ Open. 2015; 5:1–11. https:// doi.org/ 10. 1136/ bmjop en- 2014- 007079.
4. Krause N. A comprehensive strategy for developing closed-ended survey items for use in studies of older adults. J Gerontol B Psychol Sci Soc Sci. 2002; 57: 263–274. doi: 10.1093/geronb/57.5.s263.
5. Mittelmark MB, Sagy S, Eriksson M, Bauer GF, Pelikan JM, Lindström B, et al. The Handbook of Salutogenesis. New York: Springer, 2017.

CHAPTER 5

Paper 4: Orth Z, van Wyk B. A facility-based family support intervention to improve treatment outcomes for adolescents on antiretroviral therapy in the Cape Metropole, South Africa. Journal of the International Association of Providers of AIDS Care. 2021; 20:1-11. doi:10.1177/23259582211059289.

Abstract

Adolescents living with HIV (ALHIV) globally report worse treatment outcomes than adults and children on antiretroviral therapy (ART). We conducted a photovoice study with eighteen ALHIV to explore the experiences and challenges of being on ART and individual interviews with five health workers to describe the challenges of treating ALHIV. The facility implemented the Family club intervention to facilitate caregivers (parent/guardians) supporting ALHIV on treatment. The health workers revealed that 'disclosing HIV status' to children was the biggest challenge for caregivers and health workers. Participating ALHIV reported that family support and a positive mentality were instrumental for continued treatment adherence. However, disclosure of HIV status to friends remained challenging due to pervasive community stigma. Treatment fatigue and side- effects were also barriers to adherence. Family support was instrumental in facilitating adherence support for ALHIV. However, this [intervention] should include peer support to improve positive mental well-being in ALHIV.

Introduction

The increased availability of antiretroviral therapy (ART) combined with the scaling up of healthcare services and programmes aimed at supporting treatment adherence has increased the life expectancy of people living with HIV (PLHIV), including perinatally infected children who are now surviving into adolescence [1,2]. The increased survival rates of perinatally infected children and the growing number of behaviourally infected adolescents have resulted in adolescents being identified as the fastest-growing population of PLHIV. As such, adolescents have been identified as one of the key populations in the fight against HIV. According to UNAIDS 2019, the global population of adolescents living with HIV (ALHIV) was estimated at 1.7 million [3]. In South Africa, the number of ALHIV was estimated at 360,000 [230,000-500,000], with 31,000 [8,100-62,000] new infections reported in 2019 [3].

Globally, it is estimated that there has been a 45% increase in AIDS-related deaths among adolescents between 2005 and 2015 [4]. This is of great concern, as it contrasts with the decrease in AIDS-related deaths reported for all other age groups [5]. The increase in AIDS-related deaths among ALHIV suggests lapses in treatment and successful engagement. Evidence suggests that this lapse in treatment may be associated with the type of care and the quality of support that ALHIV receives [6]. Adolescence is a unique developmental period in which individuals experience significant physical, psychological, and social changes [7–9]. Our report from an exploratory study of ALHIV on ART in a low socioeconomic setting in Cape Town also revealed school vs health facility conflicts, negative household dynamics and perceiving the health facility as an unfriendly place, as reported barriers to adherence [10]. Therefore, the World Health Organisation (WHO) recommended that public healthcare facilities establish adolescent-friendly health services, which include age-appropriate treatment programmes to provide psychosocial support, sexual and reproductive health services, and improve adherence and retention in care [1]. However, poor treatment outcomes for ALHIV are also influenced by a variety of person and social factors such as treatment fatigue, delayed disclosure of HIV-status, stigma, lack of social support, mental health challenges, substance use and transitioning from paediatric to mainstream care [11, 12]. Our review of psychosocial support interventions for improved adherence and retention in care for ALHIV indicates promising results from two interventions with family-centred services, namely the family day clinic (FDC) and the VUKA family programme [13]. These interventions involved multiple components, including counselling services for ALHIV and their family members and health education workshops to improve retention in care and adherence among ALHIV [13]. Results from both interventions show a significant increase in adherence among ALHIV compared to the control groups. However, reports from the FDC showed no effect on retention in care between the control group and the intervention group [14]. Our analysis of a cohort of ALHIV newly enrolled on ART in the Western Cape Metropole showed that retention in care declined by 60% over two years [15] and that only 25% of the initial cohort attained viral load suppression [16].

In the current paper, we describe the implementation and experiences of a facility-based family support intervention (“family clinic”) in a public primary healthcare facility in the Cape Metropole in South Africa to address challenges in adherence and treatment outcomes for ALHIV on ART.

Methods

Study design

The photovoice study is part of a larger research project that aimed to improve treatment outcomes – adherence, retention in care and viral suppression - for ALHIV who were receiving ART at public health care facilities in the Cape Metropole in South Africa. Photovoice is described as a process by which participants can 'identify, represent, and enhance their community through a specific photographic technique [17,18]. We chose photovoice methods in this study to engage ALHIV in data collection in a way that allowed them to 'decide' what is important to them relative to their experiences and challenges of being on ART. The photovoice sessions aimed to give voice to ALHIV while also allowing peer interactions, with no interference by the researchers. We triangulated the findings from the photovoice sessions, with individual interviews with key healthcare workers (HCWs), to situate the ALHIV's experiences within the health services context.

Context

The public healthcare facility has been in operation since December 2014 and offers healthcare services to a catchment population of 90,000 in predominantly low socioeconomic income communities. The clinic provides 24-hour emergency services and day services from 07:30 am to 4 pm and includes a comprehensive package of care including chronic care; child health; emergency services; infectious diseases treatment; obstetrics and gynaecology; oral health; pharmacy; rehabilitation services which include occupational therapy; physiotherapy and speech therapy; digital radiography and women's health. Additionally, the clinic collaborates with non-governmental organisations (NGOs) to provide mobile HIV services, especially HIV testing and counselling, voluntary medical male circumcision, and sexual reproductive health education. However, at the time of data collection, these services were on hold due to an interruption in government funding.

Sampling and participants

During the initial phase of the study, the research team contacted key HCWs at the clinic and informed them of the purpose of the study. Due to the study's sensitive nature, the HCWs

agreed to assist the research team with identifying eligible participants. Our inclusion criteria were as follows:

- Adolescents between the ages of 10 to 19 years at the time of the study;
- with a confirmed positive HIV diagnosis and receiving ART at the clinic; and
- must have been disclosed to and aware of their HIV-positive status.

A nurse qualified in nurse-initiation and management of ART (NIMART) assisted with participant identification and initial recruitment. The researcher (ZO) met with the head nurse and potential participants to discuss the study and provided them with information sheets and assent/consent forms. Those who agreed to participate were asked to return signed consent forms by themselves and their parent or guardian and provide contact telephone numbers to arrange the group sessions.

Our realized sample consisted of 18 adolescents. We conducted six groups - three with older adolescent female groups of 3-4 participants (15-17 years) each; two with male groups of three participants (15-17 years) in each group; and one group consisting of two younger adolescent girls (both aged ten years). Additionally, the head nurse introduced us to key HCWs who had experience working with adolescents on ART. After receiving their written consent, we conducted individual interviews with five HWCs to explore how they perceived treating ALHIV and the challenges they experienced.

Procedure for photovoice sessions

In the first session, participants returned their signed consent forms and received a cell phone camera with which they would use to take their pictures. During this session, the research team provided more details and information regarding the study and showed them how to take pictures with the phone. Participants were instructed to take at least five pictures telling their stories about their experiences with ART. We explained that we were interested in understanding the challenges they may experience and their motivation for taking their treatment. Additionally, the researchers discussed safety precautions with the participants and cautioned them against using the phones in areas where they may be subject to theft or harm. The first session also allowed us

to introduce the participants to each other to facilitate group rapport. We arranged with the participants to return to the clinic a week later to participate in the focus group discussion.

During the second session, the participants were given the opportunity to share their pictures on a projector screen, prompting group discussion. Two members of the research team facilitated each session. Even though the participants conversed in English, we were aware that for most of them, English was their second language, with isiXhosa being their home language. As such, we arranged for an isiXhosa-speaking counsellor or research assistant to attend sessions to allow participants to speak in their home language whenever they prefer.

During the data collection phase, the researcher approached key HCWs to request individual interviews. Those who agreed to participate signed a consent form and arranged a time and date for the interview. The information from these interviews provided further context, which helped us to facilitate the focus groups.

Data analysis

All interviews were audio-recorded, transcribed verbatim and translated where necessary. Photos were inserted into the transcripts, where these were referred to during the photovoice discussion. All transcripts with photos were uploaded on Atlas.ti and subjected to thematic analysis.

Ethical statement

Ethical approval to conduct this study was granted by the University of the Western Cape Biomedical Research Ethics Committee (BM18/3/7) and the Western Cape Health Research Committee (WC_201807_003). As previously mentioned, all the participants included in this study were provided with information about the study in a language they understood and signed the informed consent sheets before participating. Additionally, adolescents younger than 18 were required to obtain consent from their parent/guardian before participating in the study. To protect the anonymity and confidentiality of the participants, all identifying information was changed and participants were given pseudonyms.

Findings

Our findings highlight the health facility's main interventions to deal with the challenges of maintaining consistently high levels of adherence and engagement in care among ALHIV on ART, namely the "Family club" and the "Risk of Treatment Failure" (ROTF) clinic. Other themes reflect other challenges experienced by health workers as well as ALHIV experiences of Family Club, Risk of Treatment Failure Clinic, Disclosure, Motivation and Challenges to Treatment Adherence and Family Support.

The family club

The clinic has established a family club, which the head nurse/HAST manager championed. The family club comprises 25-30 HIV+ family members who are clinically stable, meaning they have been on ART for at least six months and are virally suppressed. The family club supports patient adherence by providing patient-friendly access to ART. The family club sessions occur once every second month and last 30 minutes. During these sessions, the head nurse or another trained NIMART nurse noted attendance and briefly addressed the family club members to discuss any problems they may have experienced since the last meeting. Following this, the medication is distributed, and a date for the next meeting is confirmed. At least one family member needs to be present to collect the medication for the rest of the family. This is beneficial as the parent or child would not have to miss work or school to collect their medication, as explained by the adherence counsellor below:

> It works, and it is nice because one person will be off at work or school. Sometimes the schools are closed like this, and the child will come and pick up the medication for all of them, or else…the child will come after school to pick up the medication. They will find the medication in the same place – The adherence counsellor (Female)

However, all family members are expected to be present on the day when they need to have their blood taken for viral load monitoring - which occurs at 4 and 12 months after ART initiation and then annually after that [20]. The paediatric outpatient clinic offers a similar service to parents of stable HIV+ children. This may be useful for parents of younger children who do not yet qualify for placement in the family club.

> Uhm, there is the family day club with Head NIMART Nurse, but it is also here by us on the OPDs side because sometimes the parents want them in school as well. So, then they will come, but they will come like every- say they must come in two months, then the parents will come in 2 months and then the next time they have to come because their weight can change, the medication can change – Doctor 1 (Female)

While the family club and counselling services provide instrumental support and easy access to treatment, there is still a recognized need to provide more social support for ALHIV in the clinic.

> They need more social support, yes. Which we…I do not feel we do enough. We try, but it is not enough - Head NIMART Nurse (Female)

Risk of treatment failure clinic

The ROTF intervention was first piloted by Médecins Sans Frontières (MSF) in 2012 before being adopted by the Western Cape Department of Health (WCDoH) in 2015 to manage all patients who are failing or at risk of failing ART [20]. ROTF is designed to provide integrated adherence and clinical management to support patients whose VLs are not suppressed (above 400 copies/mL) regardless of their treatment regimen. Patients who experience a single unsuppressed VL are enrolled in a support group, while patients presenting with two consecutive unsuppressed VLs are given more intensive counselling. These counselling sessions include personalised educational activities that address the patient's reasons for defaulting on their treatment. Adherence is managed by monitoring the patients' VLs and switching to second-line ART regimens per the national guidelines. As the quote below shows, patients in the ROTF clinic are afforded more time with the HCWs and counsellors to learn specific and targeted tools that may help them overcome barriers to treatment adherence and engagement in care.

> Once you have someone defaulting, your viral load will be high. So, you were sitting with like an unsuppressed viral load. So, they go into ROTF. So now, in that ROTF, they have been doing very well because, I mean, they get the chance to see other patients' perspectives and their struggles. 'Okay, I have been doing something

> wrong as much as I do not want to admit it'. Moreover, they go home and change that behaviour. Moreover, they open up to the counsellors, and they open up in that session, that one-on-one, where…We individualise with them, and they get that specific cover that half an hour, whatever, and we sit with you, and we like, 'okay, we gonna get to the bottom of this and give you like…tools to help you to be compliant'. So, there is time for that. -Doctor 2 (Female)

In one of the photovoice discussion groups, Grace (Girl, 16) described how she received support and motivation from the head nurse to attend the ROTF clinic and, in this process, started adhering to her treatment again.

> So, that is when my viral load was so high, like 4000 or something. And then Sister made me see the point of taking my pills, and slowly I started taking them again. Because I always blamed my parents for my…situation - Grace (Girl, 16)

However, Grace (Girl, 16) reported that she struggled to relate and open up in the ROTF group because the group mainly consisted of older adults. This was in contrast to her experience of the photovoice discussions, where she was more comfortable opening up to her peers.

> When I was Sister, it was the RTX something. It was only older adults there, you know. And, you hear them talking a lot… like what am I doing here? So, I feel much more comfortable and happier now. - Grace (Girl, 16)

Disclosure of HIV status

Most of the ALHIV who participated in this study were infected from birth and recalled taking the medication from a young age. However, they were only disclosed to when they were older (between the ages of 12-13 years). The participating adolescents reflected on having different reactions to being disclosed to, from initial denial (like David below) to anger and withdrawal (like Emma and Aaliyah, who had siblings who are HIV negative) and blamed their parents (for failing to take action to protect them from infection).

> I said it can't be true. - David (Boy, 15)

> When I first found out I was…12. Yeah, I didn't speak to my mother for I think like…a week – Emma (Girl, 17)

> Because I have a younger brother and he wasn't breastfed, so I was like 'why him? Why did you have to breast feed me?'- Emma (Girl, 17)

> It was 2016… I was 13. My aunt sent me to the clinic - so I found out there. So, I was kind of…angry… and I blamed my parents…and I kept asking myself why because my younger brother doesn't have it and my older sister…so why me? – Aaliyah (Girl, 16)

However, others like Faith (Girl, 16) remembered taking the medication since she was young but reported that she did not know what the medication was for. She explained that she was fine with taking the medication once she understood the reason behind it.

> Yeah, but I took my medication since I was young, but then I didn't know. I was still young; so, I didn't understand why I am taking this medication. But like [unclear] they did do…like, I found out from the doctor that I am…[HIV] positive. So, I started asking myself so is that the reason why I have been taking my pills. And then they said it's fine as long as I keep taking my medication. So, I was fine with that. - Faith (Girl, 16).

The decision to disclose to the child his/her HIV status is usually discussed between the parent/guardian and the doctor/nurse. Once the child has been disclosed to, they will refer them for counselling to the adherence counsellor.

> We not telling them that you know, 'why I am taking this medication' – no it's doctors that doing that, then they come to us once they know why they are taking the medication. And then just to emphasise to them why it is important to them to use their medication, what can happen if they can stop their medication- all those things - Adherence counselor (Female)

In counselling the adolescent about their HIV status and being on ART, they seek to help the child understand why the medication [and adherence] is important and to focus on the

positive(s) – that they are not sick – and do all that they can to remain not sick. Every effort is made to divert the adolescent away from negative thinking about how and why they were infected and negative emotions towards their parents or their situation.

> I always say when I am speaking to them- for even if it's an adult in fact- for us to check when did you get HIV, how did you get? It's not gonna work for us. So let us put aside that 'why do I take medication?', 'when did I get? how?', because it's gonna make you stuck. You, you not gonna continue with your life if you want to know why to me? Why do I have HIV? Why me? So, I am always saying to them, once you find out- it's nice to find out, while you work on yourself, you are not sick, you just need to follow the procedures of the hospital- no one can know you are on treatment. - Adherence counsellor (Female)

According to the HCWs, delays in disclosure to adolescents about their HIV status often led to poor adherence and defaulting on treatment. The head nurse described cases where an adolescent was disclosed to quite older and when defaulting on treatment occurred, and how this disclosure affected their mental health. While there are counselling services available at the facility, it is difficult to follow up with adolescents who have depressive symptoms due to the limited capacity of the community workers and the healthcare staff.

> Uhm…I had one last week. It's actually…that is a big problem because, when the girl or the boy becomes 13/14 years old, the parents don't tell them what tablets they are taking. They give the children tablets because they just uhm, they make sure that the child don't get sick because there is flu around and everything…the children don't know that they are HIV+. When they find out, it's a big thing. They go into a depression, they come to the hospital, their viral loads are high - I had one last week that said she's fed up now of taking this tablet- she didn't know. So, the social worker is involved, I am involved, the counsellors- we counsel them, and we keep a close eye on them It's very difficult to keep a close eye on everybody because…they live in Du Noon, and there's a lot of burns and protests and things going on here. 1000 houses were burned out two weeks ago – Head NIMART Nurse (Female)

Only two participants found out about their HIV status through voluntary HIV testing. Below are the accounts of Zola (Boy, 16) and Amy (Girl, 17).

> Yes, when I got tested and saw the results. Everything in me… it felt like life just stopped. Then I found out from the lady who was assisting me that there are others living with HIV and that I could get support from a group. She really encouraged me and gave me the information that I needed. I told myself I can't change my status, I have what I have but I also have to continue living my life.- Zola (Boy, 16)

> And then I decided to just go there and…test if maybe I am HIV+ or not uhm…I tested and then was surprised it came up positive. I was like 'How?' how? how? I was asking the same questions like Amahle uhm…and then I remembered okay…it's fine, I, I did not even cry - to my surprise, I did not cry because…I, I, I kept on telling myself that's okay, it's life, maybe it's a step you have to go through… And then okay, I accepted it and then, when I see a tree…a tree is strong and it, it reminded me okay if I take my pills, I'll forever be strong - Amy (Girl, 17).

Motivation to adhere to treatment

Most participants reported being adherent to treatment. During the photovoice discussions, some participants showed pictures of flowers, trees, and the ocean to express their positivity about living with HIV and their motivation to adhere to treatment. Adam (Boy, 14) showed a picture of a tree and explained that, like the tree, under the right conditions, he will also continue to grow and thrive when he adheres to his treatment.

> 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- Adam (Boy, 14)

Figure 5.1: Adam (Boy, 14)- Tree

Participants also displayed good knowledge of the importance of treatment adherence and understood the consequences of not taking their treatment, which motivated them to adhere.

> Well, my mother encourages me, I have to take my pills because that's the only way my counts will be undetectable? And then I won't be able to uhm, infect other people – Emma (Girl, 17)

> I feel happy [about taking the treatment] because I want to be…I want to be healthy -Precious (Girl, 10)

For Zola (Boy, 16), looking healthy was also very important, as this helped him to conceal his status. This motivated him to be adherent to treatment.

> I like taking my treatment because it helps me. It makes me look and seem like I don't have what I have. Like, people can't see that I have it. It makes me feel healthy

and people don't know that I have it - Zola (Boy, 16)

Some participants' motivation was based on fear and dread. For example, Jabu (Male, 17) states he continued to take his medication because he did not want to die. Amahle (Girl, 17) took a picture of her shadow and explained that she has accepted that the virus is a constant fixture in her life and that she carries her pills in her pocket all the time.

> Guys that's me, that's my shadow. That's my friend…I have to accept it…my friend, wherever that I'm walking with my purse, in my pocket I have to because my pills, that's my- if I stop drinking it then that's the end of me. That's my friend- my virus…all the time she was- okay, all the time I must go and…all the time - Amahle (Girl, 17)

Figure 5.2: Amahle (Girl, 17) – HIV is my shadow

Many participants reported that their motivation for taking their treatment and coping with their HIV diagnosis comes from a love for and desire to take care of a family member – mother or child – as described below by Kaya (Girl, 16) and Sarah (Girl, 17)

> It's a tattoo. It was on Yara's Instagram. Yeah, I guess she posted on her phone; so I take the picture and then I take a screenshot. So, at that time I was going through a rough time. It was the same thing of like "why should I take my pills?" I really don't like taking pictures, but for some reason… like I love my mom and I need to pick a prompt for this. So, this 'thingy' just makes me believe everything will be fine, so I have to look after myself. So yeah, I took it. It gives me courage. - Kaya (Girl, 16) "My mother is the greatest born creation. Like she does everything for me so one day I have to do the same thing for her when she's old."- Kaya (Girl, 16)

Figure 5.3: Kaya (Girl, 16)- Tattoo

Similarly, Sarah explained that, like the picture of the car that was moving, she also felt motivated to move forward in life and be in a position to take care of her son.

> The second one is the picture of…okay a car. Okay, I took picture of a car, and the car is moving. It means life goes on after all. I found out that I'm HIV+…I am still a student and, I am a mother on top of that…my son needs me, I need to move forward and leave everything behind. Yes, I know that I can never forget the fact that I am HIV+…but it's the thing that I have to live with it for the rest of my life, because if I stop taking my pills, I'm going to die or leave my son behind and that's not my wish – Sarah (Girl, 17)

Figure 5.4: Sarah (Girl, 17)– moving forward in life

Grace was also motivated to live [and take her treatment] by love for her younger sister, which is stronger than the struggles she is experiencing with her HIV diagnosis.

> You know she gave me hope, like she's so young and I'm sure she doesn't want to lose her sister. And I still want to see her grow and be beautiful and all this stuff. – Grace (Girl, 16)

Grace went further to describe how the support she received from the Head NIMART nurse was instrumental in getting her to recommit to her HIV treatment.

> She's very vibrant. She's very supportive, I can say. She's like: "It's life but, you still have a long way to go. Don't make anyone decide who you are. Don't make this disease decide who you are, because you're not that" - Grace (Girl, 16)

Challenges with medication adherence

Even though participants reported that, for the most part, they do not have difficulties in taking their treatment, there were times when they found it challenging to stay motivated.

> So that is my pills [showing a picture that she took of her pills], so sometimes…sometimes I don't wanna take the pills it gets stuck in my throat - Emma (Girl, 17)

Amahle also showed a picture of a closet she used to hide in to avoid taking her treatment when she was younger. Amahle and Emma's resistance to taking their pills was based on the discomfort of the pills that are hard to swallow and becoming nauseous because of the bad taste in their mouth.

> Okay, after the syrup then, when I was in the Eastern Cape, when I was 10 years old, I moved from the syrup to the pills, but the pills- okay, why I was doing hide and seek because at first, I want to vomit after drinking, there's that aftertaste - I tell myself to be strong but after- after drinking I take a sweet – Amahle (Girl, 17)

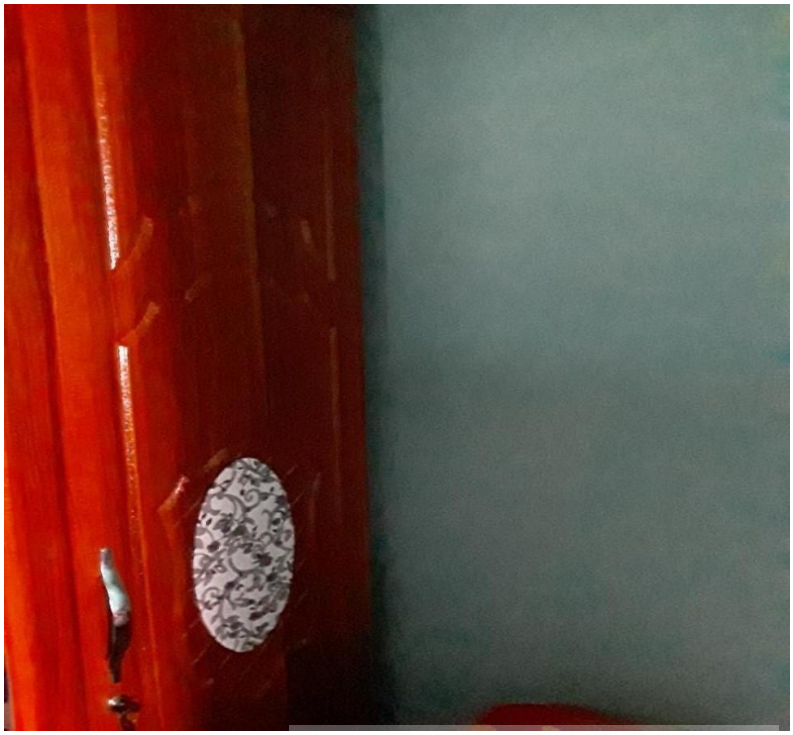

Figure 5.5: Amahle (Girl, 17)– hiding in the closet

However, her admission regarding her struggle to take the treatment prompted conversation from the other participants, who shared their struggles with dealing with the tablets' physical effects and some tips to overcome it.

Family support

Most participants relied on their parent(s) or a family member to remind them to take their tablets. In Amahle (Girl, 17) and Faith (Girl, 16) cases, they were the only HIV+ members in their household. Even so, they could still rely on their family members to remind them and support their treatment adherence.

> No- oh my parents and my sisters always remind me because I sometimes forgot and when straight to bed, after that, oh my God! – Amahle (Girl, 17)

> Yeah always, or when I forget my mom always reminds me and my cousins, so I have them - Faith (Girl, 16)

In households with more than one HIV-positive family member, as in the case of Amy

(Girl, 17) and Bongi (Boy, 15), they held each other accountable for taking their medication daily.

> If I forget to take pills, she reminds me; if she forgets, I remind her. We support each other – Amy (Girl, 17)

> Uhm, what makes is easy, it is that I…there is also my mother on my side that also has HIV, that also tell me when it is time, and we could also support each other - Bongi (Boy, 15)

However, while family members are seen as a source of structural support, some participants revealed that there are limitations to turning to family for emotional support. Kaya explained that she does not discuss her problems with her mother because she does not want to be a source of worry for her.

> Sometimes when I stay in my room then she asks me what's wrong and I don't feel comfortable because she gets so worried quickly. So, I don't want to stress her out, so I just keep quiet. But then I hate seeing her stressed. Like yah she can smile but for me I can notice that she's not ok. – Kaya (Girl, 16)

On the other hand, Amahle (Girl, 17) revealed that while her family supported her with treatment adherence, she has trouble opening up to her family because she does not trust them with her emotional problems.

> I don't trust anyone. To my sister sometimes…okay, to my other sister, I'm open to her, but not everything. And my mother used to ask me 'you okay?' so yeah. Because I'm just- I'm not a talking person, but there's times where I want just, if I talk I…if I talk to someone I just get better and no 'why, why, why, why?'- Amahle (Girl, 17)

During the interview, Thandi (Girl, 15) listened to the other participants described the support they received from their family members and started crying as she reflected on her lack of support at home. While Thandi (Girl, 15) does have a good relationship with her cousin and aunt, she described that her relationship with her father is strained.

> Uhm, how can I say? It's just that he doesn't give me enough support that I need. I don't feel like…I don't feel like he cares and… because we don't live happy"- Thandi (Girl, 15)

Disclosure of HIV status to friends

Some participants took pictures of their friends and discussed their friendship as a source of emotional support and happiness, which helps them to cope with life stressors.

> Like, I move on because when I arrive at school, I'll be happy so I, my friends are the best thing to me, so yah. - Lerato (Girl, 15)

> So uhm, that is where I like going when I am sad and all that. So, what makes me happy is uhm, going out with friends and sometimes family. I also love food [laughter] - Emma (Girl,17)

However, this prompted conversations around participants' willingness to disclose their status to their friends and the people they are close to. As the quotes below demonstrate, disclosing and sharing one's status is a complicated process. As the quotes from Emma suggest, even though she is close with her friends, she understands that these relationships may be temporary and could change as they complete school and go their separate ways. However, Emma also mentioned that she is reluctant to disclose as she believes her friend would not be comfortable with the news about her HIV status.

> I share everything but not my…sickness - Emma (Girl,17)

> Cause I wouldn't want to tell somebody and then in the future they're not part of my life - Emma (Girl,17)

> I feel like she would be uncomfortable - Emma (Girl,17)

For others like David (Boy, 15), it is about getting the timing of disclosure of HIV status to his friend right. Whereas he wants to share this information with his best friend, he is also aware that the disclosure may affect their friendship negatively if done too soon – before both parties are

ready and able to deal with this.

> No. I would tell my friend. There is a friend that I have, and I would tell them about it because I trust him. But he must be ready first. - David (Boy, 15)

In stark contrast, Grace related that her friends know about her HIV status and support her by reminding her to take her treatment.

> It's not like I'm 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 6 o'clock the send me a message "take your pills". I'm just like, what's the point anyways? – Grace (Girl, 16)

Discussion

The findings of our study demonstrate the commitment of the HCWs in this public primary health care facility to implement best-practice interventions to support ALHIV in their treatment. Previous studies have shown that enhanced adherence counselling interventions, such as the ROTF (risk of treatment failure) clinic, have a high probability of success in re-engaging patients who have defaulted on ART to be adherent again [20 – 23].

Similarly, it has been shown that psychosocial support interventions such as "family clubs" that engage families in supporting children and adolescents on treatment successfully remove or reduce barriers to adherence in addition to psychosocial support. Our findings suggest that family support interventions had high acceptability among ALHIV and their family members because, in many cases, more than one family member was on ART. However, Grimsrud et al. [20] suggest that it is necessary to balance engaging the family to support ALHIV and fostering a sense of independence and self-management as ALHIV transitions to an adult treatment programme. They suggest that the process mentioned above of transition to adult care should be accompanied by

transitioning adolescents from the Family Club to a Teen Club to facilitate adolescent-specific peer support. By definition, the Family Club is geared toward families with at least one parent and child are HIV-positive and on ART; older adolescents who were behaviourally infected are typically excluded from this model of care.

Similarly, ALHIV can only participate in the ROTF if their VLs are not suppressed. The account of ALHIV in our study in the ROTF clinic narrates that this is a lonely journey for an adolescent, where they interact mostly with adults – which leaves them unable to relate and uncomfortable sharing their challenges with treatment adherence. Research on Teen Clubs has reported that these clubs are most effective in improving adherence and motivating retention in care among ALHIV. Additionally, the growth in Teen Club memberships globally suggests a high level of acceptability among ALHIV [24,25]. It is suggestive that Teen Clubs may be a useful platform for delivering enhanced adherence counselling for ALHIV who are ROTF.

Our study confirmed that disclosure of the child's HIV status is a challenge for all adults involved. However, previous research has consensus about the benefits associated with HIV disclosure in improving mental health and well-being, adherence, and treatment outcomes [2,26]. In a review of factors influencing adherence among ALHIV, Ammon et al. [27] identified disclosure as the main barrier to adherence after stigma because the child/adolescent did not know the reason for taking the drugs. The WHO and the American Academy of Paediatrics have set out guidelines to support age-appropriate disclosure of HIV status to children to achieve better treatment outcomes and to improve psychological adjustment [28]. WHO recommends that [partial] disclosure to the child should begin at age six years, with full disclosure completed by 12 years of age [29]. This resonates with our study findings, where most of the perinatally infected participants were disclosed to as early adolescents (12-13 years). As reflected in Nichols et al.'s [26] synthesis of 14 quantitative studies reporting on the effects of disclosure on adherence - where five showed no association, 5 showed a benefit to disclosure, and 4 showed a negative impact - the experiences reported by participants in our study were varied. The negative impact of disclosure on adherence was precipitated by denial of HIV status, followed by anger, resentment towards parents, and refusal to take their medication for specified periods [26]. It has been reported that disclosure is followed by an increase in depressive symptoms which is associated with a decreased desire to form and maintain healthy adherence habits and a loss of hope for the future.

Similar to previous studies, we found that the HWCs believed that early disclosure is important as it is associated with adherence problems among ALHIV [30]. Our study indicated that delayed disclosure was attributed to the readiness of the parents/guardians rather than the readiness of the child/adolescent. To address this issue, HCWs in the participating facility followed a specified guideline to prepare parents/guardians for disclosure. The majority of ALHIV in our study reported that they were able to get over the initial shock of disclosure and come to terms with their diagnosis and focus on their health and their future aspirations. This may be attributed to the supportive environment created by the Family Club and the meaningful participation of HCWs in the disclosure process [23]. Additionally, upon being disclosed to, ALHIV receive adherence counselling which aims to help them by teaching them to take control of those aspects they have control over – their health and [hope for] future aspirations.

Disclosure of HIV status to others outside the family was problematic for most ALHIV in our study. Older adolescents in our study revealed that their friends were the most important sources of support and comfort. However, despite these bonds, most were reluctant to share their status with their friends, even when they desired to. As reported in other studies, fear of HIV-related stigma or worries that the relationship may change over time held them back [10,23,25,26,31]. This suggests that ALHIV require a high level of mutual trust to disclose to persons outside their immediate family. This also points to high levels of mistrust of others and the fear of discrimination if their status is advertently and inadvertently disclosed. Services and interventions targeted at ALHIV should provide them with appropriate tools or life skills programmes to increase their self-efficacy and confidence that they may better manage disclosure to others and the potential risks associated with it [11,20,23,25,32].

As previously mentioned, the participants in the current study reported high adherence levels at the time of data collection and discussed various motivators for taking their treatment. As already mentioned, family support was a significant motivator for treatment adherence. Participants also mentioned their friends as their sources of social support, even when not disclosing their status to them. This suggests that ALHIV who are mentally in a good space, in other words, have positive mental well- being, were motivated to be adherent and remain in care. This positive mentality was associated with high self-esteem, hopes for the future, caring/concern for others, and being healthy, which motivated adherence [23,25,32].

This study's most notable barriers to adherence were disclosure, treatment fatigue, and medication side effects [10,11,23,30,31]. However, family support and treatment motivators (i.e., health/do not want to die, future aspirations, etc.) helped to offset these challenges. This suggests that while ALHIV may experience challenges to their adherence, the effects of these challenges may be overcome by increasing family support and a positive mentality to facilitate good adherence behaviour.

Study limitations

Due to the qualitative nature of this study, there are several limitations. First, due to this study's sensitivity, we recruited participants based on thoughtful considerations taken in conjunction with their healthcare providers. Therefore, we could only recruit participants willing to engage with the project and talk about their experiences living with HIV. The study did not include adolescents who have not been disclosed to or are not comfortable discussing their status. It may be that those who choose to hide their status have different experiences with adherence than those who are willing to share their experiences. Second, as this is a specific healthcare facility case study, we cannot generalise our findings. The participants in the study represent a largely homogenous group who lived in an urban area characterised by a lack of resources and poverty. However, we believe this case study provides valuable insight into the challenges HCWs face and the experiences of ALHIV accessing treatment at this facility and similar ones in the Western Cape province. This information may be used to build on future studies to improve adolescent adherence within South African public healthcare facilities.

Conclusions

The findings from this case study provide valuable insights regarding the treatment experiences and services ALHIV receive at a public healthcare facility in the Western Cape province of South Africa. Our findings suggest that issues around disclosure remain challenging for HCWs and ALHIV and may present as a barrier to treatment adherence if not addressed, as this may result in various mental health challenges. Additionally, treatment fatigue and side effects were highlighted as potential barriers to adherence. On the other hand, ALHIV discussed that various motivators might overcome barriers to treatment adherence, including adopting a positive mentality and perceived family and peer support. Family support was instrumental in maintaining

adherence, as seen in the implementation and success of the Family Club intervention. As such, interventions aimed at improving adherence among ALHIV should incorporate family support elements. However, such interventions should also consider the multiple contexts adolescent develop and engage in. Therefore, the intervention should also include psychosocial components to help ALHIV manage issues around disclosure and increase peer support to improve their overall mental well-being.

References

1. Zanoni BC, Sibaya T, Cairns C, Lammert S, Haberer JE. Higher retention and viral suppression with adolescent-focused HIV clinic in South Africa. PLoS One. 2017; 12:1–12. doi: 10.1371/journal.pone.0190260.
2. Ngeno B, Waruru A, Inwani I, Nganga L, Wangari EN, Katana A, et al. Disclosure and clinical outcomes among young adolescents living with HIV in Kenya. J Adolesc Heal. 2019; 64:242–9. doi: 10.1016/j.jadohealth.2018.08.013.
3. UNAIDS. Aidsinfo: Global data on HIV epidemiology and response. 2019. Available from: http://aidsinfo.unaids.org/.
4. UNIADS. Ending the AIDS epidemic for adolescents, with adolescents: A practical guide to meaningfully engage adolescents in the AIDS response. 2016. Available from: https://www.unaids.org/sites/default/files/media_asset/ending-AIDS-epidemic-adolescents_en.pdf.
5. UNAIDS. Ending AIDS progress towards the 90-90-90 targets: Global AIDS update. 2017. Available from: https://www.unaids.org/sites/default/files/media_asset/Global_AIDS_update_2017_en.pdf.
6. Mavhu W, Berwick J, Chirawu P, et al. Enhancing psychosocial support for HIV positive adolescents in Harare, Zimbabwe. PLoS One. 2013; 8: 1-9. doi: 10.1371/journal.pone.0070254.
7. Armstrong A, Nagata JM, Vicari M, Irvine C, Cluver L, Sohn AH, et al. A global research agenda for adolescents living with HIV. J Acquir Immune Defic Syndr. 2018; 78:16–21. doi: 10.1097/QAI.0000000000001744.
8. Sawyer SM, Afifi RA, Bearinger LH, Blakemore SJ, Dick B, Ezeh AC, et al. Adolescence: A foundation for future health. Lancet. 2012; 379:1630–40. doi: 10.1016/S0140-6736(07)60370-5
9. Laurenzi CA, Skeen S, Gordon S, Akin-Olugbade O, Abrahams N, Bradshaw M, et al. Preventing mental health conditions in adolescents living with HIV: An urgent need for evidence. J Int AIDS Soc. 2020; 23:65–70. doi: 10.1002/jia2.25556

10. van Wyk BE, Davids LAC. Challenges to HIV treatment adherence amongst adolescents in a low socio-economic setting in Cape Town. S Afr J HIV Med. 2019;20(1): a1002. https://doi.org/10.4102/sajhivmed.v20i1.1002.
11. Zanoni BC, Sibaya T, Cairns C, Haberer JE. Barriers to retention in care are overcome by adolescent-friendly services for adolescents living with HIV in South Africa: A qualitative analysis. AIDS Behav. 2019; 23:957–65. https://doi.org/10.1007/s10461-018- 2352-6.
12. Mukumbang FC, Wyk B Van. Leveraging the photovoice methodology for critical realist theorizing. Int J Qual. 2020; 19:1–16. doi: 10.1177/1609406920958981.
13. Okonji EF, Mukumbang F, Orth Z, Vickerman-Delport S, van Wyk B. Psychosocial support interventions for improved adherence and retention in ART care for adolescents and young people living with HIV: A scoping review. BMC Pub Health. 2020;1–27. https://doi.org/10.1186/s12889-020-09717-y.
14. Graves JC, Elyanu P, Schellack CJ, Asire B, Prust ML, Prescott MR, et al. Impact of a family clinic day intervention on paediatric and adolescent appointment adherence and retention in antiretroviral therapy: A cluster randomized controlled trial in Uganda. PLoS One. 2018; 13:1–18. https://doi.org/10.1371/journal.pone.0192068
15. van Wyk BE, Kriel E, Mukumbang F. Retention in care for adolescents who were newly initiated on antiretroviral therapy in the Cape Metropole in South Africa. South Afr J HIV Med. 2020; 21(1):1–8. https://doi.org/10.4102/sajhivmed.v21i1.1077.
16. van Wyk BE, Kriel E, Chb MB, Mukumbang FC. Two-year viral load suppression among adolescents receiving antiretroviral therapy in the Cape Metropole, South Africa, 2013 - 2015: A retrospective cohort analysis. SAMJ. 2020; 110:1213–7. doi:10.7196/SAMJ.2020.v110i12.14509.
17. Wang CC. Photovoice: A participatory action research strategy applied to women's health. J Womens Health. 1999; 185-192. doi: 10.1089/jwh.1999.8.185.
18. Teti M, Murray C, Binson D. Photovoice as a community-based participatory research method among women living with HIV/AIDS: Ethical opportunities and challenges. J Empir Res Hum Res Ethics. 2012; 7:34–43. doi: 10.1525/jer.2012.7.4.34.
19. Medecins Sans Frontieres. ART adherence club report and toolkit. 2014. Available from: https://www.msf.org.za/news-and-resources/publications/art-adherence-club-report-and-toolkit.

20. Grimsrud A, Bygrave H, Wilkinson L. The case for family-centered differentiated service delivery for HIV. J Acquir Immune Defic Syndr. 2018;15: S124-S127. doi: 10.1097/QAI.0000000000001733.

21. Tsondai PR, Wilkinson LS, Grimsrud A, Mdlalo PT, Ullauri A, Boulle A. High rates of retention and viral suppression in the scale-up of antiretroviral therapy adherence clubs in Cape Town, South Africa. J Int AIDS Soc. 2017;20(4):21649. doi: 10.7448/IAS.20.5.21649.

22. Sharp J, Wilkinson L, Cox V, et al. Outcomes of patients enrolled in an antiretroviral adherence club with recent viral suppression after experiencing elevated viral loads. S Afr J HIV Med. 2019;20(1): a905. https://doi.org/10.4102/sajhivmed.v20i1.905.

23. Khumalo PN, Katirayi L, Ashburn K, Chouraya C, Mpango L, Mthethwa N, et al. 'There are no more secrets': Acceptability of a family-centered model of care for HIV positive children in Eswatini. BMC Health Serv Res. 2020; 5:1–9. https://doi.org/10.1186/s12913-020-05810.

24. Munyayi FK, van Wyk B. The effects of Teen Clubs on retention in HIV care among adolescents in Windhoek, Namibia. South Afr J HIV Med. 2020;21(1):1031. doi: 10.4102/sajhivmed.v21i1.1031.

25. MacKenzie RK, van Lettow M, Gondwe C, Nyirongo J, Singano V, Banda V, et al. Greater retention in care among adolescents on antiretroviral treatment accessing "Teen Club" an adolescent-centred differentiated care model compared with standard of care: A nested case-control study at a tertiary referral hospital in Malawi. J Int AIDS Soc. 2017;20: 1-9. doi: 10.1002/jia2.25028

26. Nichols J, Steinmetz A, Paintsil E. Impact of HIV-status disclosure on adherence to antiretroviral therapy among HIV-infected children in resource-limited settings: A systematic review. AIDS Behav. 2017;21(1):59-69. doi: 10.1007/s10461-016-1481-z.

27. Ammon, N., Mason, S., & Corkery, J. (2018). Factors impacting antiretroviral therapy adherence among human immunodeficiency virus-positive adolescents in Sub-Saharan Africa: A systematic review. Public Health. 2017:157, 20-31. doi: 10.1016/j.puhe.2017.12.010.

28. World Health Organization. Making health services adolescent friendly. 2012. Available from:

https://apps.who.int/iris/bitstream/handle/10665/75217/9789241503594_eng.pdf;jsessionid=63D 28258463D67FC5F8592E6D13162C6?sequence=1

29. World Health Organization. Guideline on HIV disclosure counselling for children up to 12 years of age. 2011. Available from: https://apps.who.int/iris/bitstream/handle/10665/44777/9789241502863_eng.pdf?sequence=1.

30. Mengesha MM, Ajema D, Teshome A, Tura AK. The association between diagnosis disclosure and adherence to antiretroviral therapy among adolescents living with HIV in sub-Saharan Africa: A protocol for systematic review and meta-analysis. Syst Rev. 2020;9(1):160. doi: 10.1186/s13643-020-01420-8.

31. Loades ME, Kagee A. Exploring our understanding of fatigue among adolescents living with HIV: Highlighting the unknown. J of Health Psych. 2019;24(1):125-136. doi:10.1177/1359105317710320.

32. Mutumba M, Mugerwa H, Musiime V, et al. Perceptions of strategies and intervention approaches for HIV self-management among Ugandan adolescents: A qualitative study. JIAPAC. 2019; 18:1-8. doi:10.1177/2325958218823246

CHAPTER 6

Paper 5: Orth Z, van Wyk B. Discourses of mental wellness among adolescents living with HIV in Cape Town, South Africa. Psychology Research and Behavior Management. 2022; 15:1435-1450. doi: 10.2147/PRBM.S360145.

Abstract

Background: Adolescence is a unique period of development where individuals transition from childhood to adulthood and 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 well-being, 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 of HIV treatment.

Method: We conducted a photovoice study with 12 groups 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: *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 delivering youth-friendly services and integrated HIV care in public healthcare facilities in South Africa and the sub- Saharan African continent.

Introduction

Improved HIV treatment regimens and successes in the 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 - 2300 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, global 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 adolescents in low to middle-income countries (LMICs) are yet to be addressed [4].

Optimal adherence to ART is necessary to achieve virological suppression, halt disease progression and decrease AIDS-related mortality [5]. Adolescents are challenged to adhere 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 during this period are associated with various risk behaviours, including tobacco and alcohol use, drug misuse, risky sexual behaviours and violence [11]. 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 more at 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,

and 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 mental wellness (i.e., self-esteem, connections to others, hopefulness, etc.), which impact motivation. If left unchecked, poor mental wellness may worsen, leading to feelings of hopelessness and feelings of 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 well-being [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 that allows participants to capture their experiences through photographs, 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 and the challenges they experienced.

Therefore, the Photovoice methodology was appropriate as it gave adolescents a creative way to express themselves and allowed them to direct the group discussion to what was important from their 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 trained to initiate patients on ART) who acted as gatekeepers at the respective health facilities to 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 and provided ART adherence support programmes in the form of youth clubs or family clinics [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 focused on older participants between 15-19 years.

Procedure

The research team (four members) received training in photovoice techniques and procedures from an experienced HIV researcher who applied photovoice methods in US settings, and these techniques were adapted to the South African setting [20]. A pilot study was conducted in one facility to train 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. The researchers obtained prior permission to attend and observe the adherence club session in these cases.

Permission was obtained from all participants to record the session's procedures (through written notes only). At the introductory session, the researchers described the research to the participants and invited them to participate if they were 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. We provided them with a cell phone with camera capabilities at this meeting. In addition, we provided them with instructions on how to be safe with their 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 –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 turns presenting their photos, with discussion and input from the group and facilitators. Participants were allowed to express themselves in the language they felt most comfortable using. A translator (the first language is Xhosa speaker) attended all group sessions to assist with facilitation where needed.

We structured each session to include 3-5 participants per group in line with traditional focus group requirements. 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; it 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 aims to analyse 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 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 of 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 understand the real-life context of the discourse that 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). Before participation, informed consent and assent were 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.

Findings

We conducted 12 photovoice groups (N = 43) with ALHIV across the three sites (Table 6.1). 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, and 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.*

Table 6.1: The 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)

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 (e.g., 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 it 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 don't 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'm sure she doesn't want to lose her sister. And I still want to see her grow and be beautiful and all this stuff. - (Amy, Girl, 16)

As seen in the quote below, other adolescents expressed that their connectedness to their family contributed to positive mental wellness and motivated them to adhere 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'm his only child. So, it's obvious I don't 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 a 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'm 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. This resulted in them gaining a friend who supports 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'm now here at the programme. So, she said she's proud of me because I'm not a person who like to still talk to people. I'm 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 navigated 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 wasn't 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 describes 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 the 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 diagnosis 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 6.1)

> I was, I was very…curious about what happened in that, what happened in that place, and also, I was also sad because some children 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)

Figure 6.1: Making sense of living conditions.

In a similar vein, 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 in 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 how they felt 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 positive 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 positively affected their mental wellness as this led to increased self-acceptance.

Self-efficacy

In this study, participants discussed their belief 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 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 when 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 positively affected their mental wellness because their belief in their own skills and capacities helps them 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

The through the discussion, 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 can't put someone in a bin, that's not right. So, the fact that I'm HIV-positive, I cannot be put in a bin, I'm 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 6.2).

Figure 6.2: People are not trash.

Another female participant presented a picture of herself reflecting on her initial reaction to seeing herself as 'different' to her peers when she first found out about her HIV diagnosis. These negative perceptions about 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 diagnosis and how she struggled with feelings of anger and blame towards her parents. Therefore, the bullying she experienced represented a breaking point, exacerbating her unresolved anger and sadness regarding her diagnosis and her relationship with 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 favourite 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 can 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 – by 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 them with truths [comprehensibility] 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're 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 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 well-being is a process they must constantly engage in and nurture (see figure 6.3).

> This flower is to show me how I will look if I keep taking my medicine. It is 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)

Figure 6.3: Nurturing health

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

> My favourite colour is pink, my hobby is dancing, I'm 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'm 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 won't have friends, kids, husband or live a life like any woman but no I thought the wrong way. Sister Anne told me it won't 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 self-reflect to understand themselves, whom 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 faces specific stressors related to their condition. This includes managing lifelong adherence to treatment and coping with external stressors related to stigma, disclosure and beliefs about living with HIV. The role of music as a coping mechanism among adolescents is well documented in research, and many participants discussed using isolation time in combination with listening to music as a way to cope when life becomes too stressful [31]. By engaging in this activity, they could 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, Lerato (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 6.4)

Figure 6.4: Weathering the storms of life.

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 increasing their motivation to be healthy and well.

Life purpose/goals

Like many adolescents, ALHIV hava 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 to achieve their goals. As is typical of adolescents, 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 clearly 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 6.5). Regardless, having aspirations and goals to work towards fosters hopefulness for the future, which positively affects 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 every day. - (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 6.5: 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 that 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 well-being emerged [15, 33 – 35]. As previously mentioned, participants enjoy participating in sports, dancing, and hanging out with their friends. To do this, participants need to feel a sense of physical well-being. 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 well-being 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 6.6).

Figure 6.6: 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 dimension (coping, resilience, life purpose/goal, engaging in

enjoyable activities, physical functioning) [36 – 38].

We observe that ALHIV in our study seems to emphasise both eudemonic (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 eudomonic pursuits is necessary for optimal mental wellness and well-being [36, 37].

We propose the model in figure 6.7 below to demonstrate mental wellness in ALHIV. In this, green represents hedonic mental wellness, and blue represents eudomonic mental wellness. As shown in the figure, a *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 the *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 a *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' relationships with others, their confidence in their abilities and overall physical well-being. As seen in the model, *Physical Functioning* and *Spirituality* are represented in *Senses 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 could positively affect 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 focuses 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].

Much empirical evidence supports 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 it. 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-exploration; therefore, they may be more susceptible to external influences and may change aspects of themselves 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 beliefs 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 essential 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 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.

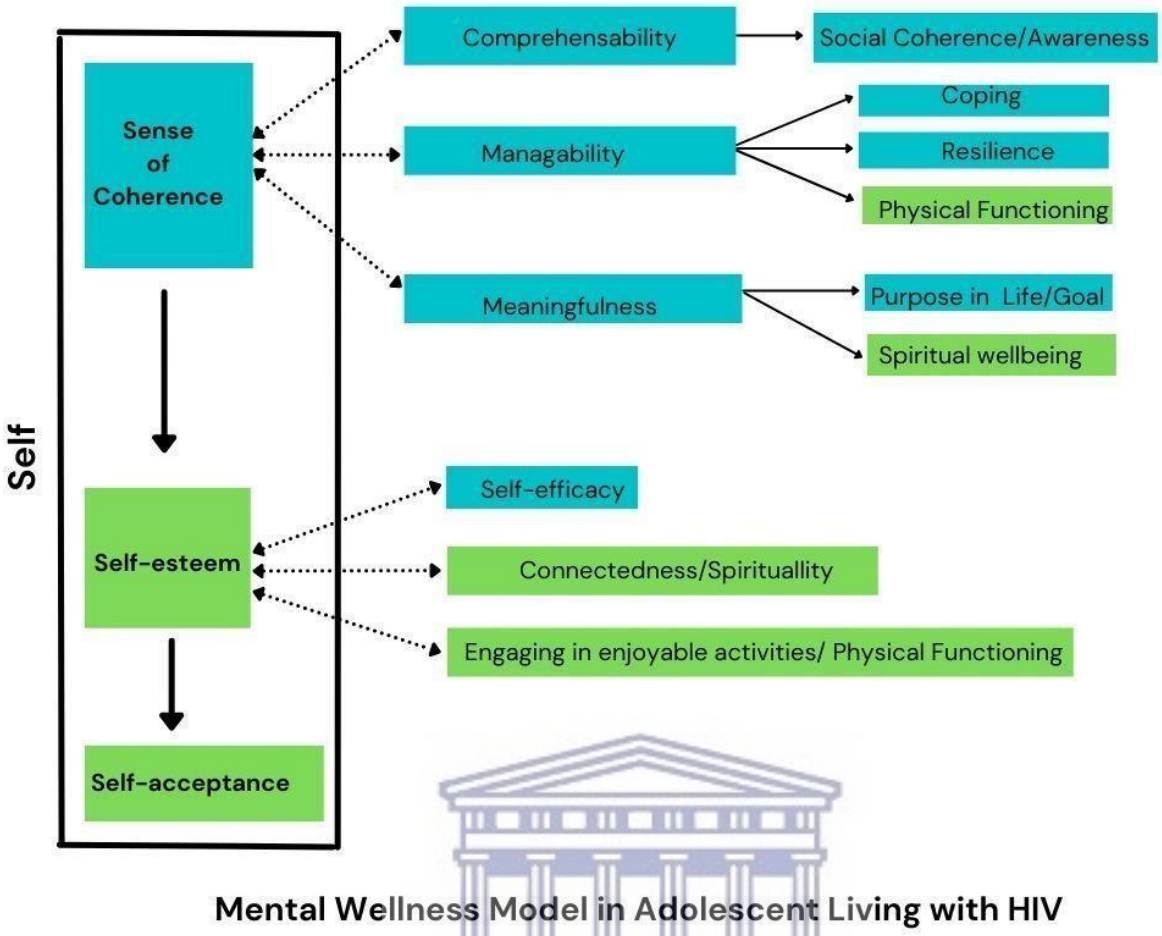

Figure 6.7: Model of Mental Wellness for Adolescents Living with HIV.

Additionally, experiencing high levels of one mental wellness concept or behaviour is insufficient to ensure overall mental wellness. As shown in figure 6.7, the mental wellness concepts and behaviours identified in this study do not exist independently. Instead, mental wellness represents a system in which each concept and behaviour represents an interconnected part that moves and works together as a whole. Some of these parts may 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, they may 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 could perpetuate other challenges to their mental wellness (i.e., 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]. Fewer studies are exploring the impact of such interventions on targeted groups like ALHIV. A scoping review by Okonji et al. [40] on psychosocial interventions explicitly aimed at ALHIV identified four psychosocial treatment modalities aimed at improving adherence among ALHIV: individual counselling, support groups, family-centred services, and treatment supporters. 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 criteria 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; 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 a history of poor adherence and disengagement from care and re-engaged prior to participating.

It is worth mentioning that youth [adherence] clubs were implemented in two health facilities, 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 and activate key mental wellness concepts and behaviours. Therefore, mental wellness should be measured as part of 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.

References

1. UNAIDS. AIDSInfo: Global data on HIV epidemiology and response. 2020. Available from: https://aidsinfo.unaids.org/.
2. Avert. Global HIV and AIDS statistics. Available from: https://www.avert.org/global-hiv-and- aids.
3. van Wyk B, Teti M. Portraits of HIV: A pilot photovoice study of adolescent experiences with HIV treatment in South Africa. J Glob Health. 2020;4: e2020025. doi:10.29392/001c.12588
4. Dow DE, Mmbaga BT, Gallis JA, et al. A group-based mental health intervention for young people living with HIV in Tanzania: Results of a pilot individually randomized group treatment trial. BMC Public Health. 2020;20(1):1358. doi:10.1186/s12889-020-09380-3.
5. Nabukeera-Barungi N, Elyanu P, Asire B, et al. Adherence to antiretroviral therapy and retention in care for adolescents living with HIV from 10 districts in Uganda. BMC Infect Dis. 2015;15(1):520. doi:10.1186/s12879-015-1265-5.
6. Dessauvagie AS, Jörns-Presentati A, Napp AK, et al. The prevalence of mental health problems in sub-Saharan adolescents living with HIV: A systematic review. Global Mental Health. 2020;7(29):1–13. doi:10.1017/gmh.2020.18.
7. Kaunda-Khangamwa BN, Kaunda-Khangamwa BN, Kaunda-Khangamwa BN, et al. Adolescents living with HIV, complex needs and resilience in Blantyre, Malawi. AIDS Res Ther. 2020;17(35):1–13. doi:10.1186/s12981-020-00292-1.
8. Bakeera-Kitaka S Exploring the health and wellbeing of adolescents living with HIV as they grow into adulthood: Unique challenges in a low resource setting [dissertation]. Antwerp: University of Antwerp; 2020.
9. Laurenzi C, Skeen S, Gordon S, et al. Preventing mental health conditions in adolescents living with HIV: An urgent need for evidence. J Int AIDS Soc. 2020; 23:1-6. doi: 10.1002/jia2.25556.
10. Crowley T, Rohwer A. Self-management interventions for adolescents living with HIV: A systematic review. BMC Infect Dis. 2021;21(1):1–29. doi:10.1186/s12879-021-06072-0.

11. World Health Organization. Adolescent mental health. Available from: https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health.
12. Rencken CA, Harrison AD, Mtukushe B, et al. Those people motivate and inspire me to take my treatment." Peer support for adolescents living with HIV in Cape Town, South Africa. J Int Assoc Provid AIDS Care. 2021; 20:1–9. doi:10.1177/23259582211000525.
13. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc. 2017;20(3):100–109. doi:10.7448/IAS.20.4.21497.
14. World Health Organization. Constitution of the World Health Organization. Available from: https://www.who.int/about/governance/constitution.
15. Ryff CD, Singer BH, Love GD. Positive health: Connecting well-being with biology. Biol Sci. 2004;359(1449):1383–1394. doi:10.1098/rstb.2004.1521.
16. Edwards SD, Ngcobo HS, Edwards DJ, Palavar K. Exploring the relationship between physical activity, psychological well-being and physical self-perception in different exercise groups. S Afr J Res Sport Phys Educ Recreat. 2006;27(1):75–90. doi:10.4314/sajrs.v27i1.25908.
17. Orth Z, van Wyk B. Adolescent mental wellness: A systematic review protocol of instruments measuring general mental health and well-being. BMJ Open. 2020;10(8):37237. doi:10.1136/bmjopen-2020-037237
18. Mukumbang FC, Wyk BV. Leveraging the photovoice methodology for critical realist theorizing. Int J Qual Methods. 2020; 19:1–16. doi:10.1177/1609406920958981
19. Orth Z, van Wyk B, Facility-based Family A. Support intervention to improve treatment outcomes for adolescents on antiretroviral therapy in the Cape Metropole, South Africa. J Int Assoc Provid AIDS Care. 2021; 20:1–11. doi:10.1177/23259582211059289.
20. Teti M, van Wyk B. Qualitative methods without borders: Adapting photovoice: from a U.S. to South African setting. Int J Qual Methods. 2020; 19:160940692092725. doi:10.1177/1609406920927253.
21. Orth Z, van Wyk B. Measuring mental wellness among adolescents living with a physical chronic condition: A systematic review of the mental health and mental well-being instruments. BMC Psychol. 2021;9(1): 1-17. doi:10.1186/s40359-021-00680-w.

22. Orth Z, Moosajee F, van Wyk B. Measuring mental wellness of adolescents: A systematic review of instruments. Front Psychol. 2022;13:1-14. doi:10.3389/fpsyg.2022.835601.
23. Steiner RJ, Sheremenko G, Lesesne C, DIttus PJ, Sieving RE, Ethier KA. Adolescent connectedness and adult health outcomes. Pediatrics. 2019;144(1): e20183766. doi:10.1542/peds.2018-3766.
24. Balthip K, McSherry W, Nilmanat K. Spirituality and dignity of Thai adolescents living with HIV. Religions. 2017;8(12):1–18. doi:10.3390/rel8120257.
25. Keyes CLM. Social Well-Being. Soc Psychol Q. 1998;61(2):121–140. doi:10.2307/2787065
26. Logan A, King F. Self-esteem: defining, measuring and promoting an elusive concept. J Spec Needs Educ Ireland. 2016;29(2):116–127. https://reachjournal.ie/index.php/reach/article/view/48/198.
27. Demirtaş AS. Cognitive flexibility and mental well-being in Turkish adolescents: The mediating role of academic, social and emotional self-efficacy. Anales de Psicologia. 2020;36(1):111–121. doi:10.6018/analesps.336681.
28. Fang BB, Lu FJ, Gill DL, Liu SH, Chyi T, Chen BA. Systematic review and meta-analysis of the effects of outdoor education programs on adolescents' self-efficacy. Percept Mot Skills. 2021;128(5):1932–1958. doi:10.1177/00315125211022709.
29. Rodríguez D, Luterbach KJ, Woolf SB, Peralta Rivera S. Self-acceptance of adolescent latino students with disabilities. Edu Consider. 2020;45(3):1–14. doi:10.4148/0146-9282.2207.
30. Popov S. When is unconditional self-acceptance a better predictor of mental health than self- esteem? J Ration. 2019;37(3):251–261. doi:10.1007/s10942-018-0310-x.
31. Miranda D, Claes M. Music listening, coping, peer affiliation and depression in adolescence. Psychol Music. 2009;37(2):215–233. doi:10.1177/0305735608097245.
32. Schaefer SM, Boylan JM, van Reekum CM, et al. Purpose in life predicts better emotional recovery from negative stimuli. PLoS One. 2013;8(11): e80329. doi:10.1371/journal.pone.0080329.
33. Giannakopoulos G, Dimitrakaki C, Pedeli X, et al. Adolescents' wellbeing and functioning: relationships with parents' subjective general physical and mental health. Health Qual Life Outcomes. 2009;7(100):1–9. doi:10.1186/1477-7525-7-100.

34. Trompetter HR, Kleine E, De, Bohlmeijer ET. Why does positive mental health buffer against psychopathology? An exploratory study on self-compassion as a resilience mechanism and adaptive emotion regulation strategy. Cognit Ther Res. 2017;41(3):459–468. doi:10.1007/s10608-016-9774-0.

35. Shaffer-Hudkins E, Suldo S, Loker T, March A. How adolescents' mental health predicts their physical health: unique contributions of indicators of subjective well-being and psychopathology. Appl Res Qual Life. 2010;5(3):203–217. doi:10.1007/s11482-010-9105-7.

36. Huta V. An overview of hedonic and eudaimonic well-being concepts. In: Reinecke L, Oliver MB, editors. Handbook of Media Use and Well-Being. New York: Routledge; 2015.

37. Witten H, Savahl S, Adams S. Adolescent flourishing: A systematic review. Cogent Psychol. 2019;6(1):1640341. doi:10.1080/23311908.2019.1640341.

38. Mankowitz DJ The African philosophical concept of Ubuntu as applied to the Emotional Intelligence of adolescents: challenging the appropriateness of Western-derived concepts [dissertation]. University of South Africa.

39. Frant IA. Implications of self-esteem in adolescence. J Plus Educ. 2016;14(1):90–99.

40. Okonji EF, Mukumbang F, Orth Z, et al. Psychosocial support interventions for improved adherence and retention in ART care for adolescents and young people living with HIV: A scoping review. BMC Public Health. 2020;20: 1–27. doi: 10.1186/s12889-020-09717-y.

CHAPTER 7

Paper 6: Orth Z & van Wyk B. Rethinking mental wellness among adolescents: An integrative review protocol of mental health components. Systematic Reviews. 2022;11(83): 1-7. doi: 10.1186/s13643-022-01961-0.

Abstract

Background: Adolescents have been overlooked in global public health initiatives as this period is generally considered the healthiest in an individual's life course. However, the growth of the global adolescent population and their changing health profiles have called attention to the diverse health needs of adolescents. The increased attention toward adolescent health has accentuated existing gaps as global health reports have emphasised a continued need for valid and reliable health data. In this context, evidence has shown that mental health issues constitute one of the greatest burdens of disease for adolescents. This integrative review aims to unpack the meaning of mental health and mental wellness among adolescents and its associated constructs by analysing and synthesising empirical and theoretical research on adolescent mental health and wellness. In doing this, we will develop a working definition of adolescent mental wellness that can be used to develop an instrument to measure adolescent mental wellness.

Methods: The integrative review is guided by the five steps described by Whittemore and Knafl. A comprehensive search strategy which will include carefully selected terms that correspond to the domains of interest (positive mental health/mental wellness), will be used to search for relevant literature on electronic databases, grey literature and government or non-governmental organisations (NGO) websites. Studies will be included if they describe and/or define general mental wellness in adolescent populations aged 10-19. The screening and reporting of the review will be conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Data from the integrative review will be analysed using narrative framework synthesis for qualitative and quantitative studies.

Discussion: This integrative review aims to search for and synthesise current research regarding adolescent mental wellness to identify how wellness is being described and conceptualised. We aim to identify gaps and contribute to a more comprehensive definition of mental wellness that can aid in developing an age- and culturally appropriate measure of adolescent mental wellness.

Background

In 2016, adolescents (10-19 years) were estimated at 1.2 billion (18%) of the world population, making them the largest population of adolescents in history [1,2]. Adolescents have been largely overlooked in global health and social policies because this period is generally considered to be the healthiest in an individual's life course [2], and the unique health problems associated with adolescence have been misconstrued or ignored in favour of more pressing public health concerns [3]. However, changing health profiles of adolescents in both developed and developing countries have called attention to the diverse health needs of adolescents [1].

According to the World Health Organization (WHO), more than 1.1 million adolescents died in 2016 - mostly from preventable or treatable causes [4]. Therefore, the considerable gains from global investments in child and maternal health programmes would yield fewer long-term benefits without simultaneous investments in adolescent health [5,6]. According to the life course approach, all stages of an individual's life are intricately intertwined and interconnected with each other, as well as with other people in society and with past and future generations of their families [7]. In other words, evidence has shown that early life experiences, including events experienced in pre-conception, play a role in determining the developmental origins and trajectories of health and wellness or disease across an individual's life course [7]. From this perspective, it is understood that the health and wellness of individuals and communities depend on interactions oscillating between multiple risk and protective factors throughout one's life. Based on this, early and appropriate interventions during the child and adolescent years are shown to be the most effective prevention strategies to promote optimal public health and human development [5,6,8]. Additionally, following the life course approach, it is argued that these early investments in child and adolescent health will yield a triple dividend as they will grow into healthier adults who can contribute positively to society, as well as the health and development of the next generation [2, 9].

Globally, mental health issues constitute one of the greatest burdens of disease for adolescents. According to the WHO, in 2016, mental health conditions accounted for 16% of the global burden of disease and injury for adolescents, with depression being identified as one of the leading causes of illness and disability among adolescents, suicide noted as the second leading

cause of death in adolescents and self-harm the third [4,9]. UNICEF propagates that half of all lifetime mental disorders have onset during adolescence [10]. The recent inclusion of adolescents on the global health agenda as a target group for intervention represents a key step toward reducing the global burden of disease attributed to mental health disorders and reducing preventable deaths [2, 10-13]. However, due to the previous neglect of mental health as a public health issue, efforts to address adolescent mental health are met with various challenges.

Currently, there is a lack of data concerning mental health conditions among adolescents, especially those in low and –middle-income countries (LMICs) [11]. The lack of a body of quality evidence can affect how adolescents are represented in national policies and how government and healthcare officials respond to treatment and prevention [2, 14]. According to WHO, a 2014 review of health policy documents from 109 countries showed that 84% had given some attention to adolescents, with three-quarters of them addressing sexual and reproductive health: one-third addressing tobacco and alcohol use, and one-quarter focusing on mental health [1]. In LMICs, efforts regarding the promotion, prevention and treatment of child and adolescent mental health services (CAMHS) are hindered by a lack of specific CAMHS policies, and resources and fewer child and adolescent psychiatrists and other mental health professionals [12,13]. Furthermore, studies from developed countries have suggested that while CAMH services and policies are in place, there is a lack of mental health service uptake among children and adolescents due to various attitudinal, stigma-related, and structural barriers to accessing mental health services [14]. These challenges and barriers to CAMH in LMICs and higher-income countries are particularly apparent among adolescents living with a chronic order or disease [15,16]. Mental health conditions are increasingly recognised in children and adolescents with chronic disorders. Studies have shown that living with a chronic health condition is associated with an increased risk of developing comorbid physical and mental health problems, influencing treatment adherence and quality of life [16–18].

Another recurring obstacle to integrating mental health into global public health initiatives and frameworks is the lack of consensus on a definition of mental health [19]. Despite the growth of mental health and wellness research in recent decades, the question of how mental wellness should be defined remains largely unresolved [20]. This has given rise to broad and ambiguous definitions, which consequently, results in concepts such as mental health, mental wellness and

mental well-being being used interchangeably. Currently, the term ‘mental health is often used as a euphemism to refer to mental illness, referring to conditions which adversely affects cognition, emotion and behaviour (i.e., depression and anxiety) [21]. This use reflects in the literature as most adolescent mental health research adopts the dominant pathological view of health by focusing on mental health *disorders* such as psychiatric disorders, general mental health disorders, emotional and behavioural problems and psychological distress [22,23]. Similarly, global health initiatives such as AAH-HA! focus majorly on the burden of disease of mental disorders by reporting on self-harm, depressive disorders, childhood behavioural disorders and anxiety [3]. This dominant pathological view of mental health persists despite the contributions of positive health and wellbeing research which argues that *wellness* and *illness* are not two ends of the same continuum as previously thought; rather these constructs represent two independent continua [19,23]. In other words, the absence of mental illness does not necessarily indicate a state of mental health/wellness [1, 23, 24].

Therefore, it is imperative to consider both mental wellness and mental illness in research and to move away from the previous ‘absence of disease’ model to one that emphasises positive psychological functioning for mental health [23,24]. In this model, wellness refers to the degree to which one feels positive about life and the capacity to manage one’s feelings, behaviours, and limitations [23]. From this model, addressing adolescent mental health is seen as more than treating and mitigating the burden of disease of mental illness; rather it is also useful in maintaining lifelong mental and physical wellness and preventing the development of mental disorders [23]. Adolescents, in particular, experience multiple physical, social, and emotional changes, which can positively or negatively impact their mental wellness. Therefore, interventions at this stage are crucial as research shows that providing psychosocial support and mental health promotion, such as psychoeducation and community empowerment, facilitates the development of mental wellness (positive mental health), which is protective against psychopathology (mental illness) [9,24].

There is a need to develop accurate and culturally appropriate measures of mental wellness to support research endeavours that aim to improve adolescent mental health. Therefore, there is a greater necessity to clarify *what* is being measured and how the resulting data from the measure should be interpreted to undertake fair and valid assessments—as such, developing a definition of mental wellness should encompass more than the description of wellness itself (as is the case with

current definitions) to a clear and definite statement of the exact meaning of the construct. To this end, this integrative review forms part of a larger study which aims to unpack the meaning of mental health and mental wellness among adolescents and its associated constructs by analysing and synthesising relevant literature and empirical and theoretical research on adolescent mental health. In doing this, we aim to use this information to develop and conceptualise adolescent mental wellness as a construct. Additionally, by focusing on conceptualising mental wellness, we hope to clarify how concepts such as mental health are used in the literature by clearly distinguishing between mental health (as a euphemism for mental illness) and mental wellness as a positive state of mental health. We aim to develop an instrument that measures mental wellness as an indicator of general mental health and wellness among adolescents.

Methodology

The integrative review has been identified as a unique tool in healthcare for synthesizing investigations available on a given topic or phenomena and for directing practice based on scientific knowledge [25]. The existing body of literature on mental health among adolescents is varied and complex as there are many concepts associated with mental health research ranging from positive aspects such as 'resilience' and 'self-efficacy' to negative aspects such as 'depression' and 'anxiety'. As such, it is not possible for one study to capture all the dimensions associated with mental health. However, by adopting the integrative review method, we will be able to include the various sources and methodologies used in research to summarise existing empirical and theoretical literature associated with [positive] mental wellness concepts to better understand and conceptualise mental wellness among adolescents. The integrative review method proposed by Whittemore and Knafl [26] will be used: 1) problem identification; 2) literature search; 3) data evaluation; 4) data analysis, and 5) presentation of the integrative review.

Problem identification

The problem identification stage is a crucial first step in an integrative review. Therefore, we aim to approach this as a phase in itself. This means going beyond the initial research questions to fully develop a framework of the problem and all its related variables. In this section, we describe some approaches we will use to identify the problem the integrative review will address. As previously mentioned, our interest lies in understanding how mental wellness is conceptualised

among adolescents to aid in the conceptualisation and development of a mental wellness instrument for adolescent populations. Based on our initial reading of the literature, we have identified two recurring issues in this regard: firstly, there is a lack of validated mental health instruments for adolescents; and secondly, despite a growing body of research, the question of how mental wellness should be defined remains largely unresolved. Based on this, we have proposed to follow two research questions to aid us in identifying the problem.

1) How is the concept of mental wellness defined in research involving adolescents?

2) What indicators of mental wellness are being explored/investigated in research?

These two questions allow us to investigate how research has approached the study of mental wellness, what variables were of interest and how these were defined. To answer these questions, we will follow an iterative approach to gather and assess the available information to clearly identify the problem and all the variables of interest. To this end, we are currently conducting a systematic review of mental health instruments used in research with adolescent populations [21].

Understanding how mental wellness has been defined in research is an integral part of our problem identification, as it will show us what theories and/or definitions of mental health are dominant, and which are missing. As Dodge et al. [20] argued, current definitions of wellness are more descriptive in the sense that they describe aspects of wellness rather than the construct itself. This lack of definition poses a problem in measurement development, as the definition of a construct ultimately influences how it is being measured and how the resulting data should be interpreted. Therefore, to further aid our problem identification, we will compare the data from the systematic review with data from qualitative interviews exploring mental wellness among adolescents living with HIV (ALHIV). As previously mentioned, this review forms part of a larger study to develop an instrument to measure mental wellness among adolescents. We have chosen to include the interviews with ALHIV for the problem identification stage as we want to develop an instrument that can measure mental wellness among healthy populations and those living with a chronic illness such as HIV. This is necessary as Manderscheid et al. [23] argue that a dual emphasis on mental and physical health is essential as studies have shown that positive health may influence biological functioning. This information will be used to identify the problem of the

integrative review (figure 7.1). Using the information from the problem identification phase, we will move on to the second phase to conduct a literature search of mental health concepts used in research with adolescent populations.

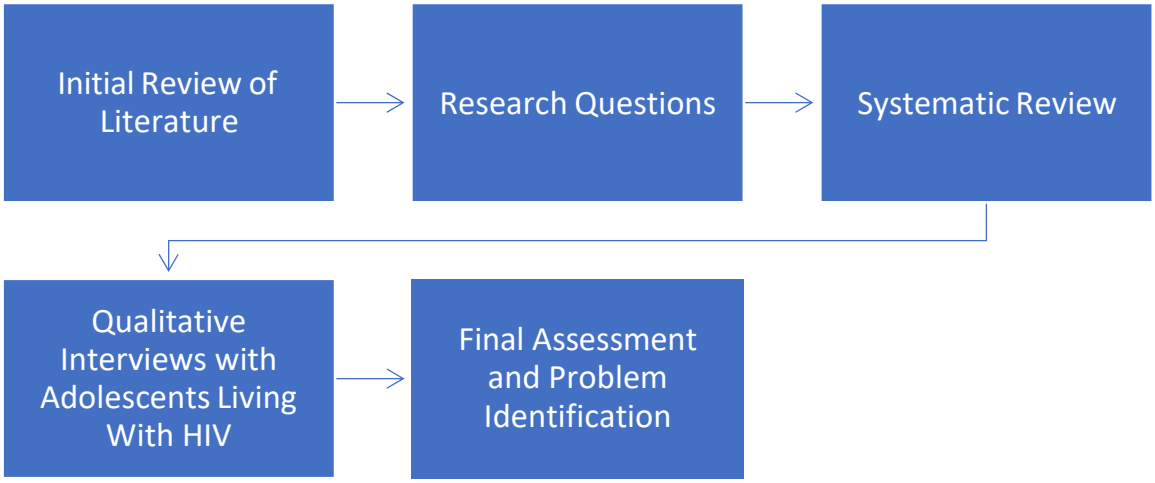

Figure 7.1: Steps followed to identify the problem for integrative review.

Literature search

A comprehensive search strategy which will include carefully selected terms that correspond to the domains of interest (mental health/mental wellness), will be used to search for relevant literature on electronic databases, grey literature and government or non-governmental organisations' (NGO) websites. A systematic database search will be performed using Ebscohost (Psycharticles, Academic Search Premier, SocIndex), Educational Resource Information Center (ERIC), Medical Literature Analysis Retrieval System Online (MEDLINE) and Sabinet. A list of initial keywords has been identified for the search strategy: "((adolescen* OR teenage* OR young people OR youth) [AND] ("psychological wellbeing" OR "mental health wellbeing" OR "mental wellness" OR "mental health"). As the integrative review allows for a more iterative process, the list of keywords will be modified as the initial search reveals more relevant and refined search terms.

Inclusion and exclusion criteria

Studies will be included if they describe and/or define mental wellness in adolescent populations. As the interest lies in conceptualising mental wellness for adolescents, only

studies dealing with general mental health, well-being and wellness will be included. In other words, studies focused on mental disorders or mental illnesses among adolescents will be excluded. For this review, studies will be included for all adolescents aged 10-19 who have not been diagnosed with a mental illness or disorder. Eligible studies will include qualitative, quantitative, and mixed-method studies published from 2000-2020. The period of the search strategy was chosen due to the paucity of research in this area [3,22,27]. Furthermore, the prioritization of adolescent health and the focus on adolescent-friendly services occurred after 2000 [28].

Screening and selection process

Study selection

The PICOT mnemonics (Table 7.1.) for reviews will be used to guide study selection.

Table 7.1. PICOT-based inclusion criteria for literature review

Patient population	Adolescents aged 10-19 years
Intervention or Interest	Definitions of mental wellness or psychological well-being, or general mental health among adolescents
Comparison	Not applicable
Outcomes	Mental wellness, psychological well-being, or general mental health
Time	2000–2020

The criteria mentioned above, and search strategy will be used to search the databases. The screening and reporting of the review will be conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA-P) guideline and checklist [29]. The number of hits for each database will be recorded, and the citations will be exported to Mendeley citation software. Following this, two reviewers will screen all the titles and abstracts to assess which articles are appropriate for inclusion. The full-text articles of the included abstracts will be downloaded and reviewed again to determine which articles should be included in the final

assessment [30]. A third party will resolve any discrepancies between the two reviewers. Additionally, based on the information retrieved from the screening, the researcher may modify the search to include other relevant sources.

Data evaluation

In this integrative review, the primary sources will include both empirical and theoretical literature - which increases the complexity of evaluating the quality of the included sources [26]. According to Whittmore and Knafl [26], integrative reviews using diverse sampling frames may adopt an approach to data evaluation similarly used in historical research. In this case, the available sources' authenticity, methodological quality, informational value, and representativeness should be discussed in the final report. To minimise bias, the two reviewers will utilise two existing quality criteria instruments to evaluate the different types of data [26]. Firstly, the Mixed Methods Appraisal Tool (MMAT) will be used to assess the methodological quality of the studies as it allows for summarising the overall quality across a range of study designs [31]. Secondly, the SFS scoring system version E will be used to assess the quality of the methodologies of the included articles [32]. The SFS scoring system version E is appropriate as it allows for the screening of both quantitative and qualitative research and the appraisal of the definitions of constructs being investigated [32].

Data analysis

Once the selection of included articles has been finalised, we will extract the relevant data into a Microsoft Excel document to organise the information and prepare for the data synthesis. The Excel sheet will include information regarding the purpose of the study, study characteristics, results, and appraisal of the study, as well as any other supporting information. All data will be cross-checked for quality purposes.

Data from the integrative review will be analysed using narrative framework synthesis for qualitative and quantitative studies. Framework synthesis begins with a tentative framework that can either be borrowed from previous studies or developed from key concepts [26,33]. With framework synthesis, the included studies are coded according to the developing framework in an iterative process until the body of evidence can be presented coherently. In the final stage, the

findings from the review will be discussed and presented in either tabular or diagrammatic form. Additionally, the review's limitations will be discussed and recommendations for future research.

Discussion

This integrative review aims to synthesise current literature on adolescent mental wellness to identify how this is being described and applied in research. The purpose of this is to identify gaps and contribute to the conceptualisation of a more comprehensive definition of mental wellness that can aid in developing an age- and culturally appropriate measure of adolescent mental wellness. Such measures are much needed in adolescent health research as they may be used to better understand the mental health needs of adolescents, as well as contribute to the development of interventions and programmes aimed at improving their psychological wellbeing and/or mental wellness.

Strengths and limitations

According to our knowledge, this protocol describes the first integrative review to investigate and describe how mental wellness is defined in research among adolescents. Understanding how mental wellness among adolescents has been conceptualised is necessary to identify the strengths and limitations of such definitions. This will allow researchers to rethink what mental wellness means to adolescents and how this can and should be measured in research. A limitation of this study is related to the search strategy, notably around the period (2000-2020) and the identification of grey literature, as not all possible literature sources may be accessed.

Ethics approval and consent to participate

This integrative review forms part of the corresponding author's PhD work and has been approved by the University of the Western Capes' Biomedical Science Research Ethics Committee. Ethics Reference Number: BM19/9/18

References

1. World Health Organization. Health for the world's adolescents: A second chance in the second decade. 2014. Available from: https:// www. who. int/ maternal_ child_ adolescent/ documents/ second- decade/ en/
2. Patton GC, Sawyer SM, Santelli JS, et al. Our future: a Lancet commission on adolescent health and wellbeing. Lancet. 2016; 387: 2423–2478. doi: 10.1016/S0140-6736(16)00579-1.
3. World Health Organization. Global accelerated action for the health of adolescents (AA-HA!): Guidance to support country implementation. 2017. Available from: http:// www. who. int/ maternal_ child_ adolescent/topics/ adolescence/ framework- accelerated- action/ en/.
4. World Health Organization. Adolescents: Health risks and solutions. 2014. Available from: http:// www. who. int/ media centre/ facts heets/ fs345/ en/.
5. James S, Pisa PT, Imrie J, Beery MP, Martin C, Skosana C, et al. Assessment of adolescent and youth friendly services in primary healthcare facilities in two provinces in South Africa. BMC Health Serv Res. 2018; 18:1–10. https:// doi. org/ 10. 1186/ s12913- 018-3623-7.
6. Sawyer SM, Afifi RA, Bearinger LH, Blakemore SJ, Dick B, Ezeh AC, et al. Adolescence: a foundation for future health. Lancet. 2012; 379:1630–40. https:// doi. org/ 10. 1016/ S0140- 6736(12) 60072-5.
7. World Health Organization. The life-course approach from theory to practice: Case stories from two small countries in Europe. 2018. Available from: http:// www. euro. who. int/ ___data/ assets/ pdf_ file/ 0004/ 374359/ lifecourse- icela nd- malta- eng. pdf? ua=1.
8. Armstrong A, Nagata JM, Vicari M, Irvine C, Cluver L, Sohn AH, et al. A global research agenda for adolescents living with HIV. J Acquir Immune Defic Syndr. 2018;78:S16–21. https:// doi. org/ 10. 1097/ QAI. 00000 00000 001744.
9. World Health Organization. Adolescent mental health. 2018. Available from: https:// www. who. int/ news- room/ fact- sheets/ detail/ adolescent- mental- health.
10. UNICEF. Measurement of mental health among adolescents at the population level (MMAP): Conceptual framework and the roadmap to the measurement of mental health. 2018. Available from: https:// data. unicef. org/ wp- conte nt/ uploa ds/ 2018/ 11/ Conce

ptual- frame work- and- Roadm ap- 19- july. pdf.

11. Guthold R, Moller AB, Azzopardi P, Ba MG, Fagan L, Baltag V, et al. The Global Action for Measurement of Adolescent health (GAMA) initiative— Rethinking adolescent metrics. J Adolesc Health. 2019; 64:697–9. https://doi. org/ 10. 1016/j. jadoh ealth. 2019. 03. 008.
12. Mokitimi S, Schneider M, de Vries PJ. Child and adolescent mental health policy in South Africa: History, current policy development and implementation, and policy analysis. Int J Ment Health Syst. 2008;12(36):1–15. https:// doi. org/ 10. 1186/ s13033- 018- 0213-3.
13. Juengsiragulwit D. Opportunities and obstacles in child and adolescent mental health services in low- and middle-income countries: a review of the literature. WHO South-East Asia J Public Health. 2015; 4:110. https:// doi. org/ 10. 4103/ 2224- 3151. 206680.
14. Campo JV, Bridge JA, Fontanella CA. Access to mental health services implementing an integrated solution. JAMA Pediatr. 2015; 169:299–300. https:// doi. org/ 10. 1001/ jamap ediat rics. 2014. 3558.
15. Sawyer SM, Drew S, Yeo MS, Britto MT. Adolescents with a chronic condition: Challenges living, challenges treating. Lancet. 2007; 369:1481–9. https:// doi. org/ 10. 1016/ S0140- 6736(07) 60370-5.
16. Delamater AM, Guzman A, Aparicio K. Mental health issues in children and adolescents with chronic illness. Int J Hum Rights Healthc. 2017; 10:163–73. https:// doi. org/ 10. 1108/ IJHRH- 05- 2017- 0020.
17. Duffus SH, Cooper KL, Agans RP, Jain N. Mental health and behavioral screening in pediatric type 1 diabetes. Diabetes Spectr. 2019; 32:171–5. https:// doi. org/ 10. 2337/ ds18- 0053. 22.
18. Lee S, Chung NG, Choi JY. Comparison of resilience and quality of life between adolescent blood cancer survivors and those with congenital heart disease: a cross sectional study. Health Qual Life Outcomes 2020; 18:1–7. https:// doi. org/ 10. 1186/ s12955- 020- 01487-w.
19. Manwell LA, Barbic SP, Roberts K, Durisko Z, Lee C, Ware E, et al. What is mental health? Evidence towards a new definition from a mixed methods multidisciplinary international survey. BMJ Open. 2015; 5:1–11. https:// doi.org/ 10. 1136/ bmjop en- 2014- 007079.

20. Dodge R, Daly AP, Huyton J, Sanders LD. The challenge of defining wellbeing. Int J Wellbeing. 2012; 2:222–35. https:// doi. org/ 10. 5502/ ijw. v2i3.4.

21. Orth Z, Van Wyk B. Adolescent mental wellness: a systematic review protocol of instruments measuring general mental health and wellbeing. BMJ Open. 2020; 10:37237. https:// doi. org/ 10. 1136/ bmjop en- 2020- 037237.

22. Vreeman RC, Mccoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc. 2017; 20:100–9. https:// doi. org/ 10. 7448/ IAS. 20.4. 21497.

23. Manderscheid RW, Ryff CD, Freeman EJ, et al. Evolving Definitions of Mental Illness and Wellness. Prev Chronic Dis. 2010; 7(1): 5–10. http://www.cdc.gov/pcd/issues/2010/jan/09_0124.htm.

24. Keyes CLM. Promoting and protecting mental health as flourishing. Am Psychol. 2005:95–108. https:// doi. org/ 10. 1037/ 0003- 066X. 62.2. 95.

25. De Souza MT, De Carvalho R. Integrative review: what is it? How to do it? Einstein. 2010; 8:102–7. https:// doi. org/ 10. 1590/ S1679- 45082 010RW 1134.

26. Whittemore R, Knafl K. The integrative review: updated methodology. J Adv Nurs. 2005;52(5):546–53. https:// doi. org/ 10. 1111/j. 1365- 2648. 2005. 03621.

27. Sherr L, Cluver LD, Toska E, He E. Differing psychological vulnerabilities among behaviourally and perinatally HIV infected adolescents in South Africa–implications for targeted health service provision. AIDS Care. 2018; 30:92–101. https:// doi. org/ 10. 1080/ 09540 121. 2018. 14766 64.

28. World Health Organization. Promoting mental health: concepts, emerging evidence, practice. 2004. Available from: https://apps.who.int/iris/bitstream/handle/10665/42940/9241591595.pdf.

29. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021;372: n71. https:// doi. org/ 10. 1136/ bmj. n71.

30. Eggar M, Smith GD, Altman DG. Systematic reviews in health care: Meta analysis in context. 2nd ed. London: BMJ Publishing Group; 2001.

31. Hong QN, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, et al. The mixed methods appraisal tool (MMAT) version 2018 for information professionals and researchers. Educ Inf. 2018; 34:285–91. https:// doi. org/10. 3233/ EFI- 180221.

32. Smith MR, Franciscus G, Swartbooi C, Munnik E, Jacobs W. The SFS scoring system. In: Smith MR (Ed., Chair). Symposium on methodological rigour and coherence: deconstructing the quality appraisal tool in systematic review methodology, conducted at the 21st National Conference of the Psychological Association of South Africa. South Africa; 2015.

33. Snilstveit B, Oliver S, Vojtkova M. Narrative approaches to systematic review and synthesis of evidence for international development policy and practice. J Dev Eff. 2012; 4:409–29. https:// doi. org/ 10. 1080/ 19439 342.2012. 710641.

CHAPTER 8

Paper 7: Orth Z & van Wyk B. Rethinking mental health wellness among adolescents living with HIV in the African context: An integrative review of mental wellness components. Frontiers in Psychology. 2022; 13:1-13. doi: 10.3389/fpsyg.2022.955869.

Abstract

Objective: Adolescents living with HIV (ALHIV) are at heightened risk for developing mental health problems compared to their peers due to the burden of living with a stigmatized condition and managing a chronic condition. Poorer mental health outcomes among ALHIV are associated with lower rates of adherence to anti-retroviral therapy (ART). It is necessary to improve mental wellness among ALHIV as this acts as a crucial buffer against developing mental health problems which, if left untreated, can evolve into mental health disorders. Research on mental wellness concepts among ALHIV is underdeveloped which is associated with a lack of appropriate measures of mental wellness. We conducted an integrative review to conceptualise mental wellness and consider the critical components for measuring mental wellness in ALHIV.

Method: An integrative review of published literature focusing on the mental wellness of ALHIV in the African context was conducted. The PRISMA operational steps guided the process. As part of our problem identification phase, we drew on findings from a previous systematic review of mental wellness instruments and a qualitative photovoice study on exploring the experiences of ALHIV to develop an initial framework of 13 mental wellness concepts and behaviours which informed the search strategy.

Results: The review included 17 articles from which we identified six mental wellness concepts: Connectedness, Sense of Coherence (SOC), Self-esteem, Self-acceptance, Hope for the Future and Spirituality, as well as six behaviours facilitating mental wellness: Coping, Resilience, Purpose in Life (goals), Self-efficacy, Adherence Self-efficacy, and Leisure Activities. All of these concepts and behaviours have been noted in our previous research (systematic review and qualitative work), with the exception of adherence self-efficacy. Based on the findings from this review and our previous work, we adapted Antonovsky's (1987) Salutogenic Model of Health to propose a Salutogenic Model of Mental Wellness (SMoMW) for ALHIV in the African context. This

SMoMW may be used to develop an age and culturally appropriate measure of mental wellness for ALHIV.

Conclusion: The findings from this review are used to conceptualise mental wellness among ALHIV, which can be used to develop a measurement of mental wellness.

Background

Mental health, as an integral component of overall health and well-being, has received global acknowledgement, as evidenced in its inclusion in the Sustainable Development Goals (SDGs), the World Health Organization's (WHO) Mental Health Action Plan (2013-2030), WHO's mental health gap action programme (mhGAP) and the United Nations Children's Fund (UNICEF) development of the Measurement of Mental Health Among Adolescents at the Population Level (MMAP) (1–3). Adolescent mental health, in particular, is receiving more attention because adolescence is a time of critical development that sets the course for mental health and wellness across the life course (4,5). UNICEF argues that since half of all mental disorders have their onset during adolescence, intervention during the adolescent years is essential to prevent the development of chronic mental illness conditions.

Further, WHO observes that 1 in 7 adolescents between 10-19 years' experience a mental health disorder (6). The prevalence of mental health disorders accounts for 13% of the global disease burden among adolescents, with suicide being reported as the fourth leading cause of death among 15-19 years old (6). It is further reported that adolescents living with HIV (ALHIV) are at increased risk of experiencing ill mental health (compared to their peers) due to the double burden of living with a stigmatized infectious disease and managing a life-long chronic condition (7–10). Findings from a recent systematic review reported high prevalence rates of mental health problems among ALHIV, with 24-27% of participants scoring positive for having a psychiatric disorder and 30-50% showing symptoms of emotional and behavioural difficulties or significant psychological distress (11). Other research with ALHIV reports high prevalence rates of symptoms of depression, anxiety, post-traumatic stress disorder (PTSD), internalized stigma, hopelessness, fear, or suicidality (9,10,12–14). Further, it is shown that these poor mental health outcomes are associated with increased incidence of risky behaviours, sub-optimal adherence to antiretroviral therapy

(ART) and low retention in care (RiC) – which, in turn, lead to viral load rebound and virologic failure (13,15,16).

WHO defines mental health as more than the absence of illness, but as "a state of well-being, in which an individual realizes his or her abilities, can cope with the normal stresses of life, can work productively and can make a contribution to his or her community" (17). However, mental health research, mental illness has predominantly been used as a euphemism for (or indicator of) mental health. This formulation of mental health excludes mental wellness, which is critical to the prevention of mental illness (or disorders) and the over-all promotion of positive mental health (18). In the case of adolescents living with a chronic condition (such as ALHIV), [positive] mental wellness is a critical buffer against developing mental health disorders and for self-management of their chronic condition.

To date, mental wellness concepts for adolescents, particularly ALHIV, are underdeveloped and lack robust measurement instruments to stimulate research on this topic. Studies on mental wellness have been done with adult populations and applied to adolescents (18–20). While research has shown some similarities between adolescents and adults, it should also be considered that adolescence is a unique developmental period characterized by rapid physiological and neurological growth and cognitive development (21,22) that occur within the social context of various transitions to adulthood. Therefore, more research is necessary to explore what mental wellness means for adolescents, especially those living with a chronic condition like HIV, to develop culturally and age-appropriate instruments that can be used to monitor and evaluate progress on improving their overall mental wellbeing. This review aims to conceptualise mental wellness among ALHIV in the African context and consider the critical components for measuring mental wellness [state and behaviour] in ALHIV (23). This integrative review forms part of a multi-phase study to develop an instrument to measure mental wellness among ALHIV.

Methods

The protocol describes the methods for this review in detail (23). The integrative review has been identified as a unique tool in healthcare for synthesizing theoretical and empirical evidence investigations available on a given topic or phenomena to provide a more comprehensive understanding of a certain healthcare problem or other phenomena. To accomplish this, various

methodologies may be utilized to fully capture the context, processes, and subjective elements of the topic under investigation (24). Therefore, integrative reviews can contribute to theory development and have practical applicability to informing policy and programmes (25). The existing body of literature on mental health among adolescents is varied and complex as there are many concepts associated with mental health research ranging from positive aspects such as 'resilience' and 'self-efficacy' to negative aspects such as 'depression' and 'anxiety'. As such, one study cannot capture all the dimensions associated with mental health. To provide a complete picture of the available literature and to thoroughly investigate the concept of mental wellness among adolescents generally and those living with a chronic condition such as HIV, we followed the integrative review steps proposed by Whittemore and Knafl (25): 1) problem identification; 2) literature search; 3) data evaluation; 4) data analysis: and 5) presentation of the integrative review guided by the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) guidelines (figure 1).

Problem identification

As described in the protocol (23), problem identification is a crucial step in an integrative review, and as such, this was treated as a phase in itself. From our initial reading of the literature, we have identified two recurring issues: firstly, there is a lack of validated mental health instruments for adolescents; and secondly, despite a growing body of research, the question of how mental wellness should be defined remains largely unresolved (19,26,27). To investigate this, we have proposed to follow two research questions to aid problem identification:

1) How is the concept of mental wellness defined in research involving adolescents?

2) What mental wellness indicators are being explored/investigated in research?

To answer the abovementioned questions, we systematically reviewed all instruments used to measure mental wellness in adolescents (28). The sub-analysis of instruments used among adolescents living with a chronic condition (29) revealed that Health-Related Quality of Life (HRQoL) instruments were frequently used to measure physical and psychosocial wellbeing among adolescents living with a physical chronic condition. However, these HRQoL instruments often include mental illness and mental wellness indicators which raises the question – to what

degree is the absence of mental disorder symptoms equal to a high degree of mental wellness? As such, we argued that more instruments need to be developed in LMICs to give insight into which constructs of mental wellness are important to improving overall mental wellbeing for adolescents living in these contexts (28,29). Though there was a lack of clear definition of mental health, we identified 13 mental wellness concepts from 79 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 (28).

To explore the relevance of these 13 concepts for ALHIV, we conducted a second-order analysis of qualitative data that emanated from a photovoice study exploring the experiences of ALHIV receiving ART at three public healthcare facilities in the Western Cape metropole of South Africa (30). The photovoice technique allowed participants to lead the narrative and express themselves creatively by photographing their experiences with cell phone cameras (30). As they spoke about their experiences, discussions about what mental wellness means to them emerged naturally. Through discourse analysis, we identified six themes that depicted mental wellness concepts that were prominent in their experiences: connectedness, spirituality and mindfulness, social coherence and awareness, self-esteem, self-acceptance, and sense of coherence. In addition, the adolescents gave accounts of six behaviours facilitating mental wellness, namely: self-efficacy, coping, resilience, life purpose, engagement in enjoyable life activities and physical functioning (30). The systematic review and photovoice study findings provided an initial framework of concepts and behaviours that informed our understanding of potential domains to include in developing a mental wellness instrument. However, as we explored each of these concepts further, we noted that traditional definition of several of the concepts were not clearly delimited and overlapped with one another. For example, the literature concepts like ‘self-esteem’, ‘self-worth’ and ‘self-acceptance’ are often not clearly distinguished from one another. To address this problem, we used the mental wellness concepts and behaviours identified in the systematic review and photovoice study and developed a search strategy for the integrative review to further investigate the meaning of these to aid in the conceptualisation of mental wellness among ALHIV.

Literature search

We systematically searched the following databases: Ebscohost (Psycharticles, Academic

Search Premier, SocIndex), Educational Resource Information Center (ERIC), Medical Literature Analysis Retrieval System Online (MEDLINE) and Sabinet. We performed multiple searches using each of the identified concepts: (connectedness OR social support OR belonging), (cope* OR coping*), (hope), (purpose in life OR meaning in life OR a sense of purpose), (physical functioning OR physical wellbeing), (resilience), (self-acceptance), (self-efficacy), (self-esteem), (sense of coherence), (spirit* OR mindful*) AND "((adolescen* OR teenage* OR young people OR youth) [AND] ("HIV OR living with HIV). The search was completed at the end of April 2022 and included all studies published up until that period.

Inclusion and exclusion criteria

The integrative review allows for an iterative process. Based on the findings from the previous studies, we adjusted the search from our original protocol, which aimed to include all adolescent populations to only focus on ALHIV (23). This review aims to identify mental wellness concepts that are significant to older ALHIV (aged 15- 19 years) to aid in the development of an instrument that can be used to measure the mental wellness of ALHIV living in South Africa.

Inclusion criteria:

- ALHIV (perinatally and behaviourally acquired) aged 10-19 years
- Studies based in the African context
- Clear focus on the identified mental wellness concept
- Qualitative, quantitative or mixed-methods studies

Exclusion criteria:

- Studies focusing on or including mental illness as a concept Studies that were not peer-reviewed

Table 8.1: PICOT-based inclusion criteria for literature review

Patient population	Adolescents living with HIV in the African context
Intervention or Interest	Definition or explanation of the identified mental wellness concepts and behaviour
Comparison	Not applicable
Outcomes	Mental wellness, psychological wellbeing, positive mental health
Time	Any time

Data evaluation

The screening and reporting of the review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline and checklist (figure 8.1). The number of hits for each search was recorded and exported to Endnote for review. The Mixed Methods Appraisal Tool (MMAT) was used to assess the methodological quality of the studies as it allows for summarising the overall quality across a range of study designs (31). This allowed us to ensure that all the included studies were of good quality. After finalizing the selection of included articles, we extracted the data into an excel sheet focusing on 1) Bibliometric data (authors, title, year, country), 2) population group (age and sample size), 3) study design (type of study, methods) and 4) outcome of interest (mental wellness concepts defined or measured in the article).

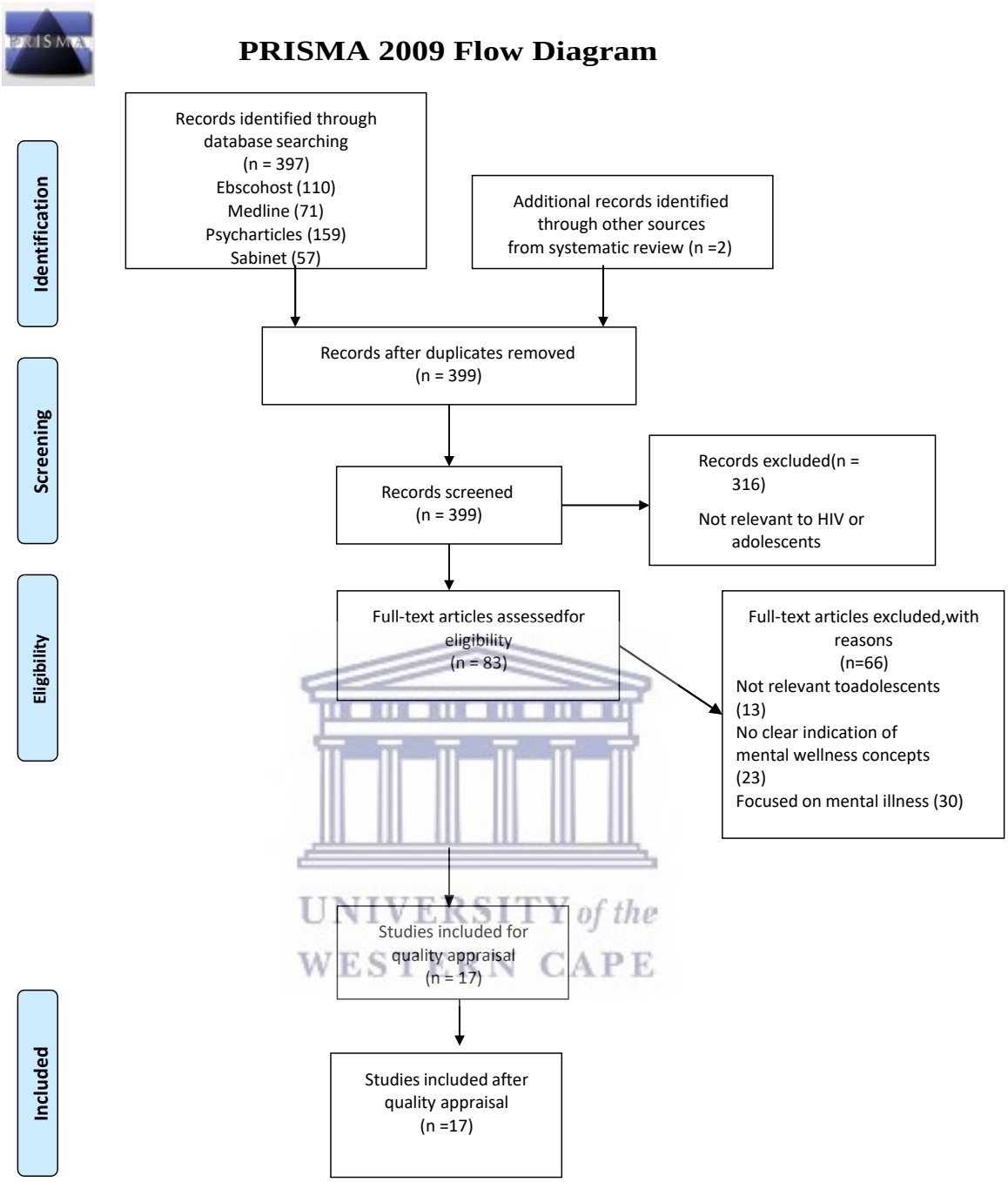

Figure 8.1: PRISMA Flow Diagram of Integrative Review

Data analysis

We extracted the relevant data and organized it in an excel sheet to prepare for the analysis. The data were analysed using a narrative framework analysis for qualitative and quantitative studies. Framework analysis involves engaging in a systematic process of data familiarisation and identifying a thematic framework to chart the data (32). Depending on the study and phenomena under investigation, an initial framework can either be borrowed from previous studies or developed from key concepts (25,32). As mentioned, our analytical framework was developed using the mental wellness concepts and behaviours identified from the systematic review (28) and photovoice data (30). We then applied the analytical framework by comparing and indexing the mental wellness concepts that were extracted from articles in the integrative review with the concepts in our framework (i.e., connectedness, coping, hope, purpose in life, physical functioning, resilience, self-acceptance, self-efficacy, self-esteem, sense of coherence, spirituality). Emerging concepts not represented in the initial framework were subsequently added to the list. Once all the concepts were presented in the updated analytical framework, we charted the data by defining each concept (as defined in the included studies) (Table 8.2).

Findings

The integrative review included 17 studies that focused on the mental wellness of ALHIV in the African context. The review included qualitative and quantitative studies with sample sizes ranging from 5-702. Most studies included in this review were conducted in South Africa (n=5) and Uganda (n=5). Most of the included studies used qualitative designs (n=12) (34–45), with only three quantitative (cross-sectional (45), longitudinal randomized clinical trial (46), secondary analysis (47)) and two mixed-methods study (48,49). This may indicate a lack of mental wellness instruments for ALHIV, or it may reflect the research trends focusing on measuring the prevalence of mental health problems in ALHIV (7,8,50).

From the included studies, we identified six mental wellness concepts: Connectedness, Sense of Coherence (SOC), Self-esteem, Self-acceptance, Hope for the Future and Spirituality, as well as six behaviours facilitating mental wellness: Coping, Resilience, Purpose in Life (goals), Self- efficacy, Adherence Self-efficacy, and Leisure Activities (Table 8.2). All these concepts and behaviours have been noted in our previous research (systematic review and qualitative work),

with the exception of adherence self-efficacy. However, as our focus for this review was on ALHIV, this finding is not surprising. Studies have shown that adherence self-efficacy plays an important role in maintaining adherence – ALHIV (behaviourally or perinatally infected) are in a stage where they gradually experience greater responsibility – including learning to manage their health. Therefore, having a high sense of adherence self-efficacy can ease their transition to adult clinical care.

Based on our research, we argue that the concepts mentioned above are significant indicators of mental wellness among ALHIV in the African context – however, Africa is a diverse continent, and ALHIV are not a heterogenous group. For example, the study by Adegoke and Stein (33) explores how resilience manifests among HIV-positive adolescent Yoruba girls. The findings from the study demonstrate how the Yoruba culture may enable resilience (through and emphasis on family ties and social cohesion) or constrain it through gender relations that often perpetuate gender inequalities which put adolescent girls (especially those living with HIV, at risk) (33). As many of the included studies are qualitative, we argue that the development of the mental wellness measure will facilitate research investigating these concepts among ALHIV in the African context to better understand the role and influence of culture on mental wellness.

Table 8.2 provides a definition of each concept followed by quotes from the included studies to illustrate how the particular mental wellness concept or behaviour is associated with improved mental wellness and/or physical health outcomes in ALHIV. Similar to the findings from our systematic review and qualitative work (28,30), the quotes confirm that mental wellness concepts and behaviours do not operate independently; rather, these are interconnected and work collaboratively to promote mental wellness. For example, the study by Dow et al. (51) focused on developing a mental health intervention for ALHIV in Tanzania to improve their resilience – to accomplish this, the intervention included resilience strategies to cope with stressful events, such as enabling and supporting strong familial and social relationships, addressing stigma (using cognitive behaviour therapy techniques to change negative thoughts to positive ones) and instilling hope for the future. According to Dow et al., the participants found the intervention to be highly acceptable and feasible and was associated with increased resilience among ALHIV. However, it is not clear from the study how mental health was measured – the authors mention that participants were given a pre-intervention questionnaire which included mental health, but this is not reported.

While the main aim of the mental health intervention was to improve resilience among ALHIV, the qualitative findings suggest that mechanisms used to trigger resilience were associated with improvements in other mental wellness outcomes such as connectedness (familial and social relationships), self-esteem and self-acceptance (stigma reduction) and hope for the future. As such, it is critical to utilise measures that can capture a range of associated mental wellness outcomes. Without appropriate instruments, it is impossible to draw conclusions about the efficacy of interventions aimed at improving mental wellness. Measures that assess various mental wellness concepts/behaviours in parallel are useful, as these provide precise indications regarding the relationship (pathways) between these concepts and behaviours. Furthermore, such measures may provide information regarding the contribution of each of these mental wellness concepts and behaviours in heterogenous populations of ALHIV, which can be critical in assessing interventions to improve treatment outcomes. This supports the need for integrated measures of mental wellness for ALHIV rather than instruments measuring single concepts/behaviours such as self-esteem.

Table 8.2: Mental wellness concepts and behaviours from the review

Mental wellness concept/behaviour	Definition or interpretation	Quotes from included studies	Citation
Connectedness	Sense that one has satisfying relationships with others, believing that one is cared for, loved, esteemed, and valued, and providing friendship or support to others	"It seems the combination of disclosure and social support gave the adolescents a unique group feeling, a feeling of belonging, which seemed to be some of the key factors in their development of self-esteem and coping with HIV" "In another study examining the benefits of family and social relationships for health and mental health of PLWH, family functioning significantly contributed to ART adherence and quality of life. Thus, strengthening positive family support and minimizing negative family interactions are crucial for increasing adherence rates" "Along with family members, peers who were also living with HIV featured prominently as a source of psychosocial support and friendship. Adolescents	(33,36,37,45,49) (38–40,46,47) (41,42,44)

		reported that through such peer connections, they could share coping strategies, make each other feel valued and offer each other a sense of identity"	
Coping	Coping refers to cognitive and behavioral efforts to manage (master, reduce, or tolerate) a troubled person-environment relationship	"At the interpersonal level, family and peer support emerged as key to assisting adolescents to cope" "Also at the individual level, a couple of adolescent respondents indicated how positive thinking and having goals for the future helped them to cope and suggested that instilling these in other children may be useful"	(9,33,38–40,49)
Self-acceptance	A positive attitude toward yourself; acknowledge and accept multiple aspects of yourself	"It has been suggested that peer support group therapy for HIV positive adolescents positively affects their acceptance and perception of their disease" "Although some adolescents reported that internalized	(35,38,43,44,52)

	including both good and bad qualities; and feel positive about your past life.	HIV stigma had affected their ability to engage socially, many of these adolescents said that they were able to accept their situation eventually, regain their self-esteem, and interact with their families and peers, which in turn strengthened their self-efficacy and resilience." "Being self-assured and accepting oneself were the basis of this self-esteem"	
Resilience	The ability to mentally withstand or adapt to uncertainty, challenges, and adversity.	"The most salient theme to emerge from the study in relation to individual-level factors that might influence adolescents' experience of living with HIV was their resilience, sometimes tempered by internalized stigma" "Features of resilience in this group were underscored by beliefs and character traits that enabled their ability to manage their adversity, as well as social behaviours that created the agency necessary for success"	(33,38,43,44,48)
Self-esteem	A person's overall subjective	"They are able to talk about their health with other HIV positive adolescents and it is also suggested that peer support groups enable the adolescents to develop good	(38,43,45,47)

	sense of personal worth or value	self-esteem" "Some of them reported that knowing their status was a strength to them, one boy stating that "*we have self-esteem because we know our status*""	
		*"*By disclosing their status to peers, the adolescents in my study showed that they were empowered and in a position to take their own decisions regarding who to disclose to and where to seek support. This indicates self-esteem and confidence"	
Hope for the future	Emotion characterized by positive feelings about the immediate or long-term future.	"Considering the participants in my study, most of them were thriving and managed to remain positive, even though they knew they had HIV and had to be on ART for the rest of their lives. Most of them had hopes and dreams for the future and had specific thoughts about what they wanted to do when they grew older" "Hope was identified as an important motivation for protection. Many hoped that if they continued to adhere	(33–35,37)

		to their treatment, they would be able to live long enough to finish school, get a good job, get married, and have their own children. Some hoped that finally a cure for HIV might be found."	
Spirituality	Psychological process of bringing one's attention to the internal and external experiences occurring in the present moment; concern for or sensitivity to things of the spirit or soul.	"Additionally, many reported that they trusted God and prayed for good health, wisdom, courage, strength and cure in future. As a result, they were more optimistic that all will be well with them in future" "A strong theme emerging from adolescent participants was the idea that their own belief systems set the stage for their ability to be resilient. Many participants demonstrated a belief in fate with a comfort in the conviction that one is on the path one should be"	(33,37,43)
Sense of Coherence	Degree of meaningfulness (motivational), comprehensibility	"HIV positive adolescents, who thrive in spite of difficult challenges, can be said to have a strong SOC and resources at hand that enable them to cope with the challenges or stressors present in their lives. The	(39,43)

	(cognitive), and manageability (behavioural) that people feel in their life	knowledge of what these resources are can be used to promote SOC, leading to increased quality of life and well-being for this group of adolescents." "In other words it can be said that disclosure was a main contributing GRR in enabling many of these adolescents develop and strengthen their SOC, which furthermore contributes to a movement towards health"	
Purpose in life (goals)	You have goals in life and a sense of directedness; feel there is meaning to your present and past life; hold beliefs that give life purpose; and have aims and objectives for living.	"Adolescents were motivated and had a sense of purpose. Some adolescents described carrying out an expanded range of duties, such as caring for their own children or younger siblings who were or were not living with HIV, with resilience, a deep sense of responsibility, hope for the future and optimism that eclipsed any sense of living with a chronic disease." "Importantly, these goals appeared to promote wellbeing by providing a sense of purpose and making them feel socially valued"	(36,39)

Self-efficacy	A person's particular set of beliefs that determine how well one can execute a plan of action in prospective situations. Self-efficacy is a person's belief in their ability to succeed in a particular situation.	"Observable ART adherence levels depend on a range of factors, including self-efficacy i.e. the person's perception of their own ability to accomplish a behavioral task, which influences a person's development or maintenance of a health behavior at the affective, cognitive and motivational levels" "In addition, many participants demonstrated self-reliance that was key to self-esteem: 'If you don't believe in yourself, who will?"	(38,45)
Leisure activities	Engaging and participating in activities that bring enjoyment	"Family, friends and leisure activities were also important positive factors that contributed to well-being" "Most of them also had leisure activities which they enjoyed, and some were very passionate about these	(39)

		activities, finding it a very important part of their lives" "Leisure activities such as sports and drama were also activities that some of the participants were very passionate about. As mentioned participation is connected to meaningfulness, which is the motivational component"	
Adherence Self-efficacy	Belief in one's ability to successfully adhere to treatment plans	"More specifically, adherence self-efficacy –defined as the confidence in one's ability to adhere to treatment plans, has been documented as an important predictor of medication adherence in the treatment of HIV and other medical conditions"	(45)

Towards a model of mental wellness

In this integrative review, we unpacked the meaning of mental wellness for ALHIV, with the express aim of informing the development of an appropriate research instrument to measure mental wellness for ALHIV. Therefore, our approach moves away from the traditional pathological inquiry of 'what causes mental illnesses to a salutogenic exploration of 'what promotes mental wellness'. As such, we turn our attention to SOC which emerged as a key concept in our research and is considered to represent 'the origins of health' from a salutogenic approach (53). SOC reflects the coping capacity of people to deal with everyday life stressors and consists of three elements: comprehensibility (cognitive – extent to which the problem/stressor is understood), manageability (behavioural – perceived availability of resources and belief in the ability to use successfully use them) and meaningfulness (motivational – extent that one wishes to cope) (53). SOC is a developmental concept which begins to form during adolescence and stabilizes by the age of 30 years (53–57). Therefore, from a life-course perspective, strengthening SOC as a health-promoting factor may improve overall physical and mental wellness in later life.

Antonovsky originally proposed SOC as the core concept of his Salutogenic Model of Health – aimed at explaining health's origins and describing how health can be promoted by focusing on wellness (53–57). The Salutogenic Model of Health was developed as an alternative to the pathological view of health/disease to improve health promotion by focusing on what makes people healthy. Unlike the pathological view, the salutogenic approach rejects the idea that homeostasis is a basic human condition; rather, it argues that disease, illness, and decline are the norm (53). From this perspective, all individuals experience daily life stressors which cause immediate tension – however, this tension may be resolved through effective coping and management strategies. Disease or illness occurs when the individual experiences long-term stress resulting from their inability to resolve the tension. As such, it is more constructive to focus on improving an individual's adaptability to daily life stressors to promote overall health and wellness (figure 8.2).

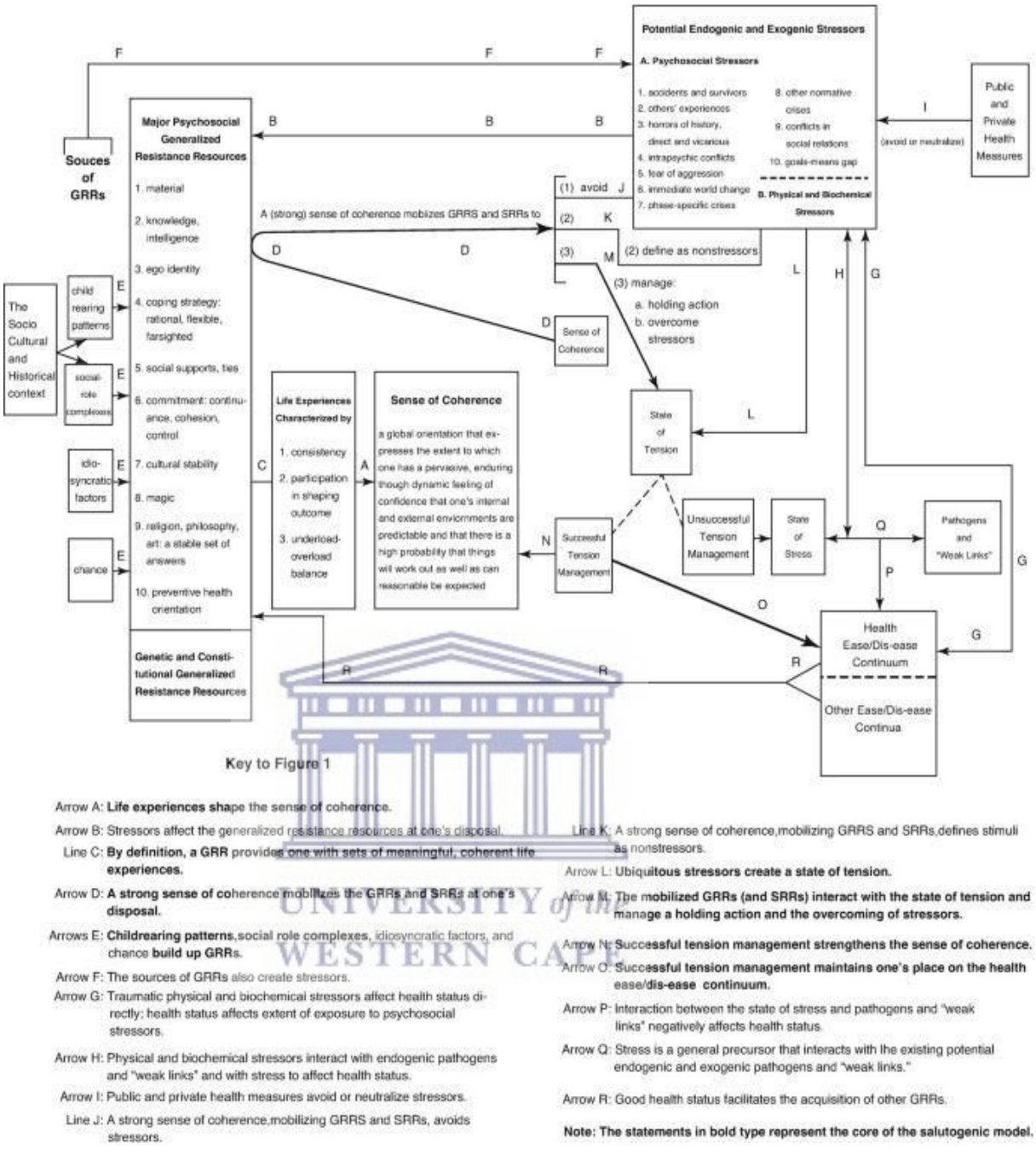

Figure 8.2: Antonovsky's Salutogenic model of health (53).

According to Antonovsky (53), the Salutogenic Model of Health represents a continuum model in which health is the result of continuous everyday life interactions between the individual, their experience of inevitable social, economic, cultural, psychosocial, and biological stressors, the availability of and access to health-promoting resources and their capabilities in identifying and

mobilise these resources to effectively overcome tensions resulting from stressors. Within this model, SOC reflects the individual capability to identify and mobilise resources, and the resources that promote health and facilitate coping with stressors are called Generalized Resistance Resources (GRRs), which can be genetic, material, constitutional and/or psychosocial resources (53). Based on this model, if an individual has a well-developed SOC and GRR, they are better able to identify SRRs and develop coping strategies to overcome specific challenges. For example, a study by Polhuis et al. (58) demonstrated how the Salutogenic Model of Health may be used to identify turning points and coping styles to help people with type 2 diabetes to adopt healthy eating habits.

In reviewing SOC and the Salutogenic Model of Health, we found it to be useful in illustrating the relationships and associations between the mental wellness concepts and behaviours identified in this review. As such, we propose an adapted Salutogenic Model of Mental Wellness (SMoMW) for ALHIV (figure 8.3) that may be used to develop an instrument to measure mental wellness among ALHIV (53,59). Like the Salutogenic Model of Health, the SMoMW views mental wellness along a continuum that may be influenced by individual interaction with everyday life stressors. As the model emphasises the role of context, it can be applied to adolescents in general or those living with a chronic condition like HIV. Within the SMoMW, the Life Situation represents the macro socio-cultural and historical context that shapes individual lived experiences. This macro context may serve to build up or detract GRRs – for example, for ALHIV, HIV knowledge acquisition is considered to be an important resistance resource (GRR). However, age (life situation) plays an important role in knowledge HIV acquisition – older ALHIV who have been disclosed to may learn more about how to effectively manage adherence than younger adolescents who have not been disclosed to. As such, younger ALHIV may experience different daily stressors than older ALHIV due to their lack of knowledge which could affect them negatively. On the other hand, stressors they experience from the lack of knowledge may be buffered by protective family relationships (connectedness) to help them manage their illness until they are old enough to be disclosed to. Similarly, as they grow older, adolescents are more likely to develop a stable Ego (self- acceptance, self-esteem etc.) which may help them process the availability of GRRs and their ability to successfully utilise them (53). Additionally, ALHIV life situations may also exacerbate or ease their exposure to and experience life stressors. For example, genetics may play a role in how an ALHIV experiences treatment fatigue or side effects (including

neurological effects from long-term use). Exposure to potential life course stressors and GRRs can influence how much an individual experiences life as coherent and meaningful. ALHIV who can utilise the GRRs available to them are more likely to experience consistency in their day-to-day lives (positive influence on adherence and development), balance responsibilities and leisure and be active participants in decisions which affect their lives. These life experiences shape SOC, reflecting the mental wellness concepts and behaviours identified in the review to promote mental wellness.

The SMoMW may be useful in developing a mental wellness measure for ALHIV. Not only does it emphasise the role of SOC and the associated concepts/behaviours as integral to mental wellness, but it also frames the dynamic interaction between SOC and health-promoting factors and stressors in relation to living with HIV over the life-course. Therefore, an instrument developed from the SMoMW may be beneficial as it would allow us to interrogate and explore the mental wellness needs of ALHIV as a heterogenous group with diverse demographic, social and clinical traits.

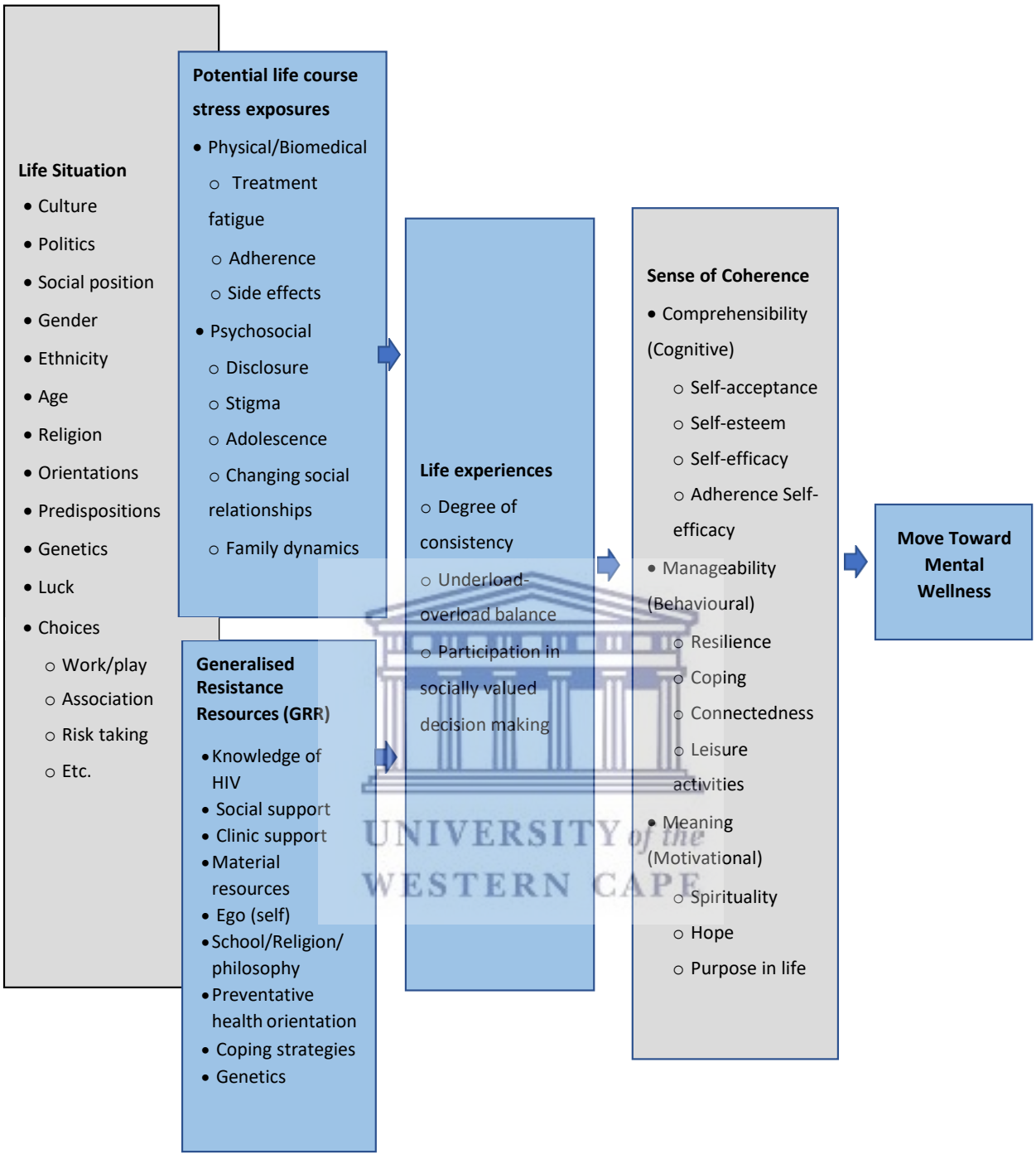

Figure 8.3: Salutogenic model of mental wellness for adolescents living with HIV

Strengths and limitations

To our knowledge, this is the first review aimed at identifying and defining mental wellness concepts and behaviours relevant to ALHIV in the African context. The integrative review method has been critiqued for its potential for bias and lack of rigour (25). However, a strength of this study is that the search strategy was developed through a rigorous process which involved a systematic review and a photovoice study which speaks to the validity of the concepts identified. However, we acknowledge that studies may have been omitted from the search due to access restrictions. Additionally, while we attempted to keep search terms as broad as possible, the lack of clear definitions of the included concepts may have resulted in articles being unintentionally omitted.

Conclusion

The findings from the integrative review highlight the mental wellness concepts and behaviours which are significant to ALHIV in the African context. Based on the findings from this review and our previous systematic review and qualitative work, we propose a Salutogenic Model of Mental Wellness for ALHIV that can be used to develop a mental wellness instrument. This instrument includes the following concepts: Connectedness, Self-esteem, Self-acceptance, Hope for the Future and Spirituality and behaviours: Coping, Resilience, Purpose in Life (goals), Self-efficacy, Adherence Self-efficacy, and Leisure Activities which are related to overall Sense of Coherence (SOC) to promote overall mental wellness. Such an instrument may be used to measure the impact of interventions aimed at measuring mental wellness among ALHIV. Additionally, the instrument may provide much-needed data on different mental wellness mechanisms that can help us to better understand the relationship between different mental wellness concepts and behaviours, the significance for diverse groups of ALHIV and how this work together to influence and support adherence behaviours.

References

1. World Health Organization. Mental health action plan 2013-2020. 2013. Available from: https://www.who.int/publications/i/item/9789241506021.
2. UNICEF. Measurement of Mental Health Among Adolescents at the Population Level (MMAP). 2019. Available from: https://data.unicef.org/resources/mmap-august-2019/.
3. World Health Organization. Enhancing mental health pre-service training with the mhGAP Intervention Guide: experiences and lessons learned. 2020. Available from: https://www.who.int/publications/i/item/9789240007666.
4. Bentley N, Hartley S, Bucci S. Systematic Review of Self-Report Measures of General Mental Health and Wellbeing in Adolescent Mental Health. Clin Child Fam Psychol. 2019; 22:225– 252. doi: 10.1007/s10567-018-00273-x.
5. World Health Organization. Health for the world's adolescents: A second chance in the second decade. 2014. Available from: https://apps.who.int/iris/handle/10665/112750.
6. World Health Organization. Adolescent mental health. 2020. Available from: https://www.who.int/news- room/fact-sheets/detail/adolescent-mental-health.
7. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc. 2017; 20: 21497. doi: 10.7448/IAS.20.4.21497.
8. Laurenzi C, Skeen S, Gordon S, et al. Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence. J Int AIDS Soc. 2020; 23:1-6. doi: 10.1002/jia2.25556.
9. Woollett N, Cluver L, Bandeira M, Brahmbhatt H. Identifying risks for mental health problems in HIV positive adolescents accessing HIV treatment in Johannesburg. J Child Adolesc Ment Health. 2017; 29(1):11–26. doi: 10.2989/17280583.2017.1283320.
10. Sherr L, Cluver LD, Toska E, et al. Differing psychological vulnerabilities among behaviourally and perinatally HIV infected adolescents in South Africa–implications for targeted health service provision. AIDS Care. 2018; 30: 92–101. doi: 10.1080/09540121.2018.1476664.
11. Dessauvagie AS, Jörns-Presentati A, Napp A-K, et al. The prevalence of mental health problems in sub-Saharan adolescents living with HIV: A systematic review. Global Mental Health. 2020;7: 1-13. doi: 10.1017/gmh.2020.18.
12. West N, Schwartz S, Mudavanhu M, Hanrahan C, France H, Nel J, et al. Mental health in

South African adolescents living with HIV. AIDS. 2019; 31(1):117–24. doi: 10.1080/09540121.2018.1533222.

13. Nguyen N, Lovero KL, Falcao J, et al. Mental health and ART adherence among adolescents living with HIV in Mozambique. AIDS Care. 2022: 1-9. doi: 10.1080/09540121.2022.2032574.
14. Okumu M, Nyoni T, Byansi W. Alleviating psychological distress and promoting mental wellbeing among adolescents living with HIV in sub-Saharan Africa, during and after COVID- 19. Global Public Health. 2021;16(6):964–73. https://doi.org/10.1080/17441692.2021.1912137
15. Hudelson C, Cluver L. Factors associated with adherence to antiretroviral therapy among adolescents living with HIV/AIDS in low- and middle-income countries: A systematic review. AIDS Care. 2015; 27(7):805–16. http://dx.doi.org/10.1080/09540121.2015.1011073.
16. Chory A, Callen G, Nyandiko W, Njoroge T, Ashimosi C, Aluoch J, et al. A pilot study of a mobile intervention to support mental health and adherence among adolescents living with HIV in Western Kenya. AIDS and Behavior. 2022; 26(1):232–42. doi: 10.1007/s10461-021- 03376-9.
17. World Health Organization. Mental health: strengthening our response. 2019. Available from: https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response.
18. Keyes CLM. Promoting and protecting mental health as flourishing. American Psychologist. 2005; 62(2):95–108. doi: 10.1037/0003-066X.62.2.95.
19. Roscoe LJ. Wellness: A review of theory and measurement for counselors. J Couns Dev. 2009; 87: 216–226. doi: 10.1002/j.1556-6678.2009.tb00570.x
20. Ahanonu EL, Jooste K. Adolescents' interpretation of the concept of wellness: A qualitative study. J Caring Sci. 2016; 5(4):337–45. doi: 10.15171/jcs.2016.035.
21. Lake L, Shung-King M, Hendricks M, Heywood M, Nannan N, Laubscher R, et al. Prioritising Child and Adolescent Health: A Human Rights Imperative. South African Child Gauge. Cape Town: University of Cape Town. 2019.
22. UNAIDS. Survive, thrive, transform: Global strategy for women's, children's and adolescents' health (2016-2030). 2016. Available from:

https://www.unaids.org/sites/default/files/media_asset/EWECGSMonitoringReport2018_en.pdf.

23. Orth, Z & van Wyk, B. (2022). Rethinking mental wellness among adolescents: An integrative review protocol of mental health components. Systematic Reviews, 11(83): 1-7. doi: 10.1186/s13643-022-01961-0.
24. Souza MT De, Carvalho R De. Integrative review: what is it? How to do it? (2010). Einstein. 8:102–7. https://doi.org/ 10.1590/S1679-45082010RW1134.
25. Whittemore R, Knafl K. (2005). The integrative review: Updated methodology. J Adv Nurs. 52(5):546–53. https://doi.org/10.1111/j.1365-2648.2005.03621.
26. Manwell LA, Barbic SP, Roberts K, Durisko Z, Lee C, Ware E, et al. (2015). What is mental health? Evidence towards a new definition from a mixed methods multidisciplinary international survey. BMJ Open.5(6):1–11. https://doi.org/ 10.1136/bmjopen-2014-007079
27. Manderscheid RW, Ryff CD, Freeman EJ, Mcknight-eily LR, Dhingra S, Strine TW. (2010). Evolving Definitions of Mental Illness and Wellness. Prev Chronic Dis. 7:5–10. http://www.cdc.gov/pcd/issues/2010/jan/09_0124.htm.
28. Orth Z, Moosajee F, van Wyk B. Measuring Mental Wellness of Adolescents: A systematic review of instruments. Front. Psychol. 2020; 13:1-14. doi: 10.3389/fpsyg.2022.835601.
29. Orth Z, van Wyk B. Measuring mental wellness among adolescents living with a physical chronic condition: A systematic review of the mental health and mental well-being instruments. BMC Psychology. 2021;9: 1-17. https://doi.org/10.1186/s40359-021-00680-w.
30. Orth Z, van Wyk B. A facility-based family support intervention to improve treatment outcomes for adolescents on antiretroviral therapy in the Cape Metropole, South Africa. J Int Assoc Provid AIDS Care. 2021; 20: 1-11. https://doi.org/10.1177/23259582211059289.
31. Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M, et al. The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. Education for Information. 2018;34(10):1-7. doi: 10.3233/EFI-180221.
32. Snilstveit B, Oliver S, Vojtkova M. Narrative approaches to systematic review and synthesis of evidence for international development policy and practice. J Dev Eff. 2012;

4:409–29. https://doi.org/10.1080/19439342.2012.710641.

33. Adegoke CO, Steyn MG. Yoruba culture and the resilience of HIV-positive adolescent girls in Nigeria. Cult Health Sex. 2018; 20(11):1287–98. https://doi.org/10.1080/13691058.2017.1422806.

34. Bakeera-Kitaka S, Colebunders R, Nöstlinger C, Musoke P. (2020). Exploring the health and wellbeing of adolescents living with HIV as they grow into adulthood: unique challenges in a low resource setting. [dissertation/master's thesis]. [Antwerp]. University of Antwerp

35. Bernays S, Seeley J, Rhodes T, Mupambireyi Z. (2015). What am I "living" with? Growing up with HIV in Uganda and Zimbabwe. Sociol Health and Illn. 37(2):270–83. doi: 10.1111/1467-9566.12189.

36. Govindasamy D, Ferrari G, Maruping K, Bodzo P, Mathews C, Seeley J. A qualitative enquiry into the meaning and experiences of wellbeing among young people living with and without HIV in KwaZulu-Natal, South Africa. Soc Sci Med. 2020; 258, 1-11. https://doi.org/10.1016/j.socscimed.2020.113103.

37. Kimera E, Vindevogel S, Kintu MJ, Rubaihayo J, de Maeyer J, Reynaert D, et al. Experiences and perceptions of youth living with HIV in Western Uganda on school attendance: Barriers and facilitators. BMC Public Health. 2020; 20(1), 1-12. https://doi.org/10.1186/s12889-020- 8198-7.

38. Mburu G, Ram M, Oxenham D, Haamujompa C, Iorpenda K, Ferguson L. Responding to adolescents living with HIV in Zambia: A social-ecological approach. Children and Youth Services Review. 2014; 45(C):9–17. https://doi.org/10.1016/j.childyouth.2014.03.033.

39. Midtbø V. Adolescents living with HIV in Botswana: What contributes to an HIV positive adolescent thriving? A qualitative study. [dissertation/master's thesis]. [Bergen]. University of Bergen, 2012.

40. Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. AIDS Care. 2010; 22(8): 970–978. https://doi.org/10.1080/09540121003623693.

41. Rencken CA, Harrison AD, Mtukushe B, Bergam S, Pather A, Sher R, et al. "Those people motivate and inspire me to take my treatment." Peer support for adolescents living with

HIV in Cape Town, South Africa. J Int Assoc Provid AIDS Care. 2021;20: 1-9. https://doi.org/10.1177/23259582211000525.

42. Shabalala F, de Lannoy A, Moyer E, Reis R. Rethinking the family in the context of care for adolescents living with HIV in Swaziland. AIDS Care. 2016; 28:8–17. https://doi-org.ezproxy.uwc.ac.za/10.1080/09540121.2016.1195482

43. Woollett N, Cluver L, Hatcher AM, Brahmbhatt H. "To be HIV positive is not the end of the world": Resilience among perinatally infected HIV positive adolescents in Johannesburg. Children and Youth Services Review. 2016; 70:269–75. https://doi.org/10.1016/j.childyouth.2016.09.039.

44. Zanoni BC, Sibaya T, Cairns C, Haberer JE. (2019). Barriers to retention in care overcome by adolescent-friendly services for adolescents living with HIV in South Africa: A qualitative analysis. AIDS and Behavior. 23(4):957–65. https://doi.org/10.1007/s10461-018-2352-6.

45. Gitahi N, Wahome S, Bukusi P, Memiah EA. The role of self-efficacy in HIV treatment adherence and its interaction with psychosocial factors among HIV positive adolescents in transition to adult care in Kenya. Vulnerable Children and Youth Studies. 2022; 17(4): 308-319. https://doi.org/10.1080/17450128.2021.1954736.

46. Nabunya P, Bahar OS, Chen B, Dvalishvili D, Damulira C, Ssewamala FM. The role of family factors in antiretroviral therapy (ART) adherence self-efficacy among HIV-infected adolescents in southern Uganda. BMC Public Health. 2020;20(1):1-9. doi: 10.1186/s12889-020-8361- 1.

47. Nöstlinger C, Bakeera-Kitaka S, Buyze J, Loos J, Buvé A. Factors influencing social self-disclosure among adolescents living with HIV in Eastern Africa. AIDS Care. 2015;27(1), 36–46. https://doi.org/10.1080/09540121.2015.1051501.

48. Kaunda-Khangamwa BN, Maposa I, Dambe R, Malisita K, Mtagalume E, Chigaru L, et al. Validating a child youth resilience measurement (CYRM-28) for adolescents living with HIV (ALHIV) in Urban Malawi. Front Psychol. 2020; 11:1–13. doi:10. 3389/ fpsyg. 2020. 01896.

49. Dow DE, Mmbaga BT, Turner EL, Gallis JA, Tabb ZJ, Cunningham CK, et al. Building resilience: a mental health intervention for Tanzanian youth living with HIV. AIDS Care. 2018; 30(4):12–20. doi: 10.1080/09540121.2018.1527008.

50. Kidia K, Ndhlovu C, Jombo S, Abas M, Makadzange AT. The mental health of HIV positive adolescents. Lancet Psychiatry. 2015; 2(6): 487–88. doi: 10.1016/S2215-0366(15)00101-7.

51. Dow D, Turner E, Shavo A, Mmbaga B, Cunningham C, O'Donnell K. Evaluating mental health and associated difficulties among HIV positive adolescents in Tanzania. AIDS Care. 2016;28(7):825–33. https://doi.org/10.1080/09540121.2016.1139043.

52. Lentoor AG, Asante KO, Govender K, Petersen I. Psychological functioning among vertically infected HIV-positive children and their primary caregivers. AIDS Care. 2016; 28(6):771–7. https://doi.org/10.1080/09540121.2015.1124979.

53. Mittelmark MB, Sagy S, Eriksson M, Bauer GF, Pelikan JM, Lindström B, et al. The Handbook of Salutogenesis. New York: Springer, 2017.

54. Hochwälder J. (2019). Sense of Coherence: Notes on some challenges for future research. SAGE Open. 9(2):1-8. https://doi-org.ezproxy.uwc.ac.za/10.1177/2158244019846687.

55. Carlén K, Suominen S, Lindmark U, Saarinen MM, Aromaa M, Rautava P, et al. Sense of coherence predicts adolescent mental health. J Affect Disord. 2020; 274: 1206–1210. https://doi.org/10.1016/j.jad.2020.04.023.

56. Braun-Lewensohn O, Idan O, Lindström B, et al. Salutogenesis: Sense of Coherence in Adolescence. In: Mittelmark MB, Sagy S, Eriksson M, et al., editors. The Handbook of Salutogenesis. New York: Springer, 2017.

57. Mjøsund, NH. A Salutogenic Mental Health Model: Flourishing as a Metaphor for Good Mental Health. In: Haugan, G., Eriksson, M. (eds) Health Promotion in Health Care – Vital Theories and Research. Cham: Springer, 2021.

58 Polhuis MM, Vaandrager L, Soedamah-Muthu, & Koelen MA. (2020). Salutogenic model of health to identify turning points and coping styles for eating practices in type 2 diabetes mellitus. Int J Equity Health. 2020;19(18):1-20. https://doi.org/10.1186/s12939-020-01194-4.

59. Benz C, Bull T, Mittelmark M, & Vaandrager L. (2014). Culture in salutogenesis: The scholarship of Aaron Antonovsky. Glob health promot. 2014;21(4):16–23. https://doi.org/10.1177/1757975914528550

SECTION IV: DEVELOPING THE INSTRUMENT

In this section, we present phase 3 of the study aimed to develop the items for each domain in the mental wellness measure and establish the content and face validity by engaging with the experts – those who have experience working in the field of instrument development, ALHIV and mental health, as well as ALHIV receiving treatment from public healthcare facilities in the Cape Metropole district of South Africa.

In **Chapter 9,** we briefly describe the item development strategy – referring to how the previous two phases informed the process. Once the items were developed, we drafted the first version of the Mental Wellness Measure for Adolescents Living with HIV (MWM-ALHIV), reviewed by participants in the Delphi Study and revised accordingly based on the group consensus.

Chapter 10 presents the findings from the cognitive interviews with ALHIV. Participants in this study received the revised MWM-ALHIV and were asked to answer the questions while engaging with the researcher in one-on-one interviews to establish if the participants understood the questions as intended. The MWM-ALHIV was revised according to the participant feedback, which enhanced the face and content validity.

Manuscript 8: Orth Z & van Wyk B. Content validation of a Mental Wellness Measuring instrument for Adolescents Living with HIV: A modified Delphi Study. Submitted to the *Journal of Adolescent Health* (under review)

Manuscript 9: Orth Z & van Wyk B. Asking the experts: Establishing the face validity of a Mental Wellness Measure for Adolescents Living with HIV through cognitive interviewing. Submitted (under review).

CHAPTER 9

Manuscript 8: Orth, Z & van Wyk, B. Content validation of a Mental Wellness Measuring instrument for Adolescents Living with HIV: A modified Delphi Study. Submitted to *Journal of Adolescent Health* (under review)

Abstract

A growing body of evidence suggests that improving the mental wellness of adolescents living with HIV (ALHIV) will also result in improved adherence to antiretroviral therapy (ART) and improve their general health and wellbeing as they age into adulthood. However, to develop effective strategies and interventions aimed at improving mental wellness, we require age and culturally appropriate instruments to build an evidence base. Currently, there is a lack of mental wellness measures developed for ALHIV, especially in the African context. To address this gap, we developed a measure of mental wellness following modified guidelines set out by DeVellis [1] and Boateng et al. as a guiding framework [2]; (1) Identifying the gap, (2) Setting the theoretical foundations and identify domains and (3); Instrument development and initial validation. For the first two steps, we conducted a systematic review, photovoice study and integrative review – which we briefly describe as the findings have been published. Following this, we describe the processes to develop the instrument and to establish content validity through a modified Delphi Study. Through this process, we were able to refine the instrument, which will be subject to further testing.

Background

The improved access and efficacy of anti-retroviral therapy (ART) and the scale-up of treatment programmes and differentiated services have resulted in various gains in the fight against HIV [3]. Along with advances in medical treatment, advocacy campaigns such as 'Undetectable =Untransmissible' (U+U) are changing the narrative around HIV as a deadly infectious disease to a chronic condition that can be managed through appropriate treatment and intervention [4]. However, despite these advances, rising challenges related to suboptimal adherence, poor retention in care and developing best practices in helping people to manage a lifelong condition ensure that HIV remains a major concern in many regions of the world [5]. This is particularly true of the Sub-Saharan African (SSA) region, as it experiences the highest burden of HIV globally and is home

to most of the world's adolescents [5].

Additionally, SSA houses most of the global population of adolescents living with HIV [6]. In 2019, approximately 1.7 million adolescents aged 10-19 were living with HIV globally, with a reported 85% of this population living in SSA [6]. Within this context, evidence suggests that ALHIV in SSA are disproportionally affected by HIV, which is evidenced in their lower achievement of the 95-95-95 HIV cascade and poorer health outcomes such as higher mortality rates, lower adherence rates and treatment failure and retention in care, in comparison to children and adults living with HIV [6]. This suggests ongoing gaps in the treatment cascade and lived experiences of ALHIV.

Improved understanding of the circumstances of ALHIV is critical in designing adolescent-friendly health services, which can aid in identifying ALHIV, their initiation to ART and adherence and retention in care [7]. Young people accessing ART face various complex challenges that are distinct from adults, which negatively impact adherence to treatment [8, 9]. Studies exploring barriers and facilitators to optimal adherence in adolescents have identified many factors that span different levels, including the individual level, the family, peers, the health care system and the wider community [7, 10, 11]. Amongst these, [lack of] psychosocial support and mental health problems have been identified as negatively affecting adolescent adherence and retention in care [12–15]. Recently, there has been an increased focus on improving adolescent mental health as evidence suggests that mental wellness [positive mental health] is a critical foundation for overall health and well-being across the life course [16, 17]. Within this context, early intervention is critical given that the peak age of onset for most mental health disorders occur during adolescence [18]. In South Africa, mental health among adolescents is seemingly in crisis as the South African Depression and Anxiety Group (SADAG) reports that prevalence rates of anxiety and depression are high among youth, and suicide is identified as one of the leading causes of death in this group [19]. For example, a study conducted in the Western Cape reported high prevalence rates of depression (41%), anxiety (16%) and post-traumatic stress disorder (PTSD) (21%) among school learners aged 14-15 years [20]. These numbers are concerning as evidence suggests that ALHIV are at greater risk of developing mental health problems than their peers due to the nature of their illness and the challenges associated with managing a stigmatized chronic condition. For example, a study conducted by Kim et al. [21] reported that being bullied for taking

HIV medications was associated with depressive symptoms among Malawian adolescents, a reported barrier to adherence. Conversely, studies have shown that improving mental wellness outcomes in ALHIV may also result in improved physical health outcomes, such as greater adherence and retention in care [22, 23]. Ultimately, mental wellness (positive mental health) is a resilience resource that protects against both physical and mental illness. Tailored treatment programmes are needed to support the mental health needs of ALHIV for improved treatment outcomes

Addressing mental health among ALHIV is challenging due significant mental health treatment gap. Therefore, there is a need to invest in research to better understand pathways to improve mental wellness among ALHIV to prevent the development of mental health problems or co-morbid mental disorders and to support optimal adherence across the life course. There is an increasing body of research on the behavioural and psychosocial outcomes of ALHIV. However, these studies rarely report on mental health outcomes specifically and tend to focus on treatment outcomes [24]. The lack of data on the effectiveness of psychosocial interventions to improve mental wellness among ALHIV is concerning as it impedes our ability to make evidence-based decisions to support optimal treatment outcomes for ALHIV. To this end, we set out to develop and validate a measure of mental wellness specifically for ALHIV.

Methods

In this section, we describe the methods related to the scale construction and initial face and construct validation of the Mental Wellness Measure for Adolescents Living with HIV (MWM-ALHIV). Various scholars have proposed guidelines for scale development which include similar steps. We followed a modified version of guidelines in scale development proposed by DeVellis [1] and Boateng et al. [2], (1) Identify the gap, (2) Set theoretical foundations and identify the domains, (3) Item development and initial validation.

Identifying the gap

Before developing a new instrument, it is necessary to determine if one is needed or if existing instruments may be used [1, 2]. To this end, we conducted a systematic review of mental health instruments used in research with adolescents [25, 26]. A key finding from the systematic

review highlighted a lack of consensus around definitions of mental wellness for adolescents. This finding reflects mental health literature stating that concepts such as ‘mental health’, ‘mental well-being’ and ‘mental wellness' are often used interchangeably or as a euphemism or synonym for ‘mental illness’ [27, 28]. This may represent a problem in measurement as mental illness and mental wellness are conceptually different. Additionally, many of the instruments identified in the review were developed in high-income countries with adult populations and subsequently validated in other contexts. This is a common strategy in research, as developing a new measure is time-consuming [29]. However, it may be that the items in these measures are not appropriate for adolescents, much less for adolescents living in markedly different contexts [29]. For example, while there may be similarities in adult and adolescent mental health, we need to consider that adolescents are not a homogenous group, and their constructions of mental health or the processes and experiences that influence their mental health are different [25, 26, 29]. Therefore, if we only focus on adapting and validating existing measures, we may miss opportunities to fully understand what mental health means for adolescents.

The systematic review provided us with an overview of mental health (focusing on symptoms of mental illness) and mental wellness instruments used for adolescents living with a physical chronic condition [25], and mental wellness instruments used with adolescents in general [26]. However, the findings from the review indicated that few measures were developed specifically for adolescents with chronic conditions, which may present a gap in the research.

We reviewed the included instruments to identify the content domains of mental wellness. The instruments we identified varied from measures of general mental wellness, which included multiple domains such as connectedness, self-esteem, spirituality etc., to instruments measuring specific domains of mental wellness. Additionally, we noted that instruments of HRQoL and QoL were used to measure mental wellness in research with adolescents living with a chronic condition.

Setting the theoretical foundations and identifying the domains

How a construct is defined determines how it will be measured [27, 28, 30]. Therefore, to develop an effective measure of mental wellness, we need to clearly understand the theoretical and operational definitions of mental wellness [27, 28, 30]. The systematic review findings helped us build a preliminary framework of mental wellness domains measured in research with adolescents.

To test the relevance of these domains, we conducted an exploratory photovoice study with ALHIV. The photovoice study allowed us to explore how ALHIV understand and talks about mental wellness in the South African context and included the perspectives of key healthcare workers working closely with ALHIV. We used the findings from these studies to refine the preliminary framework of mental wellness. To further unpack the mental wellness concepts, we used the framework to guide an integrative review of mental wellness concepts identified in research with ALHIV in the African context. This aided in the conceptualisation of mental wellness as a construct and delineated the relevant domains to be measured.

Based on the findings from these three studies, we identified six mental wellness concepts: Connectedness, Sense of Coherence (SOC), Self-esteem, Self-acceptance, Hope for the Future, and Spirituality, as well as six behaviours facilitating mental wellness: Coping, Resilience, Purpose in Life (goals), Self-efficacy, Adherence Self-efficacy, and Leisure Activities representing 12 proposed domains of mental wellness. Thus, we proposed a Salutogenic Model of Mental Wellness (SMoMW), modified from Antonovsky's Salutogenic Model of Health [31].

Instrument development and initial validation

Generating an initial pool of items

Once we were satisfied that data saturation had been reached and no new mental wellness concepts were identified following the systematic review, photovoice study and integrative review, we proceeded to the item writing phase. Based on the Salutogenic Model of Mental wellness, the proposed instrument consisted of SOC as an indicator of overall mental wellness measured across 11 sub-domains: Connectedness, Self-esteem, Self-acceptance, Hope for the Future and Spirituality, Coping, Resilience, Purpose in Life (goals), Self-efficacy, Adherence Self-efficacy, and Leisure Activities. To ensure that the content reflected the construct of interest, we noted an operational definition for each sub-domain and then began by generating an initial pool of items by drawing on the instruments already identified from the systematic review. As the items in these instruments were developed with samples of English-speaking adolescents from the Global North, we adapted the phrasing to better reflect the context and comprehension level of ALHIV in South Africa, who may speak English as a second additional language.

Additionally, we used the findings from the photovoice study to write items for each sub-domain that specifically relate to the context of HIV. According to Foxcroft and Roodt [32], provision should be made to include many more items in the initial item writing phase, as at least one-third of items are usually discarded following the piloting and testing phase. Generally, they propose to include double the number of items required for the final version, while DeVellis recommends that the initial pool be at least three to four times as large as the final scale to ensure that internal consistency is increased [1, 32]. To generate the initial pool of instruments, we used the guidelines by DeVellis [1] and the systematic review to establish a baseline of how many items needed to be developed. In the systematic review, the average scale lengths of the instruments ranged between 5-90 items. For the final measure, it is recommended that at least five items per domain should be included [1, 32]. Based on these recommendations, we decided that the final range of items included in the MWM-ALHIV would range between 60-110 [1, 32]. Therefore, for the initial pool of items, we aimed to include 10-15 items per domain, which ranged from 120-180 items across the 11 domains.

Structural decisions

We initially proposed a 5-point Likert scale as this is a widely used instrument to measure attitudes, opinions and beliefs [1, 32]. Furthermore, the Likert scale was deemed an appropriate choice as the MWM-ALHIV is a self-administered screening instrument allowing for initial evaluation and scoring of mental wellness across the different sub-domains. Additionally, this is considered an appropriate measurement type, as our goal is not to provide a clinical diagnosis of mental health problems but rather a general assessment of positive mental wellness 'strengths' which can be reinforced (through intervention programs, workshops etc.) to buffer against the development of mental health problems.

Therefore, this screening tool will allow us to categorise participants into groups (e.g. ALHIV with high mental wellness or ALHIV with low mental wellness) with reasonable accuracy and can provide information on how mental wellness is related to maintaining adherence to ART (i.e. are participants with higher mental wellness scores demonstrating adherence?) or may provide an indication of which domains of mental wellness need intervention (i.e. participants may score high in one domain and low in another). Screening instruments are considered advantageous as

they can be easily administered promptly and cost-effectively. Furthermore, the results from screening instruments are immediately available and easy to score and interpret – as such, they may be used by a variety of professionals, including health care workers, counsellors, school staff, paraprofessionals, and trained volunteers

Target group

The MWM-ALHIV is intended for older ALHIV aged 14-19 years old.

Development of the stimulus document

The information for the proposed MWM-ALHIV was drafted into a stimulus document to be reviewed by experts in the field (step 3). The stimulus document included two sections – the first presented information about the definitions of the domains, the aim of the measure, the measure type and other technical aspects. The second section provided information about the actual instrument and listed the proposed items under each domain. Participants were prompted to give qualitative feedback on each section in the document and select items they thought were the most relevant. Additionally, participants were prompted to provide feedback or suggest any changes to the items.

Expert review of items

Involving experts in the field and service users in the instrument development process is crucial to maximizing the content validity and establishing the usability of the instrument [29, 33]. Therefore, we invited a group of experts in the fields of HIV, adolescent mental health, and instrument development to participate in a modified Delphi study and provide feedback on the proposed instrument through the stimulus document. Additionally, after the completion of the Delphi Study, we aim to conduct Cognitive Interviews with another group of experts, namely, ALHIV, aged 14-19, for whom the instrument is intended.

Delphi study participants and procedures

Through snowball sampling, 20 experts were contacted and invited to participate in the Delphi Study. Each participant was contacted via email and received an information sheet and consent form. Those who indicated that they would be able to participate were asked to send back

the signed consent form and then received the stimulus document, a demographic questionnaire to capture the descriptive characteristics of the participants. Participants were asked to provide feedback within two weeks of receiving the document. Of the 20 invitations we sent out, 15 consented to participate in the study and 11 returned the stimulus document with their feedback in the 1st round. The responses from the 11 participants were captured in an excel sheet and analyzed to adjust the stimulus document for the second round. In the second round, the 11 participants received the updated stimulus document to provide feedback. After two weeks, 5 participants responded with feedback for the 2nd round. We sent a follow-up email to those who did not respond – after which three more participants responded, and three were counted as non-response. Therefore, a total of 8 participants responded to the second round.

Data analysis

For the 1st round of the Delphi Study, a consensus was defined as ≥ 70% (N=8), and in the second round, it was defined as ≥ 50% (N=4), which is considered appropriate [34]. As mentioned, we aim to further test the validity of the items through cognitive interviews with ALHIV in the next phase of the study.

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). All participants received an information sheet and consent forms, which were signed and returned before participating in the study.

Results

In the first round of the Delphi study, 11 (73%) of invitees completed the survey. Of the 11 participants, 8 (72%) completed the second survey round. The characteristics of the participants are presented in Table 9.1.

Table 9.1: Demographic characteristics of Delphi participants

Demographics	Round 1 (n=11)	Round 2 (n=8)
Qualification		
PhD	8	6
MD	1	
Psy.D. Clin Psy	2	2
Years of experience		
1-10	3	1
>10	8	7
Areas of expertise		
HIV	5	4
Adolescent health	4	2
Adolescent mental health	5	3
Epidemiology & statistics	1	1
Instrument design	7	5
Sectors		
Academic/Higher education	10	6
Medical centre/health facility	4	4
Private sector	2	2
NGO	3	2
Current profession		
Clinician	1	1
Researcher	7	5
Lecturer/Prof	4	3
Mental health specialist/Clinical Psychologist	3	3

In Table 9.2, we provide a summary of the agreement in the 1st section of the stimulus document. As shown in the table below, most participants agreed with the definition in the 1st round – however, some of the participants provided suggestions to improve the clarity of the

domain definitions or other technical aspects of the instrument. These suggestions were used to edit the stimulus document accordingly. In the first round, participants indicated that a Likert-scale was appropriate. However, there was some disagreement regarding the number of responses on the scale. Based on the suggestions, we proposed a 4-point Likers-scale in the second round, which all the participants agreed with. The second round indicates overall improvement as almost all participants endorsed the changes – except for two minor comments for the definitions of self-efficacy and coping. After the second round, a consensus for all stimulus prompts was reached. Therefore, it was determined that a third round would not be needed.

Table 9.2: Summary of qualitative feedback

Statements relating to the purpose and aim of the instrument	**Round 1 (N=11)**		**Round 2 (N=8)**	
	Yes	Suggest changes	Yes	Suggest changes
Is the definition of self-acceptance clearly stated?	7 (64%)	4 (36%)	8 (100%)	0
Is the definition of self-esteem clearly stated?	7 (64%)	4 (36%)	8 (100%)	0
Is the definition of self-efficacy clearly stated?	8 (73%)	3 (27%)	7 (88%)	1 (12%)
Is the definition of adherence self-efficacy clearly stated?	9 (82%)	2 (18%)	8 (100%)	0
Is the definition of resilience clearly stated?	9 (82%)	2 (18%)	8 (100%)	0
Is the definition of coping clearly stated?	8 (73%)	3 (27%)	7 (88%)	1 (12%)
Is the definition of connectedness clearly stated?	9 (82%)	2 (18%)	8 (100%)	0
Is the definition of leisure activities clearly stated?	7 (64%)	4 (36%)	8 (100%)	0
Is the definition of spirituality clearly stated?	8 (73%)	3 (27%)	8 (100%)	0
Is the definition of hope clearly stated?	9 (82%)	2	8 (100%)	0
Is the definition of purpose in life clearly stated?	8 (73%)	3 (27%)	8 (100%)	0
Is the aim of the measure clearly stated?	9 (82%)	2 (18%)	8 (100%)	0

Statements relating to the purpose and aim of the instrument	Round 1 (N=11)		Round 2 (N=8)	
Is the purpose of the instrument clear?	10 (91%)	1 (9%)	8 (100%)	0
Is the type of instrument appropriate?	9 (82%)	2 (18%)	8 (100%)	0
Is the type of item (5-point Likert type) an appropriate choice for the screening instrument?	4 (36%)	7 (64%)	8 (100%)	0
Is the user group clearly defined?	7 (64%)	4 (36%)	8 (100%)	0
Is the target population clearly stated?	10 (91%)	1 (9%)	8 (100%)	0

In Table 9.3, we provide an overview of changes to the number of items after each round of the Delphi Study. In both rounds, items which did not reach consensus were discarded. As shown in the table, some domains had fewer items in the second round, while others had more items.

This was due to the qualitative feedback and suggestions given by the participants during the first round, which we included in the second round. After the second round, all items that received ≥ 50% consensus were retained as the final version of the instrument.

Table 9.3: Summary of item changes after each round

Domains	Number of items in each domain		
	Round 1 (N=11)	Round 2 (N=8)	A final list of items
Self-acceptance	23	17	10
Self-esteem	11	14	9
Self-efficacy	10	10	9
Adherence self-efficacy	12	15	13
Resilience	26	20	10
Coping	33	25	10
Connectedness	41	31	10
Leisure activities	16	10	10

Domains	Number of items in each domain		
	Round 1 (N=11)	**Round 2 (N=8)**	**A final list of items**
Spirituality	13	9	7
Hope	41	28	14
Purpose in life	13	13	11
	*consensus ≥70%	*consensus ≥50%	

Table 9.4 presents the final instrument and items under each domain. This version of the instrument will be used to conduct cognitive iinterviews with ALHIV receiving treatment at a public healthcare facility in the Cape Town Metropole to ensure that the participants understand the questioning and phrases as intended

Table 9.4: Final instrument after Delphi Study

Domains	Final Items
Self-acceptance	When I fail at something important to me, I remind myself that it is part of being human
	I'm kind to myself.
	Even when I am bad at something, I still love myself.
	When something upsets me, it does not change how I feel about myself
	I am a valuable person, even if there are parts of myself that I do not like.
	I am happy with the way I am
	I feel I am a valuable person even when other people don't like me.
	I am comfortable with who I am as a person
	Living with HIV does not define who I am
	Living with HIV is part of who I am, and I am okay with that
Self-esteem	I feel good about myself.
	There are many things that I like about myself.
	I am proud of myself
	I can do things as well as other people my age.
	I do not have much to be proud of.
	I feel that I'm just as worthy as other people my age
	I wish I could like myself.
	I take a positive attitude toward myself.
	When I think about living with HIV, I feel bad about myself
Self-efficacy	I can do most things if I try

	There are many things that I do well
	I know my strengths
	Living with HIV has not affected my ability to do what I want in life
	I feel strong
	I have many talents
	There are many things I cannot do because I am living with HIV
	I don't try new things because I am scared, I will fail
	I doubt myself
Adherence self-efficacy	Taking my treatment is part of my daily routine
	I find ways to take my treatment every day, even when I am around people who don't know that I am living with HIV
	I take my treatment every day even when there are changes in my daily routine (example travelling)
	I take my treatment every day even when I don't feel well.
	I take my treatment every day even when my eating habits have changed.
	I take my treatment every day even when it gets in the way of my daily activities
	I take my treatment every day even when I am having a bad day
	I take my treatment every day even when I have problems going to the clinic.
	I take my treatment every day even when people close to me tell me not to
	I take my treatment every day even when I feel like people will judge me
	I am confident that I can manage my treatment
	I try to attend all my clinic appointments even when I have problems going to the clinic
	I do other things to try and stay healthy (e.g., eat healthy foods, drink water, exercise)

Resilience	I can work out my problems without hurting myself or others (for example by using drugs and/or being violent).
	I know where to go in my community to get help
	I do things at school that make a positive difference (i.e., make things better)
	I do things at home that make a positive difference (i.e., make things better)
	I know where to go for help when I have problems
	In general, I feel I am in control of my life
	For me, life is about learning, changing, and growing despite my circumstances
	I am confident that I can overcome the challenges in life
	Living with HIV does not stop me from accomplishing what I want in life
	When life is challenging, I give up
Coping	I try to work out problems by talking about them
	I think it is important to have new experiences that challenge how you think about yourself and the world
	I am good at managing my responsibilities.
	When I have problems, I think about different solutions to solve the problem
	When I have problems, I take action to solve it
	I try to avoid difficult situations as much as possible
	When I think of living with HIV, I remind myself that there are others who are like me
	I ask others for help when I need it
	When I feel sad or when something is bothering me, I try to think of something else
	When I feel sad, or when something is bothering me, I do activities I enjoy (e.g., playing games, listening to music, reading etc).

Connectedness	I talk to my family/caregiver(s) about how I feel
	My family has fun together
	I feel close to my sibling(s) or other family member(s) (leave blank if you have none)
	I feel comfortable around my family
	Someone in my family accepts me for who I am
	I have friends I'm really close to and trust
	I feel like I belong in my community
	My family stands by me during difficult times
	I feel supported by the clinic/hospital staff
	I feel all alone in the world
Leisure activities	I am able to do the activities I enjoy most
	I have enough time for myself
	I am able to do the things I want to do in my free time
	My daily life has been filled with things that interest me
	My daily activities often seem boring and unimportant to me.
	When I do an activity, I enjoy it so much that I lose track of time.
	I get so involved in activities I enjoy that I forget about everything else.
	It is important to me that I feel satisfied by the activities that I take part in.
	Living with HIV has not stopped me from doing the things I like
	I have no energy to do the things I like
Spirituality	When I feel lost, I look to my religious leader/elders/culture for help.
	My faith or spiritual beliefs are a source of strength for me

	I participate in organized religious activities
	I feel a sense of peace within myself
	I find comfort in my faith or spiritual beliefs
	I find strength in my faith or spiritual beliefs
	Living with HIV has strengthened my faith or spiritual beliefs
Hope	I will accomplish what I want to do in my life
	I will find good work
	I will find work I enjoy
	When I grow up, I will have a good family life
	When I grow up, I will have the life I want
	I will have good health
	I will have a long life
	I will be able to provide for myself
	I will be able to provide for my family
	I am optimistic about my future.
	I think that good things are going to happen to me.
	I believe that things will work out
	I am living with HIV, and I have a bright future
	Living with HIV will not stop me from achieving my goals
Purpose in life	Getting an education is important to me
	I think it is important to help out in my community
	I have goals and plans for the future

I feel a sense of purpose in my life

I have a reason for living

I enjoy making plans for the future and working to make them a come true

I have a sense of direction in life.

I can say that I have found what I want to do in life

I am learning more about myself and who I want to be

I struggle to think of what I want in life

I have no goals or aims

Discussion

There is a growing recognition of the importance of mental wellness and health promotion to improve overall health and wellbeing [28, 35]. For example, the importance of this issue is evidenced in the Sustainable Development Goal (SDG) agenda, indicating that mental health (wellness) promotion is essential to reduce the rate of premature deaths [36]. This is especially salient among ALHIV as evidence suggests that interventions aimed at improving their mental wellness are associated with improved rates of adherence to ART and retention in care [23, 37, 38]. Measurement is an essential part of the process – if we cannot effectively measure a social construct such as mental wellness, we will not be able to develop appropriate responses or strategies to improve and strengthen mental health promotion.

According to Krause [29] and DeVellis [1], researchers tend to focus on the technical aspects of instrument development or how data is analyzed while overlooking the importance of being well-grounded in the theories or conceptualization of the phenomena being measured. Through using multiple methods, such as reviews and photovoice studies, we were able to conceptualise and operationally define mental wellness among ALHIV. As noted in the literature, developing a new measure following this strategy is time-consuming. However, it was well worth it as it allowed us to identify which domains of mental wellness are most relevant for ALHIV in the South African context and to develop a tentative theoretical model of mental wellness to guide the development of the instrument.

Through the modified Delphi Study, we were able to engage with a range of academic and clinical experts to provide valuable feedback on the proposed instrument, which helped us to adjust the type of scale to be more user-friendly to adolescents and to refine the list of items which would be most appropriate for ALHIV in the South African context. Therefore, the Delphi Study helped to establish the initial content validity of the mental wellness measure for ALHIV. This information will prepare us to engage with the next round of experts – ALHIV, for whom this instrument is intended.

The MWM-ALHIV includes both eudemonic and hedonic dimensions of mental wellness. Previous scholars have argued that there is a need for empirical studies that go beyond life satisfaction and well-being in adolescents to include both eudemonic and hedonic

dimensions of mental wellness, explore the relationship between these dimensions and how this can be integrated into a meaningful framework to address mental wellness in a holistic manner [39–41]. Therefore, we argue that the measure's strength is that it can be used in further empirical investigation and build an evidence based on mental wellness (including both eudemonic and hedonic dimensions) among ALHIV in the South African context.

Conclusion

Interventions and mental health services aimed at improving mental wellness among ALHIV are more effective when tailored to this population's unique mental wellness needs. However, appropriate instruments are needed to provide an evidence base to guide the implementation, monitoring, and evaluation of services and interventions for ALHIV. We present the MWM-ALHIV, developed for ALHIV in the South African context. This paper underlines the importance of expert opinion in determining the acceptability of the instrument and aided in improving the overall content validity of the MWM-ALHIV. In the following stages of this research, we will advance the content and face validity of the measure by engaging with a sample of ALHIV using cognitive interview techniques. Once the foundations of sound content and validity have been established, we aim to pilot the MWM-ALHIV to establish further psychometric properties. Following this, the MWM-ALHIV can be used in clinical and research settings as a general measure to screen mental wellness among ALHIV as an indicator of overall wellbeing and to identify challenges to their mental wellness. Addressing these challenges early on can be beneficial in preventing the development of co-morbid mental health disorders.

Further, the instrument may be used to screen mental wellness among ALHIV and investigate its relationship to adherence to ART – (i.e., current research suggests that poor mental health outcomes are associated with poorer adherence. More research is needed to understand how mental wellness (positive mental health) can improve adherence) – to provide further information on how or which mental wellness indicators among ALHIV may act as a buffer against mental health problems.

References

[1] DeVellis, RF. Scale development: Theory and applications 4th ed. Thousand Oaks, CA: Sage Publications Inc, 2016.

[2] Boateng GO, Neilands TB, Frongillo EA, et al. Best practices for developing and validating scales for health, social, and behavioral research: A primer. Front Public Health 2018; 6: 1-18. doi: 10.3389/fpubh.2018.00149.

[3] UNICEF. HIV and AIDS in Adolescents. 2021. Available from: https://data.unicef.org/topic/hiv-aids/.

[4] UNAIDS. Eastern Cape becomes the first South Africa province to campaign on U = U. 2022. Available from: https://www.unaids.org/en/resources/presscentre/featurestories/2022/march/20220321_eastern- cape-u- u#:~:text=The%20Eastern%20Cape%20has%20become, maintain%20an%20undetectable%20vir al%20load.

[5] UNAIDS. Dangerous inequalities: World AIDS day report. 2022. Available from: https://www.unaids.org/sites/default/files/media_asset/dangerous inequalities_en.pdf

[6] UNAIDS. AIDSinfo. 2022. Available from: https://aidsinfo.unaids.org.

[7] Zanoni BC, Sibaya T, Cairns C, et al. Barriers to retention in care are overcome by adolescent- friendly services for adolescents living with HIV in South Africa: A qualitative analysis. AIDS Behav. 2019; 23: 957–965. doi: 10.1007/s10461-018-2352-6

[86] Nachega JB, Hislop M, Nguyen H, et al. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in Southern Africa. J Acquir Immune Defic Syndr. 2009; 51: 65–71. doi: 10.1097/QAI.0b013e318199072e.

[8] Jobanputra K, Parker LA, Azih C, et al. Factors associated with virological failure and suppression after enhanced adherence counselling in children, adolescents and adults on antiretroviral therapy for HIV in Swaziland. PLoS One. 2015; 450: 1–12. doi: 0.1371/journal.pone.0116144.

[9] Biadgilign S, Deribew A, Amberbir A, Deribe K. Barriers and facilitators to antiretroviral medication adherence among HIV-infected paediatric patients in Ethiopia: A qualitative study. SAHARA J. 2009;6(4):148-154. doi:10.1080/17290376.2009.9724943

[10] Mesic A, Halim N, MacLeod W, et al. Facilitators and barriers to adherence to antiretroviral therapy and retention in care among adolescents Living with HIV/AIDS in

Zambia: A mixed methods study. AIDS Behav. 2019; 23: 2618–2628. doi: 10.1007/s10461-019-02533-5.

[11] Fabri M, Ingabire C, Cohen M, Donenberg G. The mental health of HIV-positive adolescents. Lancet Psychiatry. 2015;2(8): e21. doi: 10.1016/S2215-0366(15)00291-6.

[12] Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc. 2017; 20: 21497. doi: 10.7448/IAS.20.4.21497

[13] Cavazos-Rehg P, Byansi W, Xu C, et al. The Impact of a Family-Based Economic Intervention on the Mental Health of HIV-Infected Adolescents in Uganda: Results from Suubi + Adherence. J Adolesc Health. 2021;4: 742-749. doi: 10.1016/j.jadohealth.2020.07.022.

[14] Haas A, Technau KG, Pahad S, et al. Mental health, substance use and viral load suppression in adolescents receiving ART at a large paediatric HIV clinic in South Africa. J Int AIDS Soc. 2020;23: 1–26. doi: 10.1002/jia2.25644.

[15] Bodeker G, Pecorelli S, Choy L, et al. Well-being and mental wellness. In: Oxford Research Encyclopedia of Global Public Health. Oxford: Oxford University Press, 2020.

[16] Trompetter HR, Kleine E de, Bohlmeijer ET. Why does positive mental health buffer against psychopathology? An exploratory study on self-compassion as a resilience mechanism and adaptive emotion regulation strategy. Cognit Ther Res. 2017; 41: 459–468. doi: 1 0.1007/s10608-016-9774-0.

[17] World Health Organization. Adolescent mental health. 2022. Available from: https://www.who.int/news- room/fact-sheets/detail/adolescent-mental-health.

[18] South African Depression and Anxiety Group. Teen suicide prevention week. 2022. Available from: www.sadag.org/teen-suicide-prevention-week.

[19] Das-Munshi J, Lund C, Mathews C, et al. Mental health inequalities in adolescents growing up in post-apartheid South Africa: Cross-sectional survey, SHaW study. PLoS One. 2016; 11: 1-16. doi: 10.1371/journal.pone.0154478.

[20] Kim MH, Mazenga AC, Yu X, et al. High self-reported non-adherence to antiretroviral therapy amongst adolescents living with HIV in Malawi: Barriers and associated factors. J Int AIDS Soc. 2017; 20: 1–12. doi: 10.7448/IAS.20.1.21437.

[21] Lowenthal ED, Marukutira TC, Chapman J, et al. Psychosocial assessments for HIV+ African adolescents: Establishing construct validity and exploring under-appreciated

correlates of adherence. PLoS One. 2014; 9: 1–8. doi: doi.org/10.1371/journal.pone.0109302.

[22] Spaan, P.; Luenen, S.; Ganesfski, N.; and Kraaiji V. Psychosocial interventions enhance HIV medication adherence: A systematic review and meta-analysis. J Health Psychol. 2018; 1–15. doi: 10.1177/1359105318755545.

[23] Laurenzi C, Skeen S, Gordon S, et al. Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence. J Int AIDS. Soc 2020; 23:1-6. doi: 10.1002/jia2.25556.

[24] Orth Z, van Wyk B. Measuring mental wellness among adolescents living with a physical chronic condition: a systematic review of the mental health and mental well-being instruments. BMC Psychol. 2021; 9:1-17. doi: 10.1186/s40359-021-00680-w.

[25] Orth Z, Moosajee F, van Wyk B. Measuring mental wellness of adolescents: A systematic review of instruments. Front Psychol. 2022; 13:1-14. doi: 10.3389/fpsyg.2022.835601.

[26] Manwell LA, Barbic SP, Roberts K, et al. What is mental health? Evidence towards a new definition from a mixed methods multidisciplinary international survey. BMJ Open. 2015; 5: 1– 11. doi: 0.1136/bmjopen-2014-007079.

[27] Eriksson C, Arnarsson ÁM, Damsgaard MT, et al. Towards enhancing research on adolescent positivemental health. Nordic Welfare Research. 2019; 4: 113–128. doi: https://doi.org/10.18261/issn.2464-4161-2019-02-08.

[28] Krause N. A comprehensive strategy for developing closed-ended survey items for use in studies of older adults. J Gerontol B Psychol Sci Soc Sci. 2002; 57: 263–274. doi: 10.1093/geronb/57.5.s263.

[29] Dambi JM, Cowan FM, Martin F, et al. Conceptualisation and psychometric evaluation of positive psychological outcome measures used in adolescents and young adults living with HIV: a mixed scoping and systematic review protocol. BMJ Open. 2022; 12: 1-8. doi: 10.1136/bmjopen-2022-066129.

[30] Mittelmark MB, Sagy S, Eriksson M, et al. The Handbook of Salutogenesis. Geneva, CH: Springer, 2017.

[31] Foxcroft C, Roodt G. An introduction to psychological assessment. Cape Town, SA: Oxford University Press, 2013.

[32] Connell J, Carlton J, Grundy A, et al. The importance of content and face validity in

instrument development: Lessons learnt from service users when developing the Recovering Quality of Life measure (ReQoL). Qual Life Res. 2018;27: 193-1902. doi: 10.1007/s11136-018-1847-y.

[33] Niederberger M, Spranger J. Delphi technique in health sciences: A map. Front Public Health. 2020; 8: 1-10. doi: 10.3389/fpubh.2020.00457.

[34] World Health Organization. Helping adolescents thrive: Guidelines on mental health promotive and preventive interventions for adolescents. 2020. Available from: https://www.who.int/publications/i/item/9789240011854.

[35] United Nations. World Youth Report: Youth and the 2030 Agenda for Sustainable Development World. 2018. Available from: https://www.un.org/development/desa/youth/wp-content/uploads/sites/21/2018/12/WorldYouthReport-2030Agenda.pdf.

[36] Bhana A, Abas MA, Kelly J, et al. Mental health interventions for adolescents living with HIV or affected by HIV in low- and middle-income countries: systematic review. BJPsych Open. 2020; 6: 1-15. doi: 10.1192/bjo.2020.67.

[37] Okumu M, Nyoni T, Byansi W. Alleviating psychological distress and promoting mental wellbeing among adolescents living with HIV in sub-Saharan Africa, during and after COVID- 19. Glob Public Health. 2021; 16: 964–973. doi: 10.1080/17441692.2021.1912137.

[38] Witten H, Savahl S, Adams S. Adolescent flourishing: A systematic review. Cogent Psychology. 2019; 6: 1-16. doi: 10.1080/23311908.2019.1640341.

[39] Keyes CLM. Promoting and protecting mental health as flourishing. American Psychologist. 2005; 62: 95–108. doi: 10.1037/0003-066X.62.2.95.

[40] Mjøsund NH. A Salutogenic Mental Health Model: Flourishing as a metaphor for good mental health. In: Haugan, G., Eriksson, M, eds. Health Promotion in Health Care – Vital Theories and Research. Geneva, Cham: Springer, 2021.

[41] Mesic A, Halim N, MacLeod W, et al. Facilitators and Barriers to Adherence to Antiretroviral Therapy and Retention in Care Among Adolescents Living with HIV/AIDS in Zambia: A Mixed Methods Study. AIDS Behav 2019; 23: 2618–2628. DOI: 10.1007/s10461-019-02533-5

[42] Mary Fabri, Charles Ingabire, Mardge Cohen, Geri Donenberg SN. The mental health of HIV- positive adolescents. Lancet Psychiatry 2015:2; e21.

[43] Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc 2017; 20: 21497. DOI: 10.7448/IAS.20.4.21497

[44] Cavazos-Rehg P, Byansi W, Xu C, et al. The Impact of a Family-Based Economic Intervention on the Mental Health of HIV-Infected Adolescents in Uganda: Results from Suubi + Adherence. Journal of Adolescent Health 2021;4: 742-749. DOI: 10.1016/j.jadohealth.2020.07.022.

[45] Haas A, Technau K-G, Pahad S, et al. Mental health, substance use and viral load suppression in adolescents receiving ART at a large paediatric HIV clinic in South Africa. J Int AIDS Soc 2020;23: 1–26. DOI: 10.1002/jia2.25644

[46] Bodeker G, Pecorelli S, Choy L, et al. Well-Being and Mental Wellness. In: Oxford Research Encyclopedia of Global Public Health. Oxford University Press, 2020.

[47] Trompetter HR, Kleine E de, Bohlmeijer ET. Why Does Positive Mental Health Buffer against Psychopathology? An Exploratory Study on Self-Compassion as a Resilience Mechanism and Adaptive Emotion Regulation Strategy. Cognit Ther Res 2017; 41: 459–468. DOI: 1 0.1007/s10608-016-9774-0

[48] World Health Organization. Adolescent mental health. Available at: https://www.who.int/news- room/fact-sheets/detail/adolescent-mental-health. Accessed 19 September 2022.

[49] South African Depression and Anxiety Group. Teen suicide prevention week. Available at: www.sadag.org/teen-suicide-prevention-week. Accessed 19 September 2022.

[50] Das-Munshi J, Lund C, Mathews C, et al. Mental health inequalities in adolescents growing up in post-apartheid South Africa: Cross-sectional survey, SHaW study. PLoS One 2016; 11: 1-16. DOI: 10.1371/journal.pone.0154478.

[51] Kim MH, Mazenga AC, Yu X, et al. High self-reported non-adherence to

antiretroviraltherapy amongst adolescents living with HIV in Malawi: Barriers and associated factors. J Int AIDS Soc 2017; 20: 1–12. DOI: 10.7448/IAS.20.1.21437

[52] Lowenthal ED, Marukutira TC, Chapman J, et al. Psychosocial Assessments for HIV+ African Adolescents: Establishing Construct Validity and Exploring Under-Appreciated Correlates of Adherence. PLoS One 2014; 9: 1–8. DOI: doi.org/10.1371/journal.pone.0109302

[53] Spaan, P.; Luenen, S.; Ganesfski, N.; and Kraaiji V. Psychosocial interventions enhance HIV medication adherence: A systematic review and meta-analysis. J Health Psychol 2018; 1–15. DOI: 10.1177/1359105318755545

[54] Laurenzi C, Skeen S, Gordon S, et al. Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence. J Int AIDS Soc 2020; 23:1-6. DOI: 10.1002/jia2.25556

[55] Orth Z, van Wyk B. Measuring mental wellness among adolescents living with a physical chronic condition: a systematic review of the mental health and mental well-being instruments. BMC Psychol 2021; 9:1-17. DOI: 10.1186/s40359-021-00680-w.

[56] Orth Z, Moosajee F, van Wyk B. Measuring Mental Wellness of Adolescents: A Systematic Review of Instruments. Front Psychol 2022; 13:1-14. DOI: 10.3389/fpsyg.2022.835601.

[57] Manwell LA, Barbic SP, Roberts K, et al. What is mental health? Evidence towards a new definition from a mixed methods multidisciplinary international survey. BMJ Open 2015; 5: 1– 11. DOI: 0.1136/bmjopen-2014-007079

[58] Eriksson C, Arnarsson ÁM, Damsgaard MT, et al. Towards enhancing research on adolescent positivemental health. Nordic Welfare Research 2019; 4: 113–128. DOI: https://doi.org/10.18261/issn.2464-4161-2019-02-08

[59] Krause N. A Comprehensive Strategy for Developing Closed-Ended Survey Items for Use in Studies of Older Adults. J Gerontol B Psychol Sci Soc Sci 2002; 57: 263–274. DOI: 10.1093/geronb/57.5.s263

[60] Dambi JM, Cowan FM, Martin F, et al. Conceptualisation and psychometric evaluation of positive psychological outcome measures used in adolescents and young adults living with HIV: a mixed scoping and systematic review protocol. BMJ Open 2022; 12: 1-8. DOI: 10.1136/bmjopen-2022-066129.

[61] Mittelmark MB, Sagy S, Eriksson M, et al. The Handbook of Salutogenesis. Geneva, CH: Springer, 2017.

[62] Foxcroft C, Roodt G. An introduction to psychological assessment. Cape Town, SA: Oxford University Press, 2013.

[63] Connell J, Carlton J, Grundy A, et al. The importance of content and face validity in instrument development: Lessons learnt from service users when developing the Recovering Quality of Life measure (ReQoL). Qual Life Res 2018;27: 193-1902. DOI: 10.1007/s11136-018-1847-y

[64] Niederberger M, Spranger J. Delphi Technique in Health Sciences: A Map. Front Public Health 2020; 8: 1-10. DOI: 10.3389/fpubh.2020.00457.

[65] World Health Organization. Helping adolescents thrive: Guidelines on mental health promotive and preventive interventions for adolescents. Available at: https://www.who.int/publications/i/item/9789240011854. Accessed 3 December 2022.

[66] United Nations. World Youth Report: Youth and the 2030 Agenda for Sustainable Development World. Available at: https://www.un.org/development/desa/youth/wp-content/uploads/sites/21/2018/12/WorldYouthReport-2030Agenda.pdf. Accessed 3 December 2022.

[67] Bhana A, Abas MA, Kelly J, et al. Mental health interventions for adolescents living with HIV or affected by HIV in low- and middle-income countries: systematic review. BJPsych Open 2020; 6: 1-15. DOI: 10.1192/bjo.2020.67.

[68] Okumu M, Nyoni T, Byansi W. Alleviating psychological distress and promoting mental wellbeing among adolescents living with HIV in sub-Saharan Africa, during and after COVID- 19. Glob Public Health 2021; 16: 964–973. DOI: 10.1080/17441692.2021.1912137

[69] Witten H, Savahl S, Adams S. Adolescent flourishing: A systematic review. Cogent Psychology 2019; 6: 1-16. DOI: 10.1080/23311908.2019.1640341.

[70] Keyes CLM. Promoting and Protecting Mental Health as Flourishing. American Psychologist 2005; 62: 95–108. DOI: 10.1037/0003-066X.62.2.95

[71] Mjøsund NH. A Salutogenic Mental Health Model: Flourishing as a Metaphor for Good Mental Health. In: Haugan, G., Eriksson, M, eds. Health Promotion in Health Care – Vital Theories and Research. Springer, Cham. https://doi-

org.ezproxy.uwc.ac.za/10.1007/978-3-030-63135-2_5

CHAPTER 10

Manuscript 9: Orth, Z & van Wyk, B. Asking the experts: Establishing the face validity of a Mental Wellness Measure for Adolescents Living with HIV through cognitive interviewing. International Journal of Environmental Research and Public Health; 20(5): 1-18. doi: 10.3390/ijerph20054061.

Abstract

There has been an increased focus on the mental health of adolescents living with HIV (ALHIV) because evidence shows that poor mental health outcomes are associated with lower rates of adherence and retention in HIV care. However, the research to date has predominantly focused on addressing mental health problems and reducing symptoms of mental illness rather than strengthening mental wellness [positive mental health]. Consequently, little is known about the critical mental wellness indicators that should be targeted in services for ALHIV. There is a need for valid and appropriate measures of mental wellness to drive research and provide evidence on the mental wellness needs of ALHIV that would inform service delivery as well as the monitoring and evaluation of treatment outcomes. To this end, we developed the Mental Wellness Measure for Adolescents Living with HIV (MWM-ALHIV) for ALHIV in the South African context. In this paper, we report on the findings from a cognitive interview study with nine ALHIV aged 15–19 years receiving treatment at a public healthcare facility in the Cape Metropole, South Africa. Through interviews, participants identified key issues related to the wording, relevance and understanding of the items and provided suggestions to improve the instrument's overall face validity.

Background

Mental wellness (positive mental health) has been identified as a significant driver of adolescent health and well-being [1]. This is evidenced in the inclusion of mental health (wellness) in the Sustainable Development Goal (SDG) target 3, which highlights mental health promotion as a critical factor in reducing premature mortality from non-communicable diseases and ensuring good health for all by 2030 [2]. This target is especially relevant for adolescents living with HIV (ALHIV), as they learn to navigate living with a highly stigmatized chronic condition and other challenges and health risks associated with adolescence [3]. Research aimed

at understanding the lived experiences of ALHIV has shed light on the various biopsychosocial challenges face, including delayed disclosure, stigma, dysfunctional families, community violence, substance use, poverty, gender inequality and bullying, to name but a few [4–7]. Their exposure to these various stressors places them at greater risk of developing mental health disorders in comparison to their peers who do not have HIV [4–7]. Various studies have reported high prevalence rates of mental health disorders such as anxiety, depression, and post-traumatic stress disorder (PTSD) [7–9]. Moreover, poor mental health has been significantly associated with low adherence to antiretroviral therapy (ART) and retention in care (RiC) among ALHIV [10,11]. Consequently, the low rates of adherence to ART and RiC are associated with higher AIDS-related deaths among ALHIV in comparison to children and adults living with HIV [12,13].

South Africa is at the epicenter of the HIV pandemic and is home to approximately 20% of the global adolescent HIV population aged 10–19 years [13]. The increased prevalence of ALHIV in South Africa is attributed to new infections as well as the successful roll-out of the ART program, which has increased the survival rate of perinatally inflected children [14]. In addition to navigating the physical, social and psychological changes experienced during adolescence and the challenges associated with managing HIV, ALHIV also have to navigate the complex myriad of socio-economic, systemic and environmental factors which shape their daily lives and impact their physical and mental health and wellbeing [14]. The current context of HIV treatment and care is rooted in the socio-political economic system from the apartheid era, which continues to perpetuate racial-based inequalities, thereby fostering conditions in which certain groups are more susceptible to HIV-infection [15]. For example, results from a 2012 population survey indicated that Black South African women were disproportionally affected by HIV in comparison to other groups [15].

Within the South African context, research has shown that structural factors such as poverty, housing, a lack of service provision in communities, racial inequalities, violence, and gender inequalities negatively impact the mental health of ALHIV [14]. For example, reports indicate that the majority of ALHIV belong to marginalized populations characterized by poverty. As a consequence, the impact of poverty is associated with limited access to resources, food insecurity and education, which in turn is associated with poor mental health outcomes and

adherence [14]. Furthermore, a study by Woollet et al. [9] aimed at identifying the mental health risks among ALHIV accessing care at public healthcare facilities in Johannesburg found that there were high levels of reported mental health problems: 27% were symptomatic for depression, anxiety, or PTSD; and 24% re-ported suicidality. Additionally, the findings indicated that hunger, violence, gender, and illness were significantly correlated with mental health problems, while mental wellness factors such as hope for the future and knowledge of status were considered as protective factors [9]. These findings indicate that ALHIV require additional support to manage their condition in relation to the contextual risks that they experience. It is critical to address the structural problems and inequalities ALHIV face, yet solutions to these problems are complex and require transforming the macro contexts and political systems. However, preventative strategies that improve the mental wellness of ALHIV are useful in strengthening their capacities to be resilient and grow to become productive members of society.

In support of mental wellness, studies evaluating the effectiveness of psychosocial interventions in improving mental health and adherence among ALHIV have shown promising results [16–19]. This evidence has increased calls and advocacy to improve mental health (wellness) promotion for ALHIV and to integrate mental health care into adolescent-friendly services [20,21]. However, many of the studies have focused on reducing mental health problems rather than promoting mental wellness. Quantitative studies that measure the effectiveness of psychosocial interventions in improving mental health among ALHIV often use instruments measuring symptoms of mental illness. Therefore, improvements to mental health in these studies are based on the measured re-duction of mental illness symptoms. To truly establish the effectiveness of psychosocial interventions or mental health services in improving mental health among ALHIV, we need to develop holistic evaluations by measuring both mental health problems and mental wellness [21,22].

There has been a proliferation of positive psychology research that focused on a range of dimensions from theory development, evaluation of positive psychology interventions, and instrument testing [23]. However, despite the relevance of positive psychology as a tool to promote health and prevent illness (especially in the context of low-resourced settings), the majority of such research has been done in Western contexts, with only small pockets of evidence emerging in the global South [23]. Furthermore, despite the increased focus on positive mental

health, a challenge of the field is the lack of consensus on how mental wellness should be conceptualized [1]. Research has identified a range of mental wellness constructs such as self-acceptance, hope, connectedness, and life satisfaction, among others, that are associated with improved well-being and positive functioning in adults and adolescents [1,24,25]. As mentioned, these concepts have mostly emerged from research in the Western context, with a number of growing studies exploring these concepts among indigenous populations and those living in the global South [26]. For example, a study on Thai ALHIV [27] found that spirituality and dignity played an essential role in maintaining mental wellness; in turn, this was associated with living responsibly and experiencing a better quality of life. There has also been an increase in instruments that measure singular mental wellness constructs (i.e., self-esteem) or general mental well-being [26,28–30]. Many of these instruments were developed with general adult and adolescent populations living in high-income countries (HICs) [26,28–30]. Due to the cost and time associated with instrument development, instruments developed in HICs are typically validated for use in other contexts, such as the KIDSCREEN measures or WHO-5 well-being index [31–33]. However, we need to be critical of how these instruments were validated and of the type of validity that was established. For example, the study by Balthip et al. indicates that spirituality is an essential indicator of mental wellness among Thai ALHIV. Nevertheless, this indicator is often not included in commonly used and validated measures such as the KIDSCREEN measure. This raises pertinent questions regarding the relevance of such instruments and what indicators of mental wellness should be targeted to improve outcomes among ALHIV in different contexts. Relatedly, the World Health Organization (WHO) published guidelines on mental health promotion and prevention interventions for adolescents in 2020 [21]. A leading recommendation of the report states that psychosocial interventions should be provided for ALHIV, as these are shown to promote positive mental health and reduce mental disorders [21]. However, the report also indicates that due to a lack of evidence, it was not possible to provide specific recommendations on psychosocial interventions to promote positive mental health, and that additional research is required to improve mental health trajectories. Throughout the re-port, mental-wellbeing and mental functioning were listed as positive mental health out-comes, while no specific indicators of positive mental health were stated [21].

As indicated, there is a limited understanding in terms of which mental wellness constructs would be most relevant to improving the health and well-being of ALHIV, especially in low- and -middle-

income countries (LMICs) [21]. While there are mental well-ness instruments that have been validated with adolescents in various contexts, and these mental wellness construct measures may be potentially relevant to ALHIV, we need to consider that mental wellness as a social construct is influenced by time, culture, and age. Therefore, the lived experiences of ALHIV shape their perception and understanding of mental wellness and its associated constructs [20]. For example, HIV is a highly stigmatized condition; therefore, approaches aimed at improving self-acceptance among ALHIV will not be the same as approaches used to improve self-acceptance among adolescents who are not living with HIV. From a health equity perspective, it is crucial that we develop a comprehensive understanding of how mental wellness is perceived by ALHIV to identify relevant indicators and develop appropriate instruments to measure mental wellness in this population in the South African context. Considering the increased conversation around defining concepts such as mental wellness and positive mental health, this is an opportune time to explore the meaning and conceptualization of these from an African perspective to ensure that cultural and indigenous views of health and wellbeing are prioritized rather than transmuting concepts from the West.

The mental wellness measure for adolescents living with HIV

There is an increasing need for mental wellness measures for ALHIV to provide much-needed data on the context and impact of mental wellness outcomes which can then be targeted in interventions and service delivery [21,34]. To address this, we developed a Mental Wellness Measure for ALHIV (MWM-ALHIV) instrument in the South African context. The MWM-ALHIV was developed by first conceptualizing mental wellness for ALHIV through a systematic review of mental health instruments used in research with adolescents [26,28], a photovoice study with ALHIV accessing treatment at three public healthcare facilities in the Cape Metropole District in South Africa [35,36], and an integrative review of mental wellness concepts emerging from research done with ALHIV in Africa [37]. The findings from the systematic review indicated that there is a lack of mental wellness measures developed specifically for adolescents living with a chronic condition (such as HIV) in the African context, thereby proving support for the development of a new instrument [26,28]. Furthermore, through the photovoice study, participants were able to lead the conversation on what mental wellness means to them and what mental wellness factors are most salient in their lives, while the integrative review provided

insight on the mental wellness concepts that are relevant in the African context, and how these are shaped by the cultural context [35–37]. From these findings, we developed the Salutogenic Model of Mental Wellness (SMoMW) (Figure 1) adapted from Antonovsky's [38] Salutogenic Model of Health as a theoretical guide to develop the MWM-ALHIV.

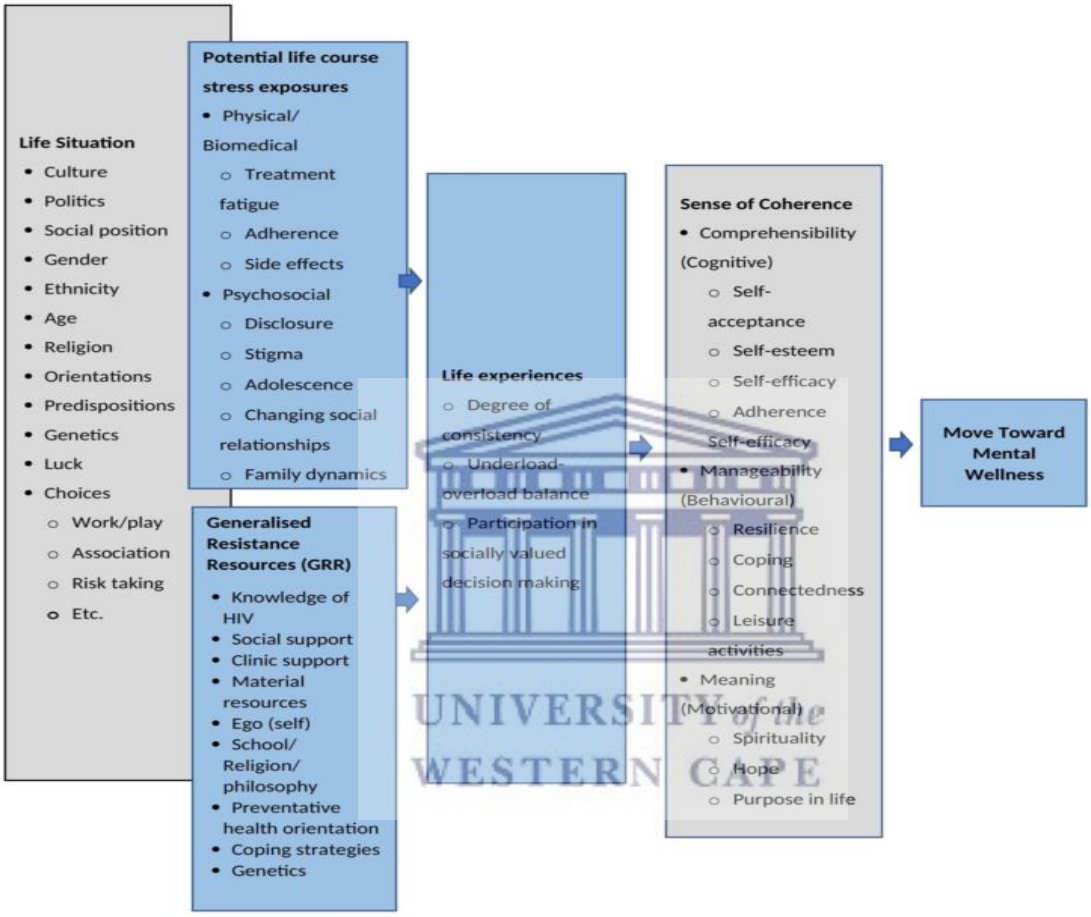

Figure 10.1 Salutogenic Model of Mental Wellness

Antonovsky originally developed the Salutgogenic Model to emphasize the conditions that lead to health rather than the determinants of health [38]. The Salutogenic Model was born out of observations that people experience various stressors in their daily lives resulting in tensions which, if left unresolved, develops into the health damaging condition of stress [38]. However, exposure to stressors does not necessarily lead to stress and illness. Rather, Antonovsky

noted that people who have access to resources are better able to cope with and resolve tensions than people with little or no resources [38]. Through the model, Antonovsky highlights the importance of focusing on the interplay of stressors and life experiences to move an individual towards health [38]. Two key concepts of this model are the generalized resistance resources (GRR), referring to any factor or characteristic which can be used to facilitate tension management, and a sense of coherence (SOC), referring to an individual's capacity to manage and overcome stressors [38]. Based on the Salutogenic paradigm, the SMoMW was developed following extensive reviews of the literature and participatory research with ALHIV accessing treatment in the Cape Metropole District in South Africa, which helped us to identify key mental wellness constructs that are relevant to ALHIV. Therefore, the SMoMW can be used to guide health promotion interventions, inform youth-friendly services, and facilitate research activities. According to the SMoMW, mental wellness is expressed as overall SOC, which comprises cognitive (comprehensibility), behavioral (manageability) and motivational (meaning) mental wellness factors. SOC, in turn, is influenced by a range of ecological factors including the life experiences of ALHIV, their access to resources, potential exposure to stressors, and their life situation. In this sense, ALHIV who have a high SOC are more likely to access and mobilize resistance resources, which will strengthen their SOC, leading to better mental wellness. The SMoMW can be used to understand how these factors influence the mental wellness of ALHIV in context, and what points of intervention would be most useful, as shown in Table 10.1. The MWM-ALHIV was developed to measure the SOC aspect of the model, highlighting the key mental wellness concepts identified by ALHIV as being salient to their experiences of living with HIV [39]. Due to the heterogeneity of the group, it would be challenging to develop a measure that takes into account all contextual aspects such as the GRRs or the potential life stressors. However, the strength of the model is that it allows for such factors to be considered when designing health promotion interventions or guiding research. Therefore, the MWM-ALHIV can be used in conjunction with the model to guide the collection of demographic data (culture, age, mode of infection etc.), select supplementary tools to measure other aspects (i.e., exposure to violence, adherence, treatment fatigue), or interpret findings.

Table 10.1: Mental wellness domains for the MWM-ALHIV

Sense of Coherence	Sub-domains (N=11)	Number of Items (N=113)
Comprehensibility (Cognitive)	Self-esteem	10
	Self-acceptance	9
	Self-efficacy	9
	Adherence Self-efficacy	13
Manageability (Behavioural)	Resilience	10
	Coping	10
	Connectedness	10
	Leisure activities	10
Meaning (Motivational)	Spirituality	7
	Hope	14
	Purpose in life	11

Ensuring validity is a crucial step in instrument development to determine the extent to which a measure accurately captures what it is intended to measure [31,40,41]. Validity testing is usually done during the pilot phase of a study, using methods such as factor analysis or Item Response Theory (IRT) [31,40,41]. However, it is equally important to test for content and face validity. In a previous study, we established content validity by engaging with experts in a modified Delphi Study to determine how adequately the domains and items represent the measurement of mental wellness among ALHIV [39]. The Delphi Study participants endorsed the measure by providing consensus on the relevance and representation of the domains and items. In its present state, the MWM-ALHIV includes 113 items and measures mental wellness as an overall SOC represented through three domains and 11 sub-domains (Table 10.1).

As mental wellness is increasingly prioritized, we need to ensure that ALHIV are part of the conversation (especially those living in LMICs) and are included in efforts to im-prove their health and well-being. According to the WHO and UNAIDS, including ALHIV in the research process is a key priority [34]. Therefore, the next step is to establish the face validity and improve on the content validity of the MWM-ALHIV by engaging with the target population as the next group of experts [34]. To this end, we conducted cognitive interviews with a group of ALHIV to

determine to what extent the items in the measure are appropriate, acceptable, sensible, and relevant for the intended users. According to UNAIDS, the participation and leadership of ALHIV are crucial at all stages of informing HIV programming, including the design, implementation, and monitoring and evaluation. The MWM-ALHIV reflects this commitment, as it was developed using a participatory photovoice method, allowing ALHIV to lead the conversation and express what aspects of mental wellness are important to them and what role it plays in their lives. The cognitive interviews followed as a logical next step to meaningfully engage with participants and collaborate with them to improve the MWM-ALHIV. Once finalized, the MWM-ALHIV can be used to implement, monitor, and evaluate youth-friendly services and HIV programming for ALHIV [21].

Methods

Cognitive interviewing is a technique used to evaluate the content and face validity and applicability of a survey or instrument [41–43]. The cognitive interview methodology was first established in the 1980s as a means to improve the validity of an instrument by understanding the cognitive processes involved in answering response items [41–43]. This technique is used during the preliminary stages of instrument development to gain insight into the participant's cognitive processes when responding to ensure they under-stand the questions as intended [41–43]. There are two main approaches to cognitive interviewing, namely the 'think-aloud' and 'verbal probing' techniques [41–43].

The think-aloud method involves participants verbalizing their thought processes while responding to each item in the instrument, with the interviewer documenting the participant's thought processes [41–43]. On the other hand, the verbal probing approach in-volves the interviewer asking a series of probing questions aimed at eliciting detailed in-formation from the participants after they have responded to the items. While the think-aloud method is advantageous in reducing biased responses, asking participants to verbalize their thoughts while answering a question can be an unnatural and difficult practice for participants, resulting in a significant cognitive burden [43]. As such, the interviews were conducted according to the verbal probing approach outlined by Willis and Artino, as this was considered appropriate for the given sample of adolescents [43].

Participants and procedures

The MWM-ALHIV is intended to measure mental wellness among ALHIV aged 14–19 years. As such, we recruited participants matching those criteria from a public healthcare facility in the Cape Metropole District of South Africa. The Cape Metropole District is located in the Western Cape Province, with reports indicating that 6.76% of people living with HIV reside in the province [15]. The healthcare facility is located in a 'low-income' community and provides free healthcare to members of the community and the surrounding areas. Additionally, to be included in the study, participants had to speak English as a first or second language. Due to the sensitive nature of the study, we first made contact with a doctor at the facility who was previously in charge of running the Youth Adherence Clubs. The doctor was given the relevant information with the study and asked to aid in the recruitment due to issues around disclosure. Those who were interested in participating were put in contact with the researcher and received information sheets as well as assent and consent forms for those younger than 18 years. Following this, the researcher set up a time and date to interview each participant at their convenience. All interviews were conducted at the public healthcare facility.

The lexical context in South Africa

Cognitive interviews are based on the assumption that we can use language (think-aloud and verbal probes) to tap into the cognitive processes of the participant and explain the way participants mentally process and respond to items in surveys or questionnaires [43]. As language plays a significant role in this process, it is salient to consider the multi-lingual context in South Africa. There are 11 official languages in South Africa, with

IsiZulu identified as being spoken by the majority of the population (23%), followed by isiXhosa (16%), Afrikaans (13.5%), English (10%), Sesotho sa Leboa (9%), Setswana (8%), Sesotho (8%), Xitsonga (4.5%), siSwati (2.5%), Tshivenda (2.5%) and isiNdebele (2%) [44]. In the Western Cape province, where this study is based, the main languages are Afrikaans (49%), isiXhosa (24.7%) and English (20.3%) [44]. During the apartheid era, English and Afrikaans were identified as the official national languages of South Africa, while Indigenous languages were marginalized [44–46]. In addition to declaring the 11 official languages, other efforts aimed at redressing the language inequality include policies which state that South African children be

taught in their mother tongue in the first three years of schooling, after which they are taught through an English or Afrikaans medium until their final year of high school [46].

In post-apartheid South Africa, Afrikaans continues to be used widely in the media and basic education system, with English dominating as the language of urban life and that predominantly used in the media, business, government, and basic and higher education systems [44,46]. Thus, despite being spoken as a home language by a minority of the population, English is used as a second language and a common language of communication in urban areas [44,46]. Furthermore, language in South Africa is fluid, with the majority of the population speaking more than two languages [44]. Census data from 2011 indicated that the average South African speaks between two and three languages. As such, South Africans are considered to be a 'code-switching' people, meaning that they may use more than one language during a conversation [44].

Data collection

The interviews were carried out by a researcher who is experienced in qualitative research, has had previous training and experience conducting cognitive interviews with adolescents, and has experience doing research with ALHIV. The interviews were conducted in a private, quiet space to allow the participant to answer honestly. Before the start of each interview, the researcher reiterated the purpose of the study, and that the participant had the right to stop the interview process at any point if they no longer wished to continue. To reduce social desirability bias and to help participants feel comfortable, the researcher explained that the questions in the instruments were derived from photovoice interviews with other ALHIV who attended the healthcare facility in 2019.

The interviews were conducted in December 2022. During the interview, the researcher sat next to the participant and read each question in the MWM-ALHIV aloud, along with the answer options, and then gave the participant the opportunity to select a response option. Following this, the researcher would ask probing questions based on the participant's answer and their experience to assess the cognitive match between the intent of the question and the participant's understanding and interpretation of the question. The probing questions included 'why did you choose that answer?', 'what does [key term from questionnaire] mean to you?',

‘can you explain what [key term] means to you in your own words?’, 'what popped in your head when I said [key term]', ‘I noticed you hesitated before answering that question, can you tell me more?’, ‘were any of the questions easy to answer?’, ‘were any of the questions hard to answer?’ These probes allowed participants the opportunity to reflect on their answers and to provide explanations to demonstrate their understanding. Additionally, the researcher asked questions to elicit macro-level engagement from the participants, which included ‘how would you ask [question from instrument] to your friends?’ or ‘what word [key term] would you and your friends use?’

As a psychologist and a woman of color who grew up in a post-apartheid South Africa, the researcher was aware of the power differences that could affect how participants interacted with her. She tried to minimize these by encouraging casual interaction with the participants, using local colloquialisms, and building a rapport with the help of the doctor. After each session the researcher had a debriefing session with the participant, giving them an opportunity to reflect on the experience and ask questions. Following this, the participants were given an incentive of ZAR 150 (USD 9) as a thank you.

Data analysis

All interviews were audio recorded and transcribed. Additionally, the researcher made detailed field notes during and after the interviews to aid with the analysis. The transcripts were analyzed thematically to identify common themes and patterns that may indicate problems with the items, ambiguous wording, or potential sources of bias.

Ethics

Ethical approval to conduct this study was granted by the University of the Western Cape Biomedical Research Ethics Committee (BM18/3/7). Each participant received and returned signed consent/assent forms before the start of the interviews. Participants who were younger than 18 years provided signed parental consent forms. Participants were reminded that they could withdraw from the study at any time without any negative consequences and that all their information would be kept private and confidential.

Findings

We conducted interviews with nine participants accessing treatment at the public healthcare facility. The aim of the current study is to establish the face validity of the instrument rather than assess the mental wellness of the participants. Therefore, according to Willis [43] this sample size is deemed sufficient to confirm patient understandability of an item. Additionally, the analysis revealed no new themes emerging. The findings yielded enough information to identify key issues in the items to be revised. As cognitive interviewing is an iterative approach, it would be more useful to integrate the revisions and then conduct additional rounds.

The participant demographics are presented in Table 10.2. As shown in the table, the majority of participants (n = 7) indicated isiXhosa as their home language and English as their second language. As indicated earlier, this would mean that the seven Xhosa-speaking participants would receive their secondary education in English. The two Afrikaans participants were educated in their home language and study English as a second additional language, in line with the Department of Basic Education's curriculum. All of the participants completed or are currently enrolled in school and are therefore considered to be literate. Furthermore, all participants were able to converse fluently in English, which, as mentioned, is a reflection of the urban setting. Two of the participants stated that they completed level 4 in the School of Skills—an alternative education institution for pupils who are unable to cope with or develop in mainstream institutions [47]. Pupils are enrolled at age 14 or 15 years and complete 4 years of schooling [47]. As Afrikaans in the predominantly spoken language in the Western Cape, it may be surprising that most of the participants in this sample spoke isiXhosa as their home language. However, this may also reflect the racial disparities and economic inequalities which drive the HIV epidemic in South Africa. Furthermore, all participants indicated that they were perinatally infected; thus, suggesting that the overrepresentation of Xhosa speaking participants in this study may be associated with the high HIV prevalence among Black South African women who lacked access to ART and the prevention of mother to child transmission (PMTCT) services (which was only initiated in 2002) [48].

Table 10.2: Participant characteristics

Participant (n=9)	Age	Gender	Home Language	Education level
A01	19	Female	Xhosa	School of Skills (level 4)
A02	18	Other	Xhosa	School of Skills (level 4)
A03	18	Female	Xhosa	Gr.12
A04	19	Female	Xhosa	Gr. 12
A05	15	Female	Afrikaans	Gr. 8
A06	19	Male	Xhosa	Gr. 12
A07	15	Male	Xhosa	Gr. 8
A08	17	Female	Xhosa	Gr. 10
A09	17	Male	Afrikaans	Gr. 10

The findings from this research highlight the value and importance of working with ALHIV; through engagement and feedback from the participants, we were able to work together to identify question failures and problems related to the face validity of the instrument which were not identified during the Delphi study.

These issues are classified into three themes, namely: *comprehension mismatch, 'big' or difficult words*, and *sentence structure and question relevance* (Table 10.3). These question failures should be understood in the context of the South African language and education landscape and raise questions about survey development in South Africa. Generally, the older participants (18/19) were more confident in verbalizing their answers and thought processes than the younger adolescents. Both participants A01 and A02 attended a School of Skills; however, A01 spoke about her learning difficulties and demonstrated an aware-ness of her strengths and limitations. As such, she was able to clearly explain how she answered specific questions and engaged with the researcher on a macro level by making suggestions.

The younger adolescents (15/17) struggled to verbalize their thought processes. As one participant said, 'I know what it means, I am just struggling to find the words to ex-plain'. In these cases, the researcher would try to elicit a response by asking participants if they could provide examples or a similar word or suggested that they say it in their home language. For

example, upon prompting, A02 said she would describe a valuable person as an ‘important’ person. In a similar study aimed at adapting a measure of grief among South African adolescents, it was noted that since cognitive interviewees are tasked with explaining how they experience and interpret specific words and phrases, polyglot contexts represent an exceedingly complex environment for research implementation [49]. This raises the question of whether participants’ struggles to verbalize their thoughts are related to a lack of understanding. Indeed, the relationship between language and cognition is a persistent question in scientific inquiry [43,49].

The participants' responses to items were analyzed in light of this context. Given that all participants were bilingual and had different literacy levels, items were revised to reflect the lowest literacy level. In other words, an item was flagged for revision even if only one participant struggled to comprehend it.

[1] Afrikaaps, also known as Kaaps, is a language created in settler colonial South Africa

which developed as a result of encounters between indigenous African groups (Khoi and San), slaves brought in from South-East Asia and Portuguese, Dutch and English settlers [53]. In contemporary South Africa, the language is commonly spoken by working class speakers in the Cape Flats (an area in Cape Town where people were forcibly moved during the apartheid era) [53]. The language has been established since the 1500s and was first taught in *madrassahs* (Islamic schools). In later years it was appropriated by Afrikaner nationalists [53].

Table 10.3: Summary of problem types and proposed revisions

Problem type	Item	Domain	Explanation	Example	Proposed Revision
Comprehension mismatch	When I fail at something important, I remind myself it is part of being human.	Self-acceptance	All of the participants struggled to answer this question and would often relate it to their experience of living with HIV	**A02:** 'Sometimes I will feel lonely because I will be like, yes, I am HIV, but that does not mean that' **A03:** I'm not going to die anytime soon, I'm going to live long.' **A01:** 'Strongly agree; yeah, I think I get really disappointed.	Remove

Even when I am bad at something, I still love myself.	Self-acceptance	Some of the participants interpreted 'bad' as doing something bad in character rather than failing at something	**A03** "I love myself even when I am bad?...bad things like doing bad things"	'I love myself even when I fail at something.'
			A07: 'I don't love myself when I do bad things.'	

When something upsets me, it does not change how I feel about myself	Self-acceptance	All the participants understood the question. However, one participant indicated that the wording may cause them to	**A04**: 'No, I strongly disagree…or is it agree?	'When something upsets me, I feel bad about myself.'

		answer incorrectly		
I am comfortable with who I am as a person	Self-acceptance	The question intends to determine if the participant accepts, but the word 'comfortable' can have a different interpretation	**A06:** 'Being in a relaxed atmosphere or something or just being in your comfort zone that could be at home or our friends'	I love myself just the way I am'
I am a valuable person, even if there are parts of myself that I do not like.	Self-acceptance	Some of the participants interpreted 'parts' to relate to the body rather than general aspects or characteristics	**A06:** 'Body parts' A01: 'Like, any marks that you [gesturing to body] - like me, I have two [skin] colours… So, sometimes I	'I love myself, even if there are things about myself that I dislike'

			look at my arms and look at my body…and I want to change it but I cant’	
I do not have much to be proud of.	Self-esteem	Some participants interpreted the question to relate to certain material possessions that they may not have	**A02**: ‘I don't have much to be proud of, but I know that I can take care of my health and some things.’ **A06:** ‘Like asset, type of things?’	‘I feel like a failure’
I feel strong	Self-efficacy	Strong was interpreted differently by	**A01:** ‘Because I don't have a lot of energy as	‘I have what it takes to succeed/achieve

participants, with some relating it	others because I have a heart	my goals' or I have the ability

		to physical strength	problem, so I don't have so much strength like others' 'Like, I mean, I feel like strong. It means that you are like you are strong. Like you have the ability to do anything.'	to do anything I want in life
I find ways to take my treatment every day, even when I am around people who don't know that I am	Adherence self-efficacy	Most participants understood the question and responded with some of the ways they would take the treatment (e.g. go to the bathroom). However, one	**A06:** "I never take treatment in front of everybody."	When I am around people who don't know my status, I will still try to find a way to take my treatment (e.g. go to the bathroom)

living with HIV		participant believed the question asked to take the treatment Infront of others		
I know where to go in my community to get help	Resilience	Some participants indicated the question may be vague. The question intends to assess whether participants know where to access resources in the community if they need it	**A04**: 'Yeah, I would ask them. I don't know. I have like, I've never been in the situation, like, to go and seek help from the community.'	"If I had a problem, I would know where to go in my community to get help"
I do things at school that make a positive	Resilience	While some participants interpreted the question	**A03:** 'Making good friends, doing different good	I work well with people my age/'I feel good

difference (i.e. make things better)	correctly, like A03, others struggled to understand and answer the question (A01).	things…playing sports.' **A01:** 'Something that's like different from the other things that I do.'	when I am at school.'

In general, I feel I am in control of my life	Some of the participants interpreted the question as referring to their ability to be independent rather than their ability to be in control of themselves, despite life challenges	**A04:** I think being in control is being independent.' **A08:** 'Disagree…I have to follow the rules at home.'	'I feel I am in control of myself.'

Question relevance	I take my treatment every day, even when my eating habits have changed.	Adherence self-efficacy	The question did not resonate with the participants	**A06:** 'My eating habits never change.' **A08:** 'No, I do not know how to answer this.'	Remove
	I take my treatment every day, even when I have problems going to the clinic.	Adherence self-efficacy	The question did not resonate with the participants	**A06:** 'How would you take your treatment if you couldn't go to the clinic?'	Remove
	I take my treatment every day, even when people close to me tell me not to	Adherence self-efficacy	The question did not resonate with the participants	**A04:** 'I never came across that.' **A03**: 'No one told me.'	Remove

I take my treatment every day even when I feel like people will judge me	Adherence self-efficacy	The question did not resonate with the participants	**A04:** 'Strongly disagree; no one has ever judged me.' **A01:** 'No, people think the tablets are for my heart.'	Remove
I know where to go for help when I have problems	Resilience	The wording of this question is similar to "I know where to go in my community when I need help. As such, we propose a revision.	**A01:** 'I talk to my mom when I have problems'	'When I have a problem, I can find what I need to solve it.'

Living with HIV has strengthened my faith and	Spirituality	The participants indicated that the question was not very relevant	**A04:** No…because, like, I feel like God has a purpose. Like	Remove

	spiritual beliefs			God created everyone. There's a reason why I'm living with HIV **A06:** No, it does not apply	
Big or difficult words and sentence structure	For me, life is about learning, changing, and growing despite my circumstances	Resilience	The wording of the question made it difficult for participants to understand	A01: 'So, yeah, there are a lot of challenges here outside.' **A09**: 'Strongly agree….I don't know'	'I see life challenges as a chance for me to learn and grow.'
	I think it is important to have new experiences that challenge how you think about	Coping	The wording of the question made it difficult for participants to understand	**A06:** 'Doing things you've never done before?'	Remove, similar to the previous question

yourself and the world				
When I have problems, I think about different solutions to solve the problem	Coping	Most participants understood the question, but A01 suggested to make it easier	**A01:** 'you can change it to make it easier'	"When I have a problem, I think about different ways to solve the problem'
I try to avoid difficult situations as much as possible	Coping	The wording of the question made it difficult for participants to understand	**A01:** 'Like, those friends, there is always that thing that you be talking about, and then there will be that one person who will report that thing, and it starts to be a big thing.'	'I avoid my problems'

I have friends I am really close to and trust	Connectedness	Participants interpreted the question as having friends that they trust. Some have close friends, but they do not trust them with their status. The question was split into two to make it easier	**A09:** 'Disagree, my friends, don't know.' A02: 'I have friends, but I have not told them about my status.'	"I have friends I am close to' AND 'I have friends I trust.'
It is important to me that I feel satisfied with the activities that I take part in.	Leisure activities	The wording of the question made it difficult for participants to understand	**A07:** 'Satisfied is…I don't know how to explain it.' **A08**: 'No, sometimes I just come home from	"I have hobbies that make me feel happy.'

school

			and do homework.'	
I will be able to provide for myself	Hope	Most participants understood the question, but A01 suggested to make it easier	**A01:**' 'Provide is a big English word. Maybe you can say 'take care of myself'	'I will be able to take care of myself.'
I will be able to provide for my family	Hope	Similar to previous		'I will be able to take care of my family'
I feel optimistic about the future		None of the participants understood the word 'optimistic.'	**A04:** 'What does that mean?' **A01:** That is another big word	"I feel good about my future.'
I feel a sense of purpose in	Purpose in life	These two questions were	**A06:** 'it's the same meaning.'	"I know where I want to go in

my life, and I have a sense seen as similar, and some life.’

of direction in life.	participants had difficulty understanding	**A03**: 'sense of direction?'	
I enjoy making plans for the future and working to make them come true	The question was seen as asking two different things. A04 provided some recommendations to split it into two questions	A04: 'The question is in-between [difficult and easy to answer]	I enjoy making plans for the future, and I work hard to achieve my goals

Discussion

There is a growing recognition on the importance of improving mental wellness among ALHIV to support lifelong adherence to ART and ensure that they reach their full potential across the course of their lives. Strengthening mental wellness among ALHIV in South Africa is especially critical considering the high prevalence rates of HIV, the impact of the epidemic, and the health risks they are exposed to as a result of pervasive inequalities within the country. While it may take years to address the structural problems, focusing on mental wellness through mental health promotion interventions may offer protection from health risks to ALHIV and strengthen their capacity to thrive. However, in re-source restrained contexts such as in South Africa, we need evidence-based responses to maximize the impact and outcome of interventions and services. To generate quality evidence, we require robust tools. Therefore, we set out to validate the MWM–ALHIV as a first step towards developing an age and culturally appropriate measure of mental wellness made for ALHIV, with ALHIV.

This study provides an example of how cognitive interviews with ALHIV in South Africa can be used to improve the face validity of the measuring instrument, MWM-ALHIV. The MWM-ALHIV was developed to address the gap in research on mental wellness among ALHIV. While there are numerous instruments aimed at measuring positive mental health, our goal was to develop an instrument that is culturally sensitive and captures the world view of ALHIV in the South African context. A strength of this measure is that it has been developed using participatory approaches with ALHIV that enabled the researchers to understand which aspects of mental wellness are important to them, how they talk about and understand it, and the role it plays in facilitating adherence to ART. The current study is concerned with improving the face validity of the instrument and represents a snapshot in the process towards establishing the psychometric properties of the instrument.

Similar to Taylor et al. [49], we found that the language issues which emerged from the interviews reflect the challenges of the South African landscape. Translating the questionnaire to Xhosa or Afrikaans is necessary to accommodate the larger population. However, this may be a challenging process. For example, when asked if the questions would be easier if they were translated to Xhosa, participant A01 suggested that it may not make a difference—even though she mainly speaks Xhosa at home, she also speaks other languages with her family and she never learned how to read or write in Xhosa. She further stated that

due to her learning difficulties, it is easier for her to hear the questions verbally and then answer rather than reading them on her own. However, this may reflect a more complex problem in South Africa related to verbal and written language use. According to Chimbga and Meier, South African learners that were tested during an international comparative evaluation of reading literacy through the Progress in Reading Inter-national Literacy Study performed poorly, despite most writing in their home language [46].

Therefore, given the complex language issues, we agree with previous recommendations made by Taylor et al. [49] in that it may be advisable to adopt a multilingual approach in conducting cognitive interviews and even the survey design itself within the South African context. In other words, during the interviews, participants should be al-lowed to answer in their language of choice or to code-switch. Following this, decisions can be made regarding the appropriate language choices for the instrument [49]. To be representative of the fluid multilingual context and code-switching nature of South Africans, considerations should be made to have the instrument translated into a version which may include multiple languages or colloquialisms – such as Afrikaaps - in addition to a standard English version of the instrument or other translations [49]. Afrikaaps (also known as Kaaps) is a language created in settler colonial South Africa which developed as a result of encounters between indigenous African groups (Khoi and San) and slaves brought in from Southeast Asia and Portuguese, Dutch and English settlers [50]. In contemporary South Africa, the language is commonly spoken by working class speakers in the Cape Flats (an area in Cape Town where people were forcibly moved during the apartheid era) [50]. The language has been established since the 1500s and was first taught in madrassahs (Islamic schools). In later years it was appropriated by Afrikaner nationalists [50]

Additionally, we found that the interviews supported the appropriateness of the instrument and supported the rationale of the SMoMW. Therefore, even though certain domains in the model and instrument are believed to reflect Western concepts and values, such as self-esteem and self-acceptance, we found that participants resonated with and responded well to these categories and reflected the findings from our previous photovoice study, thereby demonstrating the confirmability of the findings. Furthermore, even though the mental wellness concepts originated from Western perspectives, we included and adapted these based on our engagement with ALHIV participants. It may be that these concepts perform well cross-culturally, as South Africa is considered a multi-cultural country; yet many

of the systems and institutions are based on Western principles and values. While participants in this study were raised within collectivist cultures, they were also exposed to and expected to adapt to individualistic cultures and values that are perpetuated in their social circles. For example, when explaining an answer to 'someone in my family accepts me', participant A02 stated that it helped her feel like she was 'just like' her other family members and that she was 'a normal person'. Therefore, the connected-ness and acceptance she felt from her family members enabled (representing the collective values) her own self-acceptance and boosted her self-esteem (representing individualistic values) [35]. Similarly, A06 mentioned that living with HIV did not define who he is 'be-cause if it did, I would have killed myself', indicating that self-acceptance is a motivator to continue living and receiving treatment.

On the other hand, participant A05 indicated that she 'somewhat agrees' with self-acceptance questions such as 'I am kind to myself', 'I am happy with the way I am', and 'I am living with HIV, and I am okay with that'. When asked to explain her answers, the participant revealed that a few months prior she was would have answered 'disagree' to those questions, as she felt bad about herself as someone living with HIV. Consequently, this impacted her adherence to treatment. However, she described that she was on a journey, and she has started feeling more accepting of herself, but she is not 'quite there yet'. The participant was one of the younger adolescents (15 years) and was informed of her HIV status when 11 years of age. Based on the SMoMW, and her answers to the MWM-ALHIV, we can hypothesise that even though she struggled with adherence, the connectedness she feels from her family and friends and the support she received from the doctor provided a buffer which helped her along her journey of self-acceptance, which in turn is giving her the tools she needs to re-commit to her treatment. Additionally, age is considered part of the life context in the SMoMW, which can play a role in mental well-ness and health outcomes. For example, in comparison to the older participants, A05 (like her peers) is at the stage where she may be more impulsive, rebellious and/or forgetful when it comes to her treatment. During the interview, she mentioned that sometimes when she is out with her friends, she has so much fun that she forgets to take her medication, but when she does remember she would rather skip the dose if it were too late. On the other hand, older participants may have been through more life experiences which brought them further along the journey of self-acceptance. Additionally, they have been in mainstream adult care for a longer period of time, which would require them to manage their treatment independently.

The aforementioned indicates that the MWM-ALHIV has the potential to screen for mental wellness among ALHIV in a way that can indicate high levels of mental wellness but can also pick up on areas where they may be struggling, without necessarily being in 'crisis'. For example, the struggles A05 speaks about in her journey to adherence and maintaining self-acceptance may not have been flagged using instruments that are frequently used in assessing mental health among ALHIV such as the Child Depression Inventory (CDI) or the strengths and difficulties questionnaire [51]. However, her answers on the MWM-ALHIV suggest that she may benefit from additional support that specifically targets her self-acceptance and addresses issues around treatment reminders that are ap-propriate for her age.

In addition, findings from our systematic review of mental wellness instruments for adolescents indicated that there are relatively few instruments measuring mental wellness [often referred to as general mental well-being] (e.g., the Warwick-Edinburgh Mental Wellbeing Scale [52] and the Mental Health Continuum-Short Form [53]). Instead, majority of the instruments measured singular indicators of mental wellness, such as connectedness (the Milwaukee Youth Belongingness Scale [54]), or self-esteem (e.g., the Rosenberg Self-esteem Scale [55]). Instruments measuring multiple indicators are preferred over instruments that focus on one mental wellness measure, because the former can pro-vide a more comprehensive overview of both eudemonic and hedonic dimensions of mental wellness [56]. Various scholars have argued that both hedonic (feeling well) and eudemonic dimensions (functioning well) should be emphasized and included in measures to provide a more holistic view of adolescent mental wellness [57,58]. Particular strengths of the MWM-ALHIV are that the measure includes both general questions reflecting eudemonic and hedonic dimensions of mental wellness, as well as those specific to living with HIV. Furthermore, unlike the other instruments identified in the review [26,28] that originated in developed countries, the MWM–ALHIV was developed after ex-tensive research to first conceptualize mental wellness for ALHIV in the African context. The MWM–ALHIV is the first mental wellness measure for ALHIV in the South African context that was developed in a South African setting.

Conclusion

This study was principally undertaken to determine the face validity and improve upon the content validity of the MWM–ALHIV. The MWM–ALHIV was developed as an age and culturally appropriate measure for ALHIV in the South African context. Unlike other

instruments measuring general mental wellness or aspects of mental wellness that have been developed in the Western context and subsequently adapted to other cultures and contexts, the MWM–ALHIV was developed with ALHIV to ensure the appropriate-ness and relevance of the domains and to reflect their lived experiences.

The cognitive interviews represent the next logical step in the study to include the voices of ALHIV in the instrument development process. Based on the responses from participants, revisions were made to improve the overall readability and comprehension of the measure. Additionally, the interviews also provide further insight into the appropriateness and confirmability of the domains of the measure and the SMoMW. Furthermore, the findings provide insight into considerations of language and implementation related to cognitive interviews and survey development with adolescents in the South African context. This study represents a snapshot of a larger project aimed at conceptualizing and developing a measure of mental wellness for ALHIV. Following the instrument development process, we aim to pilot the instrument and engage in further rounds of cognitive interviews to establish its psychometric properties.

Study limitations and recommendations

As a qualitative study, certain limitations are noted. However, due to the amount of rich data gathered from the interviews, we view this as a pilot stage which provided les-sons learned for future rounds of cognitive interviews, which is in line with the cognitive interview iterative approach; we may conduct these rounds before the pilot testing of the instrument and after. The sample of participants in this study lived in an urban area and accessed treatment at a public healthcare facility from a specific community. We recommend further rounds of the cognitive tests be done with participants from other urban communities in addition to rural communities. Furthermore, based on the lessons learned, we would aim to recruit interviewers that speak isiXhosa so that participants may answer in the language of their choice. While the researcher offered the participants the opportunity to explain some concepts in their own language, she was limited in following up with further probing questions. As mentioned, to reflect the multilingual, fluid language of the South African landscape, we would recommend that this instrument be translated into appropriate languages and different dialects, or include some code-switching between languages, as participants may find this more relatable and easier to navigate.

References

1. Eriksson, C.; Arnarsson, M.; Damsgaard, M.T.; Löfstedt, P.; Potrebny, T.; Suominen, S.; Thorsteinsson, E.B.; Torsheim, T.; Välimaa, R.; Due, P. Towards enhancing research on adolescent positive mental health. *Nord. Welf. Res.* 2019, *4*, 113–128. https://doi.org/10.18261/issn.2464-4161-2019-02-08.
2. United Nations. World Youth Report: Youth and the 2030 Agenda for Sustainable Development World. Available online: https://www.un.org/development/desa/youth/wp-content/uploads/sites/21/2018/12/WorldYouthReport-2030Agenda.pdf (accessed on 10 December 2022).
3. UNICEF. Adolescents Living with HIV: Developing and Strengthening Care and Support Services. Available online: https://www.unicef.org/eca/sites/unicef.org.eca/files/2017-10/Adolescents_Living_with_HIV.pdf (accessed on 10 December 2022).
4. Vreeman, R.C.; McCoy, B.M.; Lee, S. Mental health challenges among adolescents living with HIV. *J. Int. AIDS Soc.* 2017, *20*, 21497, https://doi.org/10.7448/ias.20.4.21497.
5. Laurenzi, C.; Skeen, S.; Gordon, S.; Akin-Olugbade, O.; Abrahams, N.; Bradshaw, M.; Brand, A.; Du Toit, S.; Melendez-Torres, G.J.; Tomlinson, M.; et al. Preventing mental health conditions in adolescents living with HIV: An urgent need for evidence. *J. Int. AIDS Soc.* 2020, *23*, e25556. https://doi.org/10.1002/jia2.25556.
6. Nichols, J.; Steinmetz, A.; Paintsil, E. Impact of HIV-Status disclosure on adherence to antiretroviral therapy among HIV-Infected children in resource-limited settings: A Systematic Review. *AIDS Behav.* 2017, *21*, 59–69. https://doi.org/10.1007/s10461-016-1481-z.
7. Fabri, M.; Ingabire, C.; Cohen, M.; Donenberg, G.; Nsanzimana, S. The mental health of HIV-positive adolescents. *Lancet Psychiatry* 2015, *2*, e21.
8. Boyes, M.E.; Cluver, L.D.; Meinck, F.; Casale, M.; Newnham, E. Mental health in South African adolescents living with HIV: Correlates of internalising and externalising symptoms. *AIDS Care* 2019, *31*, 95–104. https://doi.org/10.1080/09540121.2018.1524121.
9. Woollett, N.; Cluver, L.; Bandeira, M.; Brahmbhatt, H. Identifying risks for mental health problems in HIV positive adolescents accessing HIV treatment in Johannesburg.

J. Child Adolesc. Ment. Health 2017, *29*, 11–26. https://doi.org/10.2989/17280583.2017.1283320.

10. Nguyen, N.; Lovero, K.L.; Falcao, J.; Brittain, K.; Zerbe, A.; Wilson, I.B.; Kapogiannis, B.; De Gusmao, E.P.; Vitale, M.; Couto, A.; et al. Mental health and ART adherence among adolescents living with HIV in Mozambique. *AIDS Care* 2022, 1–9, https://doi.org/10.1080/09540121.2022.2032574.
11. UNICEF. Mental Health and Antiretroviral Treatment Adherence among Adolescents Living with HIV: Evidence on Risk Pathways and Protective Factors. Available online: https://www.unicef.org/esa/documents/mental-health-and-antiretroviral-treatment-adherence (accessed on 21 December 2022).
12. Zanoni, B.C.; Sibaya, T.; Cairns, C.; Lammert, S.; Haberer, J.E. Higher retention and viral suppression with adolescent-focused HIV clinic in South Africa. *PLoS ONE* 2017, *12*, e0190260, https://doi.org/10.1371/journal.pone.0190260.
13. UNAIDS. AIDSinfo. Available online: https://aidsinfo.unaids.org/ (accessed on 19 September 2022).
14. Zungu, N.; Naidoo, I.; Hodes, R.; North, A.; Mabaso, M.; Skinner, D.; Gittings, L.; Sewpaul, R.; Takatshana, S.; Jooste, S.; et al. *Adolescents living with HIV in South Africa*; Human Sciences Research Council: Pretoria, South Africa, 2021.
15. Mabaso, M.; Makola, L.; Naidoo, I.; Mlangeni, L.L.; Jooste, S.; Simbayi, L. HIV prevalence in South Africa through gender and racial lenses: Results from the 2012 population-based national household survey. *Int. J. Equity Health* 2019, *18*, 167. https://doi.org/10.1186/s12939-019-1055-6.
16. Greifinger, R.; Dick, B. Provision of psychosocial support for young people living with HIV: Voices from the field. *SAHARA-J J. Soc. Asp. HIV/AIDS* 2011, *8*, 33–41. https://doi.org/10.1080/17290376.2011.9724982.
17. Mavhu, W.; Berwick, J.; Chirawu, P.; Makamba, M.; Copas, A.; Dirawo, J.; Willis, N.; Araya, R.; Abas, M.A.; Corbett, E.L.; et al. Enhancing psychosocial support for HIV positive adolescents in Harare, Zimbabwe. *PLoS ONE* 2013, *8*, e70254. https://doi.org/10.1371/journal.pone.0070254.
18. Okonji, E.F.; Mukumbang, F.C.; Orth, Z.; Vickerman-Delport, S.A.; Van Wyk, B. Psychosocial support interventions for improved adherence and retention in ART care for adolescents and young people living with HIV: A scoping review. *BMC Public Health* 2020, *20*, 1841. https://doi.org/10.1186/s12889-020-09717-y.

19. World Health Organization. A Qualitative Review of Psychosocial Support Interventions for Young People Living with HIV. Available online: https://apps.who.int/iris/handle/10665/70174 (accessed on 20 December 2022).
20. World Health Organization. Integration of Mental Health and HIV Interventions. Available online: https://www.who.int/publications/i/item/9789240043176 (accessed on 20 December 2022).
21. World Health Organization. Helping Adolescents Thrive: Guidelines on Mental Health Promotive and Preventive Interventions for Adolescents. Available online: https://www.who.int/publications/i/item/9789240011854 (accessed on 3 December 2022).
22. Dambi, J.M.; Cowan, F.M.; Martin, F.; Sibanda, S.; Simms, V.; Willis, N.; Bernays, S.; Mavhu, W. Conceptualisation and psychometric evaluation of positive psychological outcome measures used in adolescents and young adults living with HIV: A mixed scoping and systematic review protocol. *BMJ Open* 2022, *12*, e066129, https://doi.org/10.1136/bmjopen-2022-066129.
23. Wilson Fadiji, A.; Wissing, M.P. Positive Psychology in Sub-Saharan Africa. In *The International Handbook of Positive Psychology*; Chang, E.C., Downey, C., Yang, H., Zettler, I., Muyan-Yılık, M., Eds.; Springer: Cham, Switzerland, 2022.
24. Canfield, J.P.; Harley, D.; Hunn, V.; Haddad, K.L.; Kim, S.-H.; Elliott, W.; Mangan, L. Development and initial validation of the urban adolescent hope scale. *J. Evid. Inf. Soc. Work* 2018, *15*, 243–257. https://doi.org/10.1080/23761407.2018.1431576.
25. Ganga, N.S.; Kutty, V.R. Measuring positive mental health: Development of the Achutha Menon Centre Positive Mental Health Scale. *Asia Pac. J. Public Health* 2015, *27*, NP1893–NP1906. https://doi.org/10.1177/1010539512444119.
26. Orth, Z.; Moosajee, F.; Van Wyk, B. Measuring mental wellness of adolescents: A systematic review of instruments. *Front. Psychol.* 2022, *13*, 835601. https://doi.org/10.3389/fpsyg.2022.835601.
27. Balthip, K.; McSherry, W.; Nilmanat, K. Spirituality and dignity of Thai adolescents living with HIV. *Religions* 2017, *8*, 257. https://doi.org/10.3390/rel8120257.
28. Orth, Z.; van Wyk, B. Measuring mental wellness among adolescents living with a physical chronic condition: A systematic review of the mental health and mental well-being instruments. *BMC Psychol.* 2021, *9*, 176. https://doi.org/10.1186/s40359-021-00680-w.

29. Rose, T.; Joe, S.; Williams, A.; Harris, R.; Betz, G.; Stewart-Brown, S. Measuring mental wellbeing among adolescents: A systematic review of instruments. *J. Child Fam. Stud.* 2017, *26*, 2349–2362. https://doi.org/10.1007/s10826-017-0754-0.

30. Bentley, N.; Hartley, S.; Bucci, S. Systematic review of self-report measures of general mental health and wellbeing in adolescent mental health. *Clin. Child Fam. Psychol. Rev.* 2019, *22*, 225–252. https://doi.org/10.1007/s10567-018-00273-x.

31. Krause, N. A comprehensive strategy for developing closed-ended survey items for use in studies of older adults. *J. Gerontol. Ser. B Psychol. Sci. Soc. Sci.* 2002, *57*, 263–274. https://doi.org/10.1093/geronb/57.5.s263.

32. de Wit, M.; Pouwer, F.; Gemke, R.J.; de Waal, H.A.D.-V.; Snoek, F.J. Validation of the WHO-5 well-being index in adolescents with type 1 diabetes. *Diabetes Care* 2007, *30*, 2003–2006. https://doi.org/10.2337/dc07-0447.

33. Ravens-Sieberer, U.; Auquier, P.; Erhart, M.; Gosch, A.; Rajmil, L.; Bruil, J.; Power, M.; Duer, W.; Cloetta, B.; Czemy, L.; et al. The KIDSCREEN-27 quality of life measure for children and adolescents: Psychometric results from a cross-cultural survey in 13 European countries. *Qual. Life Res.* 2007, *16*, 1347–1356. https://doi.org/10.1007/s11136-007-9240-2.

34. UNAIDS. Ending the AIDS Epidemic for Adolescents, with Adolescents A Practical Guide to Meaningfully Engage Adolescents in the AIDS Response. Available online: https://www.unaids.org/sites/default/files/media_asset/ending-AIDS-epidemic-adolescents_en.pdf (accessed on 3 December 2022).

35. Orth, Z.; van Wyk, B. Discourses of mental wellness among adolescents living with HIV in Cape Town, South Africa. *Psychol. Res. Behav. Manag.* 2022, *15*, 1435–1450. https://doi.org/10.2147/PRBM.S360145.

36. Orth, Z.; van Wyk, B. A facility-based family support intervention to improve treatment outcomes for adolescents on antiretroviral therapy in the Cape Metropole, South Africa. *J. Int. Assoc. Provid. AIDS Care* 2021, *20*, 1–11. https://doi.org/10.1177/23259582211059289.

37. Orth, Z.; van Wyk, B. Rethinking mental health wellness among adolescents living with HIV in the African context: An integrative review of mental wellness components. *Front. Psychol.* 2022, *13*, 955869. https://doi.org/10.3389/fpsyg.2022.955869.

38. Mittelmark, M.B.; Bauer, G.F.; Vaandrager, L.; Pelikan, J.M.; Sagy, S.; Eriksson, M.; Lindström, B.; Meier Magistretti, C. *The Handbook of Salutogenesis*. Springer: Cham, Switzerland, 2017.

39. Orth, Z.; van Wyk, B. Content validation of a Mental Wellness Measuring instrument for Adolescents Living with HIV: A modified Delphi Study. 2023, *Unpublished manuscript*.
40. Connell, J.; Carlton, J.; Grundy, A.; Buck, E.T.; Keetharuth, A.D.; Ricketts, T.; Barkham, M.; Robotham, D.; Rose, D.; Brazier, J. The importance of content and face validity in instrument development: Lessons learnt from service users when developing the Recovering Quality of Life measure (ReQoL). *Qual. Life Res.* 2018, *27*, 1893–1902, https://doi.org/10.1007/s11136-018-1847-y.
41. DeVellis, R.F.; Thorpe, C.T. *Scale Development: Theory and Applications*, 4th ed.; Sage Publications Inc.: Thousand Oaks, CA, USA, 2016.
42. Knafl, K.; Deatrick, J.; Gallo, A.; Holcombe, G.; Bakitas, M.; Dixon, J.; Grey, M. Focus on research methods the analysis and interpretation of cognitive interviews for instrument development. *Res. Nurs. Health* 2007, *30*, 224–234. https://doi.org/10.1002/nur.20195.
43. Willis, G.B.; Artino, A.R. What do our respondents think we're asking? Using cognitive interviewing to improve medical education surveys. *J. Grad. Med. Educ.* 2013, *5*, 353–356, https://doi.org/10.4300/jgme-d-13-00154.1.
44. South African Gateway. The 11 Languages of South Africa. Available online: https://southafrica-info.com/arts-culture/11-languages-south-africa/ (accessed on 23 December 2022).
45. De Klerk, S.; Jerosch-Herold, C.; Buchanan, H.; Van Niekerk, L. Cognitive Interviewing during Pretesting of the Prefinal Afrikaans for the Western Cape Disabilities of the Arm, Shoulder and Hand Questionnaire following Translation and Cross-Cultural Adaptation. *Occup. Ther. Int.* 2020, *2020*, 3749575, https://doi.org/10.1155/2020/3749575.
46. Chimbga, W.W.M.; Meier, C. The language issue in South Africa: The way forward? *Mediterr. J. Soc. Sci.* 2014, *5*, 1424–1433. https://doi.org/10.5901/mjss.2014.v5n20p1424.
47. Western Cape Government Education. Adapted Curriculum and Assessment Policy Statement for Schools of Skills and Schools with Skills Units. 2013. Available online: https://wcedonline.westerncape.gov.za/Specialised-ed/SpecialSchools/SchoolofSkills/SoS-Curr/Curr-Maintenance.pdf (accessed on 23 December 2022).

48. Sherman, G.G.; Mazanderani, A.H.; Barron, P.; Bhardwaj, S.; Niit, R.; Okobi, M.; Puren, A.; Jackson, D.J.; Goga, A.E. Toward elimination of mother-to-child transmission of HIV in South Africa: How best to monitor early infant infections within the Prevention of Mother- to-Child Transmission Program. *J. Glob. Health* 2017, *7*, 010701. https://doi.org/10.7189/jogh.07.010701.

49. Taylor, T.M.; Thurman, T.R.; Nogela, L. "Every time that month comes, I remember":using cognitive interviews to adapt grief measures for use with bereaved adolescents in South Africa. *J. Child Adolesc. Ment. Health* 2016, *28*, 163–174, https://doi.org/10.2989/17280583.2016.1210154.

50. 50. University of Cape Town. The Importance of the First-Ever Afrikaaps Dictionary. Available online: https://www.news.uct.ac.za/article/-2021-08-30-the-importance-of-the-first-ever-afrikaaps-dictionary (accessed on 29 December 2022).

51. Dessauvagie, A.; Jörns-Presentati, A.; Napp, A.-K.; Stein, D.; Jonker, D.; Breet, E.; Charles, W.; Swart, R.L.; Lahti, M.; Suliman, S.;et al. The prevalence of mental health problems in sub-Saharan adolescents living with HIV: A systematic review. Glob. Ment. Health 2020, 7, e29. https://doi.org/10.1017/gmh.2020.18.

52. Hoffman, S.; Rueda, H.; Lambert, M.C. Confirmatory factor analysis of the Warwick-Edinburgh Mental Wellbeing Scale among youth in Mexico. Int. Soc. Work 2019, 62, 309–315. https://doi.org/10.1177/0020872817727576.

53. Echeverría, G.; Torres, M.; Pedrals, N. Validation of a Spanish Version of the Mental Health Continuum-Short Form Questionnaire. Psicothema 2017, 29, 96–102. https://doi.org/10.7334/psicothema2016.3.

54. Slaten, C.D.; Rose, C.A.; Bonifay, W.; Ferguson, J.K. The Milwaukee Youth Belongingness Scale (MYBS): Development and validation of the scale utilizing item response theory. Sch. Psychol. 2019, 34, 296–306. https://doi.org/10.1037/spq0000299

55. Rosenberg, M. Conceiving the Self; Basic Books: New York, NY, USA, 1979.

56. Witten, H.; Savahl, S.; Adams, S. Adolescent flourishing: A systematic review. Cogent Psychol. 2019, 6, 1640341. https://doi.org/10.1080/23311908.2019.1640341

57. Huta, V. An overview of hedonic and eudaimonic well-being concepts. In Handbook of Media Use and Well-Being; Reinecke, L., Oliver, M.B., Eds.; Routledge: New York, NY, USA, 2016.

58. Gentzler, A.L.; DeLong, K.L.; Palmer, C.A.; Huta, V. Hedonic and eudaimonic motives to pursue well-being in three samples of youth. Motiv. Emot. 2021, 45, 312–326. https://doi.org/10.1007/s11031-021-09882-6.

CHAPTER 11

Conclusions and Recommendations

Executive summary

"Curing the negatives does not produce the positives" – Martin Seligman

The quote by Seligman encapsulates the crux of this thesis, which is to catalyse a change in health service delivery for ALHIV from a perspective primarily concerned with reducing disease severity towards one which empowers ALHIV to adhere to treatment and lead healthier lives through strengthening their mental wellness.

To this end, this doctoral study aimed to develop a screening instrument which can be used to measure mental wellness among ALHIV in South Africa. The need for this measure emerged due to several compounding issues related to addressing mental health among ALHIV. Firstly, the link between mental health and HIV outcomes is well-established in the literature [1–4]. Compelling evidence suggests a positive relationship between mental health and adherence outcomes, as several studies have indicated that poor mental health indicators such as depression and anxiety are associated with poor adherence outcomes and retention in care [5–8]. Conversely, studies evaluating the effectiveness of psychosocial interventions for ALHIV report that various types of positive mental health mechanisms, such as peer and family support, mindfulness and CBT, successfully improve mental health and subsequent adherence outcomes [9–13]. These findings seem promising – unfortunately, 'improved mental health outcomes' in such studies are mostly measured as reductions in poor mental health symptomology rather than an increase in mental wellness capacities. Some studies include instruments of mental wellness to measure positive indicators of mental health in addition to those instruments measuring indicators of mental illness symptomology.

However, in such cases, the meaning of mental wellness is not clearly defined, indicating that the instruments to measure these indicators are not comprehensive and are often limited to measuring certain aspects of mental wellness such as self-esteem or family support. Although few studies have aimed to investigate related concepts of mental wellness, such as resilience [14–17], there is a dearth of studies aimed at systematically delineating the entire content domain of mental wellness for ALHIV [18,19]. A second problem related to research on mental wellness among ALHIV arises from the fact that many mental wellness measures

have been developed with general adult or adolescent populations living in high-income countries (HIC) [20,21]. This is problematic as the nature and meaning of mental wellness may differ across developmental stages and cultural contexts. In other words, even instruments developed with general adolescent populations may not be entirely appropriate or relevant for ALHIV in South Africa. Therefore, this study aimed to develop a cost-effective, easy-to-use, culturally and age-appropriate instrument which can be used to assess the mental wellness of ALHIV as part of current treatment practices.

To meet the aims and objectives of the study, we used test construction theory guided by the frameworks proposed by DeVellis [22] and Boateng et al. [23] to first conceptualise mental wellness among ALHIV and subsequently develop the measurement instrument. The frameworks proposed by DeVellis [22] and Boateng et al. [23] provided a useful guide for the current doctoral study by emphasising the collaborative and iterative nature of the processes involved in conceptualising mental wellness and item development, as well as framing the way forward to complete scale development, establish the psychometric properties of the instrument and translating it to other languages commonly spoken in the South African context. The test construction process was conducted over 3 phases:

Phase 1 was part of the conceptualisation process or what DeVellis [22] refers to as 'determining what needs to be measured'. Mental wellness is an elusive concept. As such, the first step in this process involved identifying the gap in the literature and establishing the need for an instrument to be developed by conducting a systematic review of all mental health instruments used with adolescents globally.

Phase 2 represented a continuation of the conceptualisation process. Using multiple qualitative methods as a means of triangulation, we identified and clarified what mental wellness means for ALHIV and which mental wellness concepts should be targeted in interventions aimed at improving their mental health. The photovoice interviews with ALHIV were particularly insightful in helping us to go beyond identifying the key dimensions of mental wellness and map how the relations between these concepts work to support their overall mental health, navigate the challenges associated with adolescence and manage their treatment effectively. Reflecting on the continuous and dynamic process of test construction, we used the findings from phases 1 and 2 to develop the Salutogenic Model of Mental Wellness (SMoMW) which we adapted from Antonovsky's [24] Salutogenic Model of Health.

Phase 3 represents the item generation, instrument development and initial validation of the instrument. Using the SMoMW as a guide, we developed a draft of the Mental Wellness Measure for ALHIV (MWM-ALHIV) and established the content validity by presenting it to a panel of experts who participated in a Delphi Study. Once consensus was reached, we aimed to establish further face validity through cognitive interviews with a sample of ALHIV.

Contribution of the study

This thesis provides important theoretical and methodological contributions to the field of mental wellness for ALHIV South Africa – through following the test construction theory guidelines proposed by DeVellis [22] and Krause [25], we engaged in an iterative and collaborative research process which culminated in the development of the Salutogenic Model of Mental Wellness (SMoMW) which was used as the theoretical base to develop the Mental Wellness Measure for Adolescents Living with HIV (MWM-ALHIV). The SMoMW provides a new way to conceptualize and understand the role of mental wellness in overall health for ALHIV and clearly distinguishes mental wellness factors which should be targeted in intervention, policy, and future research. Unlike the mental health continuum model – which is commonly used to illustrate a linear perspective of mental health phases ranging from thriving to crises – the SMoMW illustrates the role and interplay of life course factors (i.e., age, genetics, culture), exposure to potential life stressors (adherence, stigma, disclosure), access to resources (i.e., knowledge of HIV, clinic support) and mental wellness among ALHIV [26]. Additionally, the SMoMW identifies specific cognitive, behavioural and motivational mental wellness factors, represented through the salutogenic concept of SOC. Therefore, a strength of the SMoMW is that it can be used as an analysis framework or tool to identify and understand the mental wellness needs of ALHIV in context.

Using a multi-phase approach, we developed the MWM-ALHIV. Despite the need for cultural and age-appropriate instruments for ALHIV, there are few measures specifically developed for this population, as designing a new measure is a time-consuming and costly process [25]. Due to these challenges, arguments are made to justify the adaption of existing instruments [25]. However, while such instruments may demonstrate statistically sound reliability and validity – thereby providing justification that these measures are potentially transferable to diverse populations and contexts – we should also be cognizant of the fact that there are nuances in the lived experiences of ALHIV in LMICs like South Africa, which may result in differential perceptions of the phenomena (like mental wellness). Indeed, if we apply

the SMoMW to draw comparisons between ALHIV and adolescents in the general population, we may elucidate these differences. For example, all adolescents may struggle with issues around self-acceptance. However, for ALHIV, self-acceptance plays a key role in reframing their perception of living with HIV, which can support their ability and desire to adhere to ART. Therefore, MWM-ALHIV represents an instrument designed specifically for ALHIV by drawing on findings from the reviews and direct engagement with ALHIV. This instrument allows researchers to study mental wellness among adolescents living with HIV more accurately.

Additionally, we established the content and face validity through a modified Delphi study technique with experts in the field of mental health and HIV, and engaged with ALHIV as 'experts' using cognitive interviewing. Therefore, the MWM-ALHIV is ready to be piloted to establish the reliability and further validity among ALHIV in South Africa. Additionally, the measure can be translated and adapted to reflect the diverse language profiles of South Africa and the African context. In its current state the MWM-ALHIV represents a formative tool that has undergone rigorous development and is ready to be piloted for further development. Once the MWM-ALHIV has been piloted and undergone psychometric testing we propose that it can be used to screen mental wellness in clinical and research settings, which can help identify those ALHIV who may be struggling with their mental health but would not be considered as having a mental health problem. Using the MWM-ALHIV, healthcare workers and other professionals working with ALHIV will be able to identify which mental wellness factors should be targeted in health promotion and prevent the onset of mental illness. In conclusion, this study has provided a novel contribution to the field of mental wellness research among adolescents living with HIV in South Africa.

Recommendations

More research is needed to understand the role of mental wellness in supporting adherence outcomes and overall health among ALHIV in South Africa. There is a growing body of qualitative research exploring the lived experiences of ALHIV, which sheds light on the importance of mental wellness factors such as resilience, connectedness, hopefulness etc. The lack of quantitative research may be related to a lack of clear and standardised mental wellness measures. Furthermore, tool development can be a time consuming and expensive process. As such, we recommend that future studies build on the work from this study by using the formative MWM-ALHIV to pilot, adapt and validate it in different contexts.

We also recommend that this measure be translated to other languages commonly spoken in South Africa and the African context and piloted [27]. Once validated, this instrument should be used to build evidence-based mental wellness among ALHIV to guide the development, implementation and monitoring of interventions and mental health promotion activities to improve the delivery of youth-friendly services and guide the integration of mental wellness services in public healthcare.

References

1. Cluver LD, Sherr L, Toska E, et al. From surviving to thriving: Integrating mental health care into HIV, community, and family services for adolescents living with HIV. Lancet Child Adolesc Health. 2022;6(8):582-592. doi:10.1016/S2352-4642(22)00101-8
2. Bhana A, Abas MA, Kelly J, et al. Mental health interventions for adolescents living with HIV or affected by HIV in low- and middle-income countries: systematic review. BJPsych Open. 2020; 6: 1-15. doi: 10.1192/bjo.2020.67.
3. Okumu M, Nyoni T, Byansi W. Alleviating psychological distress and promoting mental wellbeing among adolescents living with HIV in sub-Saharan Africa, during and after COVID-19. Glob Public Health. 2021; 16: 964–973. doi: 10.1080/17441692.2021.1912137
4. UNICEF. Mental health and antiretroviral treatment adherence among adolescents living with HIV: Evidence on risk pathways and protective factors. Available from: https://www.unicef.org/esa/documents/mental-health-and-antiretroviral-treatment-adherence.
5. Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. J Int AIDS Soc. 2017; 20: 21497. doi: 10.7448/IAS.20.4.21497.
6. Hudelson C, Cluver L. Factors associated with adherence to antiretroviral therapy among adolescents living with HIV/AIDS in low- and middle-income countries: A systematic review. AIDS Care. 2015; 27(7): 805–816. doi: 10.1080/09540121.2015.1011073.
7. Kim MH, Mazenga AC, Yu X, et al. High self-reported non-adherence to antiretroviraltherapy amongst adolescents living with HIV in Malawi: Barriers and associated factors. J Int AIDS Soc. 2017; 20: 1–12. doi: 10.7448/IAS.20.1.21437.
8. Boyes ME, Cluver LD, Meinck F, et al. Mental health in South African adolescents living with HIV: correlates of internalising and externalising symptoms. AIDS Care. 2019; 31: 95–104. doi: 10.1080/09540121.2018.1524121.
9. Laurenzi CA, Melendez-Torres GJ, Page DT, et al. How Do Psychosocial Interventions for Adolescents and Young People Living with HIV Improve Adherence and Viral Load? A Realist Review. J Adolesc Health. 2022; 71: 254–269. doi: 10.1016/j.jadohealth.2022.03.020.
10. Mavhu W, Berwick J, Chirawu P, et al. Enhancing psychosocial support for HIV

positive adolescents in Harare, Zimbabwe. PLoS One. 2013; 8: 1-9. doi: 10.1371/journal.pone.0070254.

11. World Health Organization. A qualitative review of psychosocial support interventions for young people living with HIV. Available from: https://apps.who.int/iris/handle/10665/70174.
12. Spaan, P.; Luenen, S.; Ganesfski, N.; and Kraaiji V. Psychosocial interventions enhance HIV medication adherence: A systematic review and meta-analysis. J Health Psychol. 2018; 25 1326–1340. doi: 10.1177/1359105318755545.
13. Okonji EF, Mukumbang F, Orth Z, et al. Psychosocial support interventions for improved adherence and retention in ART care for adolescents and young people living with HIV: A scoping review. BMC Public Health. 2020;20: 1–27. doi: 10.1186/s12889-020-09717-y.
14. Adegoke CO, Steyn MG. Yoruba culture and the resilience of HIV-positive adolescent girls in Nigeria. Cult Health Sex. 2018: 20(11); 1287–98. https://doi.org/10.1080/13691058.2017.1422806.
15. Bhana A, Mellins CA, Small L, et al. Resilience in perinatal HIV+ adolescents in South Africa. AIDS Care. 2016; 28(2): 49–59. doi: 10.1080/09540121.2016.1176676.
16. Kaunda-Khangamwa BN, Kaunda-Khangamwa BN, Kaunda-Khangamwa BN, et al. Adolescents living with HIV, complex needs and resilience in Blantyre, Malawi. AIDS Res Ther. 2020;17(35):1–13. doi:10.1186/s12981-020-00292-1.
17. Dow DE, Mmbaga BT, Gallis JA, et al. A group-based mental health intervention for young people living with HIV in Tanzania: results of a pilot individually randomized group treatment trial. BMC Public Health. 2020;20(1):1358. doi:10.1186/s12889-020-09380-3.
18. Dambi JM, Cowan FM, Martin F, et al. Conceptualisation and psychometric evaluation of positive psychological outcome measures used in adolescents and young adults living with HIV: a mixed scoping and systematic review protocol. BMJ Open. 2022; 12: 1-8. doi: 10.1136/bmjopen-2022-066129.
19. World Health Organization. Helping adolescents thrive: Guidelines on mental health promotive and preventive interventions for adolescents. 2020. Available from: https://www.who.int/publications/i/item/9789240011854.
20. Orth Z, van Wyk B. Measuring mental wellness among adolescents living with a physical chronic condition: a systematic review of the mental health and mental well-being instruments. BMC Psychol. 2021; 9:1-17. doi: 10.1186/s40359-021-00680-w.

21. Orth Z, Moosajee F, van Wyk B. Measuring Mental Wellness of Adolescents: A Systematic Review of Instruments. Front Psychol. 2022; 13:1-14. doi: 10.3389/fpsyg.2022.835601.
22. DeVellis, RF. Scale development: Theory and applications 4th ed. Thousand Oaks, CA: Sage Publications Inc, 2016.
23. Boateng GO, Neilands TB, Frongillo EA, et al. Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. Frontiers in Public Health. 2018; 6: 1-18. doi: 10.3389/fpubh.2018.00149.
24. Mittelmark MB, Sagy S, Eriksson M, et al. The Handbook of Salutogenesis. Geneva, Chsm: Springer, 2017.
25. Krause N. A comprehensive strategy for developing closed-ended survey items for use in studies of older adults. J Gerontol B Psychol Sci Soc Sci. 2002; 57: 263–274. doi: 10.1093/geronb/57.5.s263.
26. Orth Z, van Wyk B. Discourses of mental wellness among adolescents living with HIV in Cape Town, South Africa. Psychology Res Behav Management. 2020. 15:1435-1450. doi: 10.2147/PRBM.S360145.
27. Taylor TM, Thurman TR, Nogela L. "Every time that month comes, I remember": Using cognitive interviews to adapt grief measures for use with bereaved adolescents in South Africa. J Child Adolesc Ment Health. 2016; 28: 163–174. doi: 10.2989/17280583.2016.121015.

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F: +27 21 959 3170
E: research-ethics@uwc.ac.zawww.uwc.ac.za

APPENDIX A: Ethics Letters

07 April 2021

Ms Z Orth
School of Public

Faculty of Community and Health Sciences Ethics Reference Number: BM19/09/18

Project Title: Conceptualisation and assessment of mental health wellness of adolescents living with HIV and on antiretroviral therapy in the Western Cape province, South Africa

Approval Period: 12 March 2021 – 12 March 2024

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

Permission to conduct the study must be submitted to BMREC for record-keeping.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

NHREC Registration Number: BMREC-130416-050

OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535
South Africa
T: +27 21 959 4111/2948
F: +27 21 959 3170
E: research-ethics@uwc.ac.za
www.uwc.ac.za

19 December

2019 Ms Z Orth
School of Public Health

Faculty of Community and Health Science Ethics Reference Number: BM19/9/18

Project Title: Conceptualisation and assessment of mental health wellness of adolescents living with HIV and on antiretroviral therapy in the Western Cape Province, South Africa.

Approval Period: 18 December 2019 – 18 December 2020

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee
Officer University of the Western
Cape

NHREC REGISTRATION NUMBER -130416-050

APPENDIX B: Delphi Study Stimulus Documents

Stimulus Document: Mental Wellness Instrument for Adolescents Living with HIV

Date:
Researcher: Zaida Orth
Supervisor: Prof Brian van Wyk
Participant: (Please fill in your unique ID number)

Delphi Study: First Round

Dear participant, thank you again for agreeing to take part in this study and share your expertise and knowledge to help facilitate the development of a mental wellness instrument for adolescents living with HIV (ALHIV), which forms part of the researcher's PhD. In this round we provide you with 3 sections in which you will be presented with certain prompts and provide your expert opinion on the suitability and appropriateness of the material. The aim of this study is to collate your feedback in successive rounds until a consensus is reached. However, we anticipate these successive rounds will be shorter as the main focus will be on the feedback provided. As such, we ask that you complete the rounds as soon as possible within the given timeframe to facilitate the process that we may complete the study in a timely manner.

1. **SECTION A: Purpose and aim of the instrument**

In this section, we provide you with information regarding the purpose, aim and definitions of the core construct. Please answer all questions and prompts based on your experience and expertise.

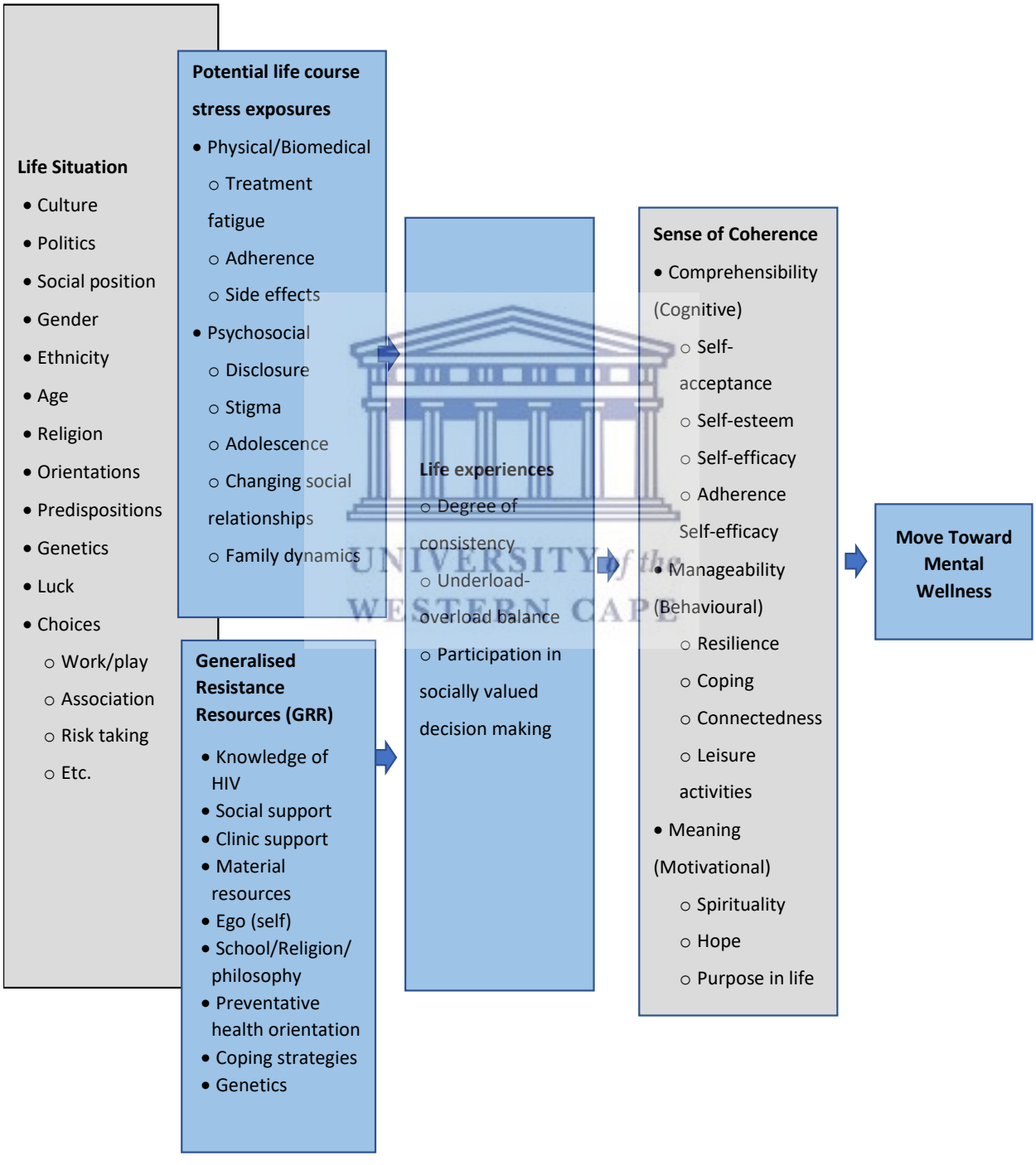
Mental Wellness:

This section provides more information on the theoretical on operational definitions of the mental wellness construct and domains to be measured in the instrument:

The proposed instrument, Mental Wellness Measure for Adolescents Living with HIV (MWM-ALHIV) has been formulated as part of the researcher's PhD studies. To aid in the conceptualisation of mental wellness as a measurable construct, we first completed a systematic review of mental wellness instruments used in research with adolescent populations. The systematic review of mental wellness instruments for adolescents provided us with an overview of instruments used for adolescents living with a physical chronic condition [1] and instruments used with adolescents in general [2]. We were then able to review the included instruments to determine the content domains of mental wellness. The instruments we identified varied from measures of general mental wellness, which included multiple domains such as connectedness, self-esteem, spirituality etc. to instruments measuring specific domains of mental wellness. Additionally, we noted that instruments of HRQoL and QoL were used to measure mental wellness in research with adolescents living with a chronic condition. Secondly, we conducted a qualitative photovoice study, which allowed us to explore how ALHIV understand and talk about mental wellness in the South African context [3], including the perspectives of key healthcare workers working closely with ALHIV [4]. We used the findings from these studies to develop a preliminary framework of mental wellness to guide the integrative review. Based on the findings from these three studies, we identified six mental wellness concepts: *Connectedness, Sense of Coherence (SOC), Self-esteem, Self-acceptance, Hope for the Future,* and *Spirituality* as well as six behaviours facilitating mental wellness*: Coping, Resilience, Purpose in Life (goals), Self-efficacy, Adherence Self-efficacy,* and *Leisure Activities* representing. From this, identified SOC as an emerging concepts which is considered to be the 'origins of health' from a salutogenic perspective. SOC reflects the coping capacity of people to deal with

everyday life stressors and consists of three elements: comprehensibility (cognitive – extent to which the problem/stressor understood), manageability (behavioural – perceived availability of resources and belief in ability to use successfully use them) and meaningfulness (motivational – extent that one wishes to cope). SOC is a developmental concept which begins to form during adolescence and stabilizes by the age of 30 years. Therefore, from a life-course perspective, strengthening SOC as a health promoting factor may improve overall physical and mental wellness in later life. As such, we developed a Salutogenic Model of Mental Wellness (SMoMW) (see figure), which was modified from Antonovsky's Salutogenic Model of Health [5] to guide the development of an age and culturally appropriate instrument for Mental Wellness among ALHIV in the South African context.

Figure 2. Salutogenic Model of Mental Wellness for Adolescents Living with HIV



Domains:
Based on the model, SOC represents a core domain and indicator of mental wellness. From this we have the following sub-domains:
Comprehensibility (cognitive)

1. **Self-acceptance:**

-A positive attitude toward yourself; acknowledge and accept multiple aspects of yourself including both good and bad qualities; and feel positive about your past life.
-based on internal validation
- ALHIV accept themselves and overcome internalised stigma related to HIV

Is the definition of self-acceptance clearly stated? **If no, provide comment on possible revisions you would recommend**

2. **Self-esteem**

-A person's overall subjective sense of personal worth or value
-Self-esteem is based on external feedback and validation, therefore may fluctuate
-ALHIV with high self-esteem talk about themselves in a positive light, highlight their best qualities

Is the definition of self-esteem clearly stated? **If no, provide comment on possible revisions you would recommend**

3. **Self-efficacy**

-A person's particular set of beliefs that determine how well one can execute a plan of action in prospective situations. Self-efficacy is a person's belief in their ability to succeed in a particular situation.

Is the definition of self-efficacy clearly stated? **If no, provide comment on possible revisions you would recommend**

4. **Adherence self-efficacy**

-Belief in one's ability to successfully adhere to treatment plans
-ALHIV can successfully manage their treatment by taking it correctly and on time every day

Is the definition of adherence self-efficacy clearly stated?

If no, provide comment on possible revisions you would recommend

Manageability (behavioural)

5. Resilience

-The ability to mentally withstand or adapt to uncertainty, challenges, and adversity.
-includes having access to knowledge and resources to withstand or adapt to stressors.

Is the definition of resilience clearly stated?

If no, provide comment on possible revisions you would recommend

6. Coping

-Coping refers to cognitive and behavioural efforts to manage (master, reduce, or tolerate) a troubled person-environment relationship
-ALHIV may engage in a range of coping mechanisms to deal with daily life stressors as well as those associated with managing a lifelong condition
-This may include engaging in activities they enjoy, connecting with others, engaging in meaningful activities.

Is the definition of coping clearly stated?

If no, provide comment on possible revisions you would recommend

7. Connectedness

-Sense that one has satisfying relationships with others, believing that one is cared for, loved, esteemed, and valued, and providing friendship or support to others
-feelings of belonging
-feeling taken care of, and wanting to take care of others (for ALHIV, this can come in the form of having family remind them to take medication, or reminding their family members to take medication in the case others in the household are HIV+)
-ALHIV may experience support from clinic staff
-spending time with friends
-Engaging in community activities

Is the definition of connectedness clearly stated?

If no, provide comment on possible revisions you would recommend

8. Leisure activities

-Engaging and participating in activities that bring enjoyment

-Like their peers, ALHIV engage in diverse interest and hobbies such as listening to music, sports, reading, dancing etc. these activities help them to cope, connect with others and find enjoyment in life. Additionally, engaging in such activities is indicative of a sense of physical wellbeing.

Is the definition of leisure activities clearly stated? **If no, provide comment on possible revisions you would recommend**

Meaning (motivational)

9. Spirituality

-Psychological process of bringing one's attention to the internal and external experiences occurring in the present moment; concern for or sensitivity to things of the spirit or soul.

- ALHIV may attend religious ceremonies and activities
- Belief in a higher power
- Connect with cultural heritage
- For ALHIV, spirituality can help them cope with life stressors by finding meaning in situations

Is the definition of spirituality clearly stated? **If no, provide comment on possible revisions you would recommend**

10. Hope

-Emotion characterized by positive feelings about the immediate or long-term future.

-ALHIV show a positive attitude toward life and their future

-Hopes and dreams for the future may motivate ALHIV to stay on treatment

-Some hope to finish school, get a good job, get married, start a family or even a cure for HIV.

-Like many adolescents, ALHIV may be idealistic about their future dreams (i.e. wants to be a singer or soccer star etc).

Is the definition of hope clearly stated? **If no, provide comment on possible revisions you would recommend**

11. Purpose in life

-You have goals in life and a sense of directedness; feel there is meaning to your present and past life; hold beliefs that give life purpose; and have aims and objectives for living.

- More than hope (less idealistic, more realistic), purpose in life represents a sense of purpose in their lives like caring for their younger siblings or family members
- Sense of responsibility
- Identified goals and understands the steps needed to reach them

Is the definition of purpose in life clearly stated? **If no, provide comment on possible revisions you would recommend**

Aim:

The aim of the instrument is to measure mental wellness among ALHIV

1.1.Is the aim of the measure clearly stated? **1.2.If no, please provide feedback**

Purpose:

The purpose of the instrument is as follows:

To screen mental wellness among ALHIV as an indicator of overall wellbeing

To screen mental wellness among ALHIV and investigate its relationship to adherence to ART

To provide further information on mental wellness among ALHIV as a buffer against mental health problems

1.3.Is the purpose of the instrument clear? **1.4.If no, please provide feedback and possible recommendations**

Type of measure:

The proposed measure is a screening instrument as this allows for initial evaluation and scoring of mental wellness across different domains. Additionally, this is considered an appropriate measurement type, as our goal is not to provide a clinical diagnosis of mental health problems, rather a general assessment of positive mental wellness 'strengths' which can be reinforced (through intervention programs, workshops etc.) to buffer against the development of mental health problems. Therefore, this screening tool will allow us to categorise participants into groups (e.g. ALHIV with high mental wellness or ALHIV with low mental wellness) with reasonable accuracy and can provide information on how mental wellness is related to maintaining adherence to ART (i.e. are participants with higher mental wellness scores demonstrating adherence?) or may provide an indication of which domains of mental wellness need intervention (i.e. participants may score high in one domain and low in another). Screening instruments are considered advantageous as they can be easily

administered in a timely and cost-efficient manner. Furthermore, the results from screening instruments are immediately available and easy to score and interpret – as such it may be used by a variety of professionals, including health care workers, counsellors and school staff.

1.5.Is the type of instrument appropriate?

1.6.Does the type of instrument align with the aim and purpose?

1.7.If no, please provide feedback and possible recommendations

Type of scale:
We propose a 5 point Likert type scale is used to allow respondents to express how much they agree or disagree with a particular statement

1.8.Is the type of item (Likert type) an appropriate choice for the screening instrument?

1.9.If no, please motivate, and provide recommendations for revision.

User group:
The proposed instrument may be administered by any researcher or professional that has experience working with ALHIV, or any professional that has substantial interaction (at least 3 months of day-to-day interaction with the participant).

1.10. Is the user group clearly defined?

1.11. If no, please provide feedback and possible recommendations

Target population:
The proposed instrument is intended for ALHIV aged 15-19

1.12. Is the target population clearly stated?

1.13. If no, please provide feedback and possible recommendations

Language:
The primary instrument will be developed in English. However, subsequent versions may be adapted and translated into other languages.

Technical Information:
This section includes questions on the administration, scoring and interpretation of the proposed instrument.
General information for administers:

The Mental Wellness Measure for Adolescents Living with HIV (MWM-ALHIV) can be administered as a pencil and paper survey or computer-based survey. There are two parts namely; Part 1, which prompts the participant for demographic information and Part 2, which contains the MWM-ALHIV. The survey should be completed in one sitting, in a space where the participant is comfortable and can focus without disruptions. Participants should be reminded that their answers are private and anonymous and should be encourage to honest all questions honestly to avoid bias. As such, participants are encouraged to go with their first response, as this is considered the most natural response. We anticipate that the final survey should take approximately 15-20 minutes to complete.

1.14.	**Is the general information provided to users sufficient?**
1.15.	**If no, please comment on possible revisions**

2. SECTION B: Mental Wellness Measure for Adolescents Living with HIV

This section is divided into 2 parts. In the first section, we present the demographic information section followed by the items formulated to assess mental wellness across the sub-domains.

Demographic Questionnaire:
Hello!
We would like to know a little more about you and how you are feeling. Let's start with some general information in the questions below. Remember, all of this information will be kept private! If there is anything you are not comfortable filling out, please skip and move on to the next.

What is your age?
What is your gender?
Do you have any siblings?
What is your birth order (oldest, youngest middle child)?
What would you identify as your ethnic or cultural group?
What is your home language?
What grade are you in at school or what is the last grade that you have passed in school?
Do you have any disabilities?
Who are you living with/who are your caregivers?

2.1.Do you agree with the demographic information asked?
2.2.Are there any other demographical points you feel should be included?
2.3.Please provide any additional comments and/or recommendations

Proposed items of the instrument:

(The opening message and items formulated for the respective sub-domains are presented below)

Opening message for participants:

This is the second part of the survey. In this section we want to know more about how you are feeling about yourself, your family and friends and life in general. Please read each question carefully and think about what answer comes to your mind first. When you think about your answers, please try to remember how you felt in the last week. Tick the box that fits your answer the best. Remember, there are no right or wrong answers, this is all about you! You do not have to show your answers to anybody, and all your answers will be kept private. We hope you enjoy filling out this survey!

2.4. What do you think about the opening message? Please provide feedback and/or possible revisions.

Domain: Sense of Coherence

Sub-domains: Comprehensibility (Cognitive)

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect self-acceptance

1. **Self-acceptance**
   - 1.1. I'm disapproving and judgmental about my own flaws and inadequacies.
   - 1.2. When I'm feeling down I tend to obsess and fixate on everything that's wrong.
   - 1.3. When things are going badly for me, I see the difficulties as part of life that everyone goes through.
   - 1.4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.
   - 1.5. I try to be loving towards myself when I'm feeling emotional pain.
   - 1.6. When I'm down, I remind myself that there are lots of other people in the world feeling like I am.
   - 1.7. When times are really difficult, I tend to be tough on myself.
   - 1.8. When something upsets me I try to keep my emotions in balance.
   - 1.9. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.
   - 1.10. I'm intolerant and impatient towards those aspects of my personality I don't like.
   - 1.11. When I'm going through a very hard time, I give myself the caring and tenderness I need.
   - 1.12. When something painful happens I try to take a balanced view of the situation.
   - 1.13. I try to see my failings as part of the human condition
   - 1.14. When I fail at something important to me I try to keep things in perspective.
   - 1.15. When I'm really struggling, I tend to feel like other people must be having an easier time of it.
   - 1.16. I'm kind to myself when I'm experiencing suffering.
   - 1.17. When I'm feeling down I try to approach my feelings with curiosity and openness.
   - 1.18. I'm tolerant of my own flaws and inadequacies.
   - 1.19. When something painful happens I tend to blow the incident out of proportion.
   - 1.20. I try to be understanding and patient towards those aspects of my personality I don't like.
   - 1.21. Are you able to accept your bodily appearance?

1.22. How satisfied are you with yourself?
1.23. Have you been happy with the way you are?

In general, are the items appropriate relative to the definition and personal attributes of self-acceptance?

Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

2. **Self-esteem**

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect self-esteem?

2.1. 1. On the whole, I am satisfied with myself.
2.2. 2. At times I think I am no good at all.
2.3. 3. I feel that I have a number of good qualities.
2.4. 4. I am able to do things as well as most other people.
2.5. 5. I feel I do not have much to be proud of.
2.6. 6. I certainly feel useless at times.
2.7. 7. I feel that I'm a person of worth, at least on an equal plane with others.
2.8. 8. I wish I could have more respect for myself.
2.9. 9. All in all, I am inclined to feel that I am a failure.
2.10. 10. I take a positive attitude toward myself.
2.11. People think that I am fun to be with

In general, are the items appropriate relative to the definition and personal attributes of self-esteem?

Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

3. **Self-efficacy**

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect self-efficacy

3.1. I can do most things if I try
3.2. There are many things that I do well
3.3. I believe I know what my best potentials are and I try to develop them whenever possible.
3.4. Other people usually know better what would be good for me to do than I know myself.
3.5. I usually know what I should do because some actions just feel right to me.

3.6. When I engage in activities that involve my best potentials, I have this sense of really being alive.
3.7. I am confused about what my talents really are.

In general, are the items appropriate relative to the definition and personal attributes of self-efficacy?
Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

4. Adherence Self-efficacy

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect adherence self-efficacy

4.1. Stick to your treatment plan even when side effects begin to interfere with daily activities?
4.2. Integrate your treatment into your daily routine?
4.3. Integrate your treatment into your daily routine even if it means taking medication or doing other things in front of people who don't know you are HIV-infected?
4.4. Stick to your treatment schedule even when your daily routine is disrupted?
4.5. Stick to your treatment schedule when you aren't feeling well?
4.6. Stick to your treatment schedule when it means changing your eating habits?
4.7. Continue with your treatment even if doing so interferes with your daily activities?
4.8. Continue with the treatment plan your physician prescribed even if your T-cells drop significantly in the next three months?
4.9. Continue with your treatment even when you are feeling discouraged about your health?
4.10. Continue with your treatment even when getting to your clinic appointments is a major hassle?
4.11. Continue with your treatment even when people close to you tell you that they don't think that it is doing any good?
4.12. Get something positive out of your participation in treatment, even if the medication you are taking does not improve your health?

In general, are the items appropriate relative to the definition and personal attributes of adherence self-efficacy?
Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

Manageability (Behavioural)
Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect resilience
1. Resilience

1.1. I am able to solve problems without harming myself or others (for example by using drugs and/or being violent).
1.2. If I am hungry, there is enough to eat
1.3. I try to finish what I start
1.4. I know where to go in my community to get help
1.5. I have opportunities to show others that I am becoming an adult and can act responsibly
1.6. I am aware of my own strengths
1.7. I have opportunities to develop skills that will be useful later in life (like job skills and skills to care for others).
1.8. I do things at home that make a difference (i.e.make things better)
1.9. I help my family make decisions
1.10. At school, I decide things like class activities or rules
1.11. I do things at school that make a difference (i.e. make things better)
1.12. I can work out my problems
1.13. I know where to go for help when I have a problems
1.14. Have you enough money to meet your needs?
1.15. How available to you is the information you need in your daily life?
1.16. To what extent do you have the opportunity for leisure activities?
1.17. How well are you able to get around physically?
1.18. How satisfied are you with your ability to perform your daily living activities?
1.19. How satisfied are you with the conditions of your living place?
1.20. How satisfied are you with your access to health services?
1.21. How satisfied are you with your transport?
1.22. Have you felt pleased that you are alive?
1.23. In general, I feel I am in charge of the situation in which I live.
1.24. For me, life has been a continuous process of learning, changing, and growth'
1.25. I have difficulty arranging my life in a way that is satisfying to me

In general, are the items appropriate relative to the definition and personal attributes of resilience?
Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

2. Coping

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect coping

2.1. When I need help, I find someone to talk to
2.2. I try to work out problems by talking about them
2.3. The demands of everyday life often get me down
2.4. I think it is important to have new experiences that challenge how you think about yourself and the world
2.5. "I have been able to build a living environment and a lifestyle for myself that is much to my liking."

2.6. I am quite good at managing the many responsibilities of my daily life."
2.7. I often feel overwhelmed by my responsibilities

Active Handling

2.8. Finding out all about the problem
2.9. Making several alternative plans for handling a problem
2.10. Considering different solutions to the problem
2.11. Making a direct intervention when problems occur
2.12. Using a direct approach in order to solve the problem
2.13. Considering problems as a challenge
2.14. Realising every cloud has a silver lining

Passive-Avoidance

2.15. Being totally pre-occupied with the problems
2.16. Feeling unable to do anything
2.17. Worrying about the past
2.18. Taking a gloomy view of the situation
2.19. Giving in, in order to avoid difficult situations
2.20. Resigning oneself to the situation
2.21. Trying to avoid difficult situations as much as possible

Problem Sharing

2.22. Sharing one's worries with someone
2.23. Asking someone to help
2.24. Seeking sympathy and comfort from somebody
2.25. Showing there are things which are bothering you
2.26. Showing one's feelings

Palliative Reactions

2.27. Looking for distraction
2.28. Directing one's thoughts towards other matters
2.29. Trying to dispel one's worries temporarily by taking a break
2.30. Trying to make oneself feel better one way or the other
2.31. Telling oneself that other people also have their problems from time to time

Negative Expression

2.32. Showing one's anger with those responsible for the problem
2.33. Showing one's annoyance

In general, are the items appropriate relative to the definition and personal attributes of coping?

Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

3. Connectedness

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect connectedness

3.1. I talk to my family/caregiver(s) about how I feel
3.2. My family has fun together

3.3. I have a lot of fun with my brother(s) or sister(s). (leave blank if you have none)
3.4. It is important that my parents trust me
3.5. I feel close to my brother(s) of sister(s). (leave blank if you have none)
3.6. My parents and I disagree about many things.
3.7. I try to spend time with my brothers/sisters when I can. (leave blank if you have none)
3.8. My parents and I get along well.
3.9. I try to avoid being around my brother/sister(s). (leave blank if you have none)
3.10. I care about my parents very much.
3.11. I feel comfortable around my family
3.12. My family members like to spend time with me
3.13. Someone in my family accepts me for who I am
3.14. Spending time with friends is not so important to me
3.15. I spend a lot of time with kids around where I live.
3.16. I have friends I'm really close to and trust completely
3.17. Spending time with my friends is a big part of my life.
3.18. My friends and I talk openly with each other about personal things.
3.19. I spend as much time as I can with my friends.
3.20. I hang out a lot with kids in my neighbourhood.
3.21. I get along well with people my age
3.22. I am liked by other kids my age
3.23. I enjoy spending time with people my age
3.24. I get along well with the other students in my classes.
3.25. I try to get along with my teachers.
3.26. My classmates often bother me.
3.27. I care what my teachers think of me.
3.28. I have a strong sense of belonging to my community
3.29. I feel a strong attachment towards my community
3.30. The adults at my school like me as much as they like other students
3.31. There is an adult at my school that cares about me
3.32. I enjoy going to my school
3.33. I am proud of my ethnic background
3.34. I feel I belong at my school
3.35. My family stands by me during difficult times
3.36. My friends stand by me during difficult times
3.37. I am treated fairly in my community
3.38. I enjoy my family's/caregiver's cultural and family traditions.
3.39. I enjoy my community's traditions.
3.40. I am proud to be (Nationality: _____)?
3.41. How satisfied are you with your personal relationships?

In general, are the items appropriate relative to the definition and personal attributes of connectedness?

Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the

action e.g. revise/ omit

4. Leisure activities

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect leisure activities

4.1. How much do you enjoy life?
4.2. Do you have enough energy for everyday life?
4.3. How healthy is your physical environment?
4.4. I could do sports and exercise that other kids my age could do
4.5. I have been physically able to do the activities I enjoy most
4.6. Have you been able to do the things that you want to do in your free time?
4.7. Has your life been enjoyable?
4.8. Have you had fun?
4.9. Have you felt so bad that you didn't want to do anything?
4.10. Have you had enough time for yourself?
4.11. Have you been able to do the things that you want to do in your free time?
4.12. My daily life has been filled with things that interest me
4.13. My daily activities often seem trivial and unimportant to me."
4.14. When I do an activity, I enjoy it so much that I lose track of time.
4.15. I get so involved in activities that I forget about everything else.
4.16. It is important to me that I feel fulfilled by the activities that I engage in.

In general, are the items appropriate relative to the definition and personal attributes of leisure activities?

Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

Meaning (Motivational)

1. Spirituality

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect spirituality

1.1. I know my cultural/spiritual name.
1.2. When I am feeling spiritually disconnected, I look to my religious leader/elders/culture for help.
1.3. Spiritual beliefs are a source of strength for me
1.4. I participate in organized religious activities
1.5. I feel peaceful
1.6. My life has been productive
1.7. I have trouble feeling peace of mind
1.8. I am able to reach down deep into myself for comfort

1.9. I feel a sense of harmony within myself
1.10. I find comfort in my faith or spiritual beliefs
1.11. I find strength in my faith or spiritual beliefs
1.12. My illness has strengthened my faith or spiritual beliefs
1.13. I know that whatever happens with my illness, things will be okay

In general, are the items appropriate relative to the definition and personal attributes of spirituality?

Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

2. Hope

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect hope

2.1. I will accomplish what I want to do in my life
2.2. I will acquire the things I want
2.3. I will find good work
2.4. I will achieve the level of education I want
2.5. I will find work I enjoy
2.6. I will find stable work
2.7. I will always have enough to eat and live on
2.8. I will feel satisfaction with myself
2.9. The money I earn with my spouse will be sufficient
2.10. My work will give me opportunities to feel proud of myself
2.11. I will get married
2.12. I will have children
2.13. I will get married before I am 25 years old
2.14. My marriage will last forever
2.15. I will participate in many church activities
2.16. I will regularly go to Mass or other religious services
2.17. I will be a leader in my community
2.18. I will have good health
2.19. I will have a long life
2.20. I will have a healthy diet
2.21. I will participate in sports in my community
2.22. I will provide my children with a safe place to life
2.23. My children will live in a time of peace
2.24. My children will have a long life.
2.25. I am the sort of person who believes that life is full of meaning.
2.26. I generally believe that my life will be valuable and productive
2.27. I really believe that the children of today CANNOT expect much from their futures
2.28. I generally believe that my future will be very active

2.29. I often fear that the rest of my life will NOT be worthwhile
2.30. Even when things go right, I often fear that my future is NOT under my control
2.31. I often feel that I will be less and less comfortable with my body as time goes on
2.32. I generally look forward to sharing my life with others
2.33. I generally am NOT enthusiastic about my future
2.34. I generally believe that I will get what I want out of life"
2.35. I often fear that I will NOT have the personal support that I need in the future"
2.36. I think I will be successful when I grow up
2.37. I live life one day at a time and don't really think about the future
2.38. I am optimistic about my future.
2.39. I think that good things are going to happen to me.
2.40. I believe that things will work out, no matter how difficult they seem.
2.41. In uncertain times, I expect the best

In general, are the items appropriate relative to the definition and personal attributes of hope?

Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

3. Purpose in Life

Please use the highlighter or tick mark to indicate which of the following items appropriately measure or reflect purpose in life

3.1. Getting an education is important to me
3.2. I know how to behave in different social situations
3.3. I think it is important to help out in my community
3.4. I have goals and plans for the future
3.5. I feel a sense of purpose in my life
3.6. I have a reason for living
3.7. My life lacks meaning and purpose
3.8. To what extent do you feel your life to be meaningful?
3.9. "I enjoy making plans for the future and working to make them a reality."
3.10. I have a sense of direction and purpose in life
3.11. I don't have a good sense of what it is I'm trying to accomplish in life
3.12. As yet, I've not figured out what to do with my life.
3.13. I can say that I have found my purpose in life.

In general, are the items appropriate relative to the definition and personal attributes of purpose in life?

Please provide comment on the appropriate action you would recommend for items that you did not select. In the comment box provide the number of the item and the action e.g. revise/ omit

THANK YOU FOR YOUR PARTICIPATION IN THE FIRST ROUND OF THE DELPHI STUDY

You will receive an updated version of the survey as soon as comments and feedback have been integrated. As mentioned, the updated version will be shorter.

REFERENCES

[1] Orth Z, van Wyk B. Measuring mental wellness among adolescents living with a physical chronic condition: a systematic review of the mental health and mental well-being instruments. *BMC Psychology*; 9. Epub ahead of print December 1, 2021. DOI: 10.1186/s40359-021-00680-w.

[2] Orth Z, Moosajee F, van Wyk B. Measuring Mental Wellness of Adolescents: A Systematic Review of Instruments. *Frontiers in Psychology*; 13. Epub ahead of print March 9, 2022. DOI: 10.3389/fpsyg.2022.835601.

[3] Orth Z, van Wyk B. Discourses of Mental Wellness Among Adolescents Living with HIV in Cape Town, South Africa. *Psychology Research and Behavior Management* 2022; Volume 15: 1435–1450.

[4] Orth Z, van Wyk B. A Facility-based Family Support Intervention to Improve Treatment Outcomes for Adolescents on Antiretroviral Therapy in the Cape Metropole, South Africa. *J Int Assoc Provid AIDS Care*; 20. Epub ahead of print November 1, 2021. DOI: 10.1177/23259582211059289.

[5] Mittelmark MB, Sagy S, Eriksson M, Bauer GF, Pelikan JM, Lindström B, et al. (2015). The Handbook of Salutogenesis. New York. Springer.

Stimulus Document: Mental Wellness Instrument for Adolescents Living with HIV (ROUND 2)

Stimulus Document: Mental Wellness Instrument for Adolescents Living with HIV

Date:
Researcher: Zaida Orth
Supervisor: Prof Brian van Wyk
Participant: (Please fill in your unique ID number)

Delphi Study Round 2:
Dear participant, thank you for the valuable feedback provided during the 1st round. This gave us the opportunity to refine the items for the instrument. The feedback was integrated based on group consensus – items from the 1st round were included in the second round if 70% of participants agreed on that item. Some of the items were also re-worded and refined based on qualitative feedback. For this round, we ask that you please review and provide any feedback and comments where necessary. Our goal is to reduce the number of items to 5-10 per domain – for this we ask that you select the items that you feel are most relevant. Once the delphi study is complete, we will present the instrument to a small sample of ALHIV participants to evaluate the items through cognitive interviewing.

SECTION A: Purpose and aim of the instrument
Domains:
Based on the model, SOC represents a core domain and indicator of mental wellness. From this we have the following sub-domains:
Comprehensibility (cognitive)

12. Self-acceptance:

-Acknowledging and embracing every aspect of yourself including both good and bad qualities as you accept that this forms part of who you are. Therefore, it involves developing a realistic sense of self (understanding) – a subjective awareness of your strengths, weaknesses and circumstances

- To be self-accepting implies accepting yourself unconditionally in the present despite past behaviours or circumstances. It involves accepting parts of ourselves that we may not necessarily like, without offering justification for any of them (e.g., ALHIV do not need to feel the need to justify their status, as indicated in our study on mental wellness discourses, ALHIV needed to overcome internalised stigma around HIV to accept themselves as 'beautiful' and 'normal' regardless of their status) (Orth & van Wyk, 2022), as well as acknowledging the worthiness that is inherent in each one of us despite our flaws and shortcomings.
- Research shows that self-acceptance and self-esteem are conceptually different, yet closely related constructs. While both self-acceptance and self-esteem seem to show positive correlation with mental health outcomes, studies suggest that self-esteem is more closely related to affect, while self-acceptance relates to general psychological wellbeing (Popov, 2018). A high level of self-esteem is a prerequisite for self-acceptance.

Feedback:

13. Self-esteem

-Self-esteem is based on how we see ourselves in relation to our own expectations (internal

assessments) and with others (external feedback and validation). Self-esteem can be influenced by many factors within our environment, especially during adolescence, such as socializing with others, school performance, self-efficacy etc.

-Unlike self-acceptance, self-esteem can be divided into high or low self-esteem.

-ALHIV with high self-esteem talk about themselves in a positive light, highlight their best qualities, feel confident and good about themselves, make choices that reflect a positive self-view

Feedback:

14. Self-efficacy

-Self-efficacy is a person's belief in their ability to succeed in a particular situation. It includes the belief in one's ability to overcome and effectively negotiate life challenges and to complete goals and aspirations.

Feedback:

15. Adherence self-efficacy

-Belief in one's ability to successfully adhere to treatment plans which may include ALHIV successfully managing their treatment by taking medication correctly and on time every day, maintaining appointments, collecting medication and observing other requirements outlined by their healthcare providers. Additionally, ALHIV can maintain their treatment plan even if they experience a change in circumstances or new stressors.

Feedback:

Manageability (behavioural)

16. Resilience

-The ability to mentally withstand or adapt to uncertainty, challenges, and adversity.

-The ability, determination, and strength to overcome stressful life situations

- The ability to thrive despite obstacles or disadvantageous circumstances

-Includes navigating access to knowledge and resources to withstand or adapt to stressors.

Feedback:

17. Coping

-Coping refers to positive cognitive and behavioural efforts to manage (master, reduce, or tolerate) daily life stressors in healthy ways.

-ALHIV may engage in a range of coping mechanisms to deal with daily life stressors as well as those associated with managing a lifelong condition

-This may include engaging in activities they enjoy, connecting with others, engaging in meaningful activities.

Feedback :

18. Connectedness

-Sense that one has satisfying relationships with others, believing that one is cared for, loved, esteemed, and valued, and providing friendship or support to others

-Feelings of belonging and acceptance in different environments and contexts (i.e. family, school, community)

-Feeling taken care of, and wanting to reciprocate by taking care of others which also fostered a sense of purpose and meaning (in our study, participants expressed that they felt taken care of when family members reminded them to take medication, or reminding their family members to take medication in the case others in the household are HIV+, wanting to do well in life so that they can support their loved ones)

-ALHIV may experience support from family, clinic staff, spending time with friends, engaging in community activities

Feedback:

19. Leisure activities

-Engaging and participating in healthy activities that bring enjoyment and relaxation (de-stress)

-Like their peers, ALHIV engage in a range diverse interest and hobbies based on their personal interests, for example - listening to music, sports, reading, dancing etc. these activities help them to cope, connect with others and find enjoyment in life. Additionally, engaging in such activities is indicative of a sense of physical wellbeing.

Feedback:

Meaning (motivational)

20. Spirituality

- Spirituality is a broad concept comprising of several key attributes, meaning and purpose, transcendence, connectedness, relationships and religiosity (Puchalski et al. 2014). Can include a experiencing a relationship or connection with a higher being or power outside oneself or the psychological process of bringing one's attention to the internal and external experiences occurring in the present moment, concern for or sensitivity to things of the spirit or soul. Spirituality confers inner strengths, comfort, peace and wellness. Experiencing a sense of inner peace, contentment and happiness with oneself and others.
- ALHIV may attend religious ceremonies and activities, express a belief in a higher power, connection with cultural/spiritual heritage and traditions. For ALHIV, spirituality can help them cope with life stressors by finding meaning in situations

Feedback:

21. Hope

-Process of thinking about one's goals, along with the motivation to move towards those goals (agency) and ways to achieve those goals (pathways)

Emotion characterized by positive feelings about the immediate or long-term future. Optimistic view of the future and life that will lead to positive outcomes

- For ALHIV it contributes to a "process of meaning-making which enables people to psychologically cope with the stressful life event of HIV infection and helps them to maintain a psychological balance" (Plattner and Meiring 2006: 244).

-Indicative in ALHIV showing a positive attitude toward life and their future

-Hopes and dreams for the future may motivate ALHIV to stay on treatment. Some hope to finish school, get a good job, get married, start a family or even a cure for HIV. Like many adolescents, ALHIV may be idealistic about their future dreams (i.e. wants to be a singer or soccer star etc).

Feedback:

22. Purpose in life

- Adolescence is a formative period for cultivating a sense of purpose in life.

-You have goals in life and/or a sense of directedness; feel there is meaning to your present, past and future life. Purpose is a part of one's personal search for meaning, but it also has an external component, the desire to make a difference in the world, to contribute to matters larger than the self. More than hope (less idealistic, more realistic), purpose in life represents a sense of meaning in their lives like caring for their younger siblings or family members, developing goals to achieve future success

Feedback:

Aim:

The aim of the instrument is to measure mental wellness (indicators of positive mental health) among ALHIV

Feedback:

Purpose:

The purpose of the instrument is to provide a general measure to:

To screen mental wellness among ALHIV as an indicator of overall wellbeing and to identify challenges to their mental wellness.

To screen mental wellness among ALHIV and investigate its relationship to adherence to ART (i.e. current research suggests that poor mental health outcomes are associated with poorer adherence. More research is needed to understand how mental wellness (positive mental health) can improve adherence). To provide further information on how or which mental wellness indicators among ALHIV may act as a buffer against mental health problems

Feedback:

Type of measure:
The proposed measure is a self-administered/self-report screening instrument as this allows for initial evaluation and scoring of mental wellness across different domains. Additionally, this is considered an appropriate measurement type, as our goal is not to provide a clinical diagnosis of mental health problems, rather a general assessment of positive mental wellness 'strengths' which can be reinforced (through intervention programs, workshops etc.) to buffer against the development of mental health problems. Therefore, this screening tool will allow us to categorise participants into groups (e.g. ALHIV with high mental wellness or ALHIV with low mental wellness) with reasonable accuracy. In research, this may be used to provide information on the relationship between mental wellness and maintaining adherence to ART (i.e. are participants with higher mental wellness scores demonstrating adherence?) or may provide an indication of which domains of mental wellness need intervention (i.e. participants may score high in one domain and low in another). Screening instruments are considered advantageous as they can be easily administered in a timely and cost-efficient manner. Furthermore, the results from screening instruments are immediately available and easy to score and interpret – as such it may be used by a variety of professionals, including health care workers, counsellors, school staff, paraprofessionals and trained volunteers.

Feedback:

Type of scale:
We propose to pilot a 4- point Likert type scale

Item	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
	1	2	3	4

Feedback:

User group:
The proposed is meant to be self-administered by the adolescent. However, where needed, instrument a researcher, professional, paraprofessional or trained volunteer may assist the participant in filling out the survey.

Feedback:

Target population:
The proposed instrument is intended for older ALHIV aged 15-19

Feedback:

Language:
The primary instrument will be developed in English. However, subsequent versions may be adapted and translated into other languages.

Technical Information:
This section includes questions on the administration, scoring and interpretation of the proposed instrument.
General information for researchers/administers:
The Mental Wellness Measure for Adolescents Living with HIV (MWM-ALHIV) is a self-administered tool that can be completed as a pencil and paper survey or computer-based survey. There are two parts namely; Part 1, which prompts the participant for demographic information and Part 2, which contains the MWM-ALHIV. The survey should be completed in one sitting, in a space where the participant is comfortable and can focus without

disruptions. Participants should be reminded that their answers are private and anonymous, that there are no correct or incorrect answers, and should be encouraged to answer all questions honestly to avoid bias. As such, participants are encouraged to go with their first response, as this is considered the most natural response. Where needed (due to literacy or language issues for example), participants may require assistance to fill out the survey). We anticipate that the final survey should take approximately 15-20 minutes to complete. Please note, that the instrument asks questions related to mental wellness and some participants may find it distressing to think about these issues. As such, it is advisable that arrangements should be made for appropriate support and counselling if needed.

Feedback to consider:

3. **SECTION B: Mental Wellness Measure for Adolescents Living with HIV**

This section is divided into 2 parts. In the first section, we present the demographic information section followed by the items formulated to assess mental wellness across the sub-domains.

Demographic Questionnaire:

Hello

We would like to know a little more about you and how you are feeling. Let's start with some general information in the questions below. Remember, all of this information will be kept private. If there is anything you are not comfortable filling out, please skip and move on to the next.

What is your age?

☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19

What gender do you identify with?

☐ Man ☐ Woman ☐ Other (please specify_____) ☐ Prefer not to say

Do you have any siblings?

☐Yes ☐ No

If yes, how many siblings do you have?

_____

What would you identify as your ethnic or cultural group?

_____

What religion do you identify with?

☐Christianity ☐Islam ☐Judaism ☐Traditional African ☐Hinduism ☐None ☐Other

What is your home language?

☐English ☐Afrikaans ☐Xhosa ☐Zulu ☐Sotho ☐Tsonga ☐Tswana ☐Venda ☐Swati ☐Ndebele ☐Other

What grade are you in at school or what is the last grade that you have passed in school?

_____

If you are not at school are you at

☐University ☐College ☐FET ☐Working ☐Not working

Who are you living with?

☐ Parents ☐ Grandparents ☐Family ☐ Other

Who are your caregivers/guardians?

☐ Parent/s ☐ Grandparent/s ☐Family member ☐ Other

Feedback:

Proposed items of the instrument:
(The opening message and items formulated for the respective sub-domains are presented below)
Opening message for participants:

In this section we want to know more about how you feel about yourself, your family, friends and life. Please read each question carefully. When you think about your answers, please try to remember how you felt in the **last week.** Tick the box that fits your answer the best. Remember, there are no right or wrong answers, this is all about you. You do not have to show your answers to anybody, and all your answers will be kept private.

Feedback:

Domain: Sense of Coherence

Sub-domains: Comprehensibility (Cognitive)

Please use the highlighter or tick mark to indicate which items you think are **most** relevant

Self-Acceptance	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
I dislike my own flaws/weaknesses	1	2	3	4
When I think about the things I can't do, I feel bad about myself	1	2	3	4
When times are hard, I tend to be tough on myself.	1	2	3	4
There are parts of my personality that I don't like that I want to change	1	2	3	4
When I fail at something important to me, I remind myself that it is part of being human	1	2	3	4
I'm kind to myself.	1	2	3	4
Even when I am bad at something, I still love myself.	1	2	3	4
I feel good about myself, even if I am not successful in meeting goals that are important to me	1	2	3	4
When something upsets me, it does not change how I feel about myself	1	2	3	4

I am a valuable person, even if there are parts of myself that I do not like.	1	2	3	4
I am happy with the way I am	1	2	3	4
I feel I am a valuable person even when other people don't like me.	1	2	3	4
I am comfortable with who I am as a person	1	2	3	4
My status does not define who I am	1	2	3	4
Being HIV+ is part of who I am, and I am okay with that	1	2	3	4
I am special – there is no one else like me	1	2	3	4
Even though I have HIV, I still see myself as an amazing person				

Feedback:
Do the items listed capture the construct? Is there anything missing that you would recommend adding?

Please use the highlighter or tick mark to indicate which items you think are **most** relevant

steem	**gly disagree**	**ree**	**what Agree**	**gly Agree**
good about myself.				
es I dislike myself.				
are many things that I like about myself.				
roud of myself				
good when other people compliment me				
I can do things as well as other people my age.				
ot have much to be proud of.				
hat I'm just as worthy as other people my age				
I could like myself.				
hat I am a failure.				
a positive attitude toward myself.				
people are proud of me				
I think about being HIV+ I feel bad about myself				
ad about myself when other people criticize me				

Feedback:
Do the items listed capture the construct? Is there anything missing that you would recommend adding?

Please use the highlighter or tick mark to indicate which items you think are **most** relevant

ficacy	gly disagree	ree	what Agree	gly Agree
ve I can do most things if I try				
are many things that I do well				
ve I know what my strengths are				
tus has not affected my abilities				
people usually know better what would be good for me				
trong				
many talents				
are many things I cannot do because of my status				
try new things because I am scared, I will fail				
t myself				

Feedback:
Do the items listed capture the construct? Is there anything missing that you would recommend adding?

ence Self-efficacy	gly disagree	ree	what Agree	gly Agree
g my treatment is part of my daily routine				
ways to take my treatment every day, even when I am around people who don't know my status.				
my treatment every day even when there are changes in my daily routine (example travelling)				
I take my treatment every day even when I don't feel well.				
my treatment every day even when my eating habits have changed.				
my treatment every day even when it gets in the way of my daily activities				
my treatment every day even when I am having a bad day				
my treatment every day even when I have problems going to the clinic.				
my treatment every day even when people close to me tell me not to				
my treatment every day even when I feel like people will judge me				
I do what my doctor/nurse tells me to do because I know it will help me stay healthy				
I am confident that I can manage my treatment				
I know that if I follow my treatment plan, I will be strong and healthy				
I try to attend all my clinic appointments even when I have problems going to the clinic				

I do other things to try and stay healthy (e.g. eat healthy foods, drink water, exercise)				

Feedback:
Do the items listed capture the construct? Is there anything missing that you would recommend adding?

Manageability (Behavioural)
Please use the highlighter or tick mark to indicate which items you think are **most** relevant

Resilience	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
I can work out my problems without hurting myself or others (for example by using drugs and/or being violent).	1	2	3	4
I know where to go in my community to get help	1	2	3	4
I have opportunities to show others that I am becoming an adult	1	2	3	4
I have opportunities to develop skills that will be useful later in life (like job skills and skills to care for others).	1	2	3	4
I do things at school that make a positive difference (i.e. make things better)	1	2	3	4
I do things at home that make a positive difference (i.e. make things better)	1	2	3	4
I know where to go for help when I have problems	1	2	3	4
In general, I feel I am in control of my life	1	2	3	4
For me, life is about learning, changing, and growing despite my circumstances	1	2	3	4
I struggle to do things in my life in a way that is satisfying to me	1	2	3	4
When I am struggling, I know where to look for help	1	2	3	4
Learning about my status has helped me to better manage my life	1	2	3	4
There are people in my life that I can share my feelings with	1	2	3	4
I am confident that I can overcome the challenges in life	1	2	3	4
When times are tough, I do not know what to do	1	2	3	4
Being HIV+ will not stop me from accomplishing what I want in life	1	2	3	4
Being HIV+ is not a challenge	1	2	3	4
I feel helpless	1	2	3	4
When life is challenging, I give up	1	2	3	4
Living with HIV is a struggle				

Feedback:
Do the items listed capture the construct? Is there anything missing that you would recommend adding?

Please use the highlighter or tick mark to indicate which items you think are **mos**t relevant

Coping	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
I try to work out problems by talking about them	1	2	3	4
My problems get me down	1	2	3	4
I think it is important to have new experiences that challenge how you think about yourself and the world	1	2	3	4
I am good at managing my responsibilities.	1	2	3	4
I often feel overwhelmed by my responsibilities	1	2	3	4
When I have problems I think about different solutions to solve the problem	1	2	3	4
When I have problems, I take action to solve it	1	2	3	4
I try to avoid difficult situations as much as possible	1	2	3	4
I have someone to talk to about my status	1	2	3	4
When I think of being HIV+ I want to hide away	1	2	3	4
When I think of being HIV+ I remind myself that there are others who are like me	1	2	3	4
When I think of being HIV+ I remind myself that I am loved	1	2	3	4
Sometimes, I like to imagine that I do not have HIV	1	2	3	4
I ask others for help when I need it	1	2	3	4
I look for sympathy and comfort from others when I need it	1	2	3	4
I do not hide my feelings	1	2	3	4
When I feel sad or when something is bothering me, I try to think of something else	1	2	3	4
When I feel sad, or when something is bothering me, I do activities I enjoy (e.g. playing games, listening to music, reading etc).	1	2	3	4
I think my situation is unfair	1	2	3	4
I do not care about my life	1	2	3	4
I am ashamed of my status	1	2	3	4
I make jokes about my problems to feel better	1	2	3	4
I accept the situation I am in	1	2	3	4
I ignore my problems	1	2	3	4
I pretend that I am okay	1	2	3	4

Feedback:

Do the items listed capture the construct? Is there anything missing that you would recommend adding?

Please use the highlighter or tick mark to indicate which items you think are **most** relevant

Connectedness	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
I talk to my family/caregiver(s) about how I feel	1	2	3	4
My family has fun together	1	2	3	4
I have a lot of fun with my sibling(s) or other family member(s) I feel close to. (leave blank if you have none)	1	2	3	4
It is important that my parents trust me	1	2	3	4
I feel close to my sibling(s) or other family member(s) (leave blank if you have none)	1	2	3	4
I feel close to my sibling(s) or other family member(s) (leave blank if you have none)	1	2	3	4
I try to spend time with sibling(s) or other family member(s) I feel close to when I can. (leave blank if you have none)	1	2	3	4
My parents and I get along well.	1	2	3	4
I try to avoid being around my sibling or other family member(s) (leave blank if you have none)	1	2	3	4
I feel comfortable around my family	1	2	3	4
My family members like to spend time with me	1	2	3	4
Someone in my family accepts me for who I am	1	2	3	4
I have friends I'm really close to and trust	1	2	3	4
Spending time with my friends is important to me	1	2	3	4
My friends and I talk openly with each other about personal things.	1	2	3	4
I get along well with people my age	1	2	3	4
Kids my age like me	1	2	3	4
I enjoy spending time with people my age	1	2	3	4
I try to get along with my teachers.	1	2	3	4

I feel like I belong in my community	1	2	3	4
I feel a strong attachment towards my community	1	2	3	4
There is an adult at my school that cares about me	1	2	3	4
I am proud of my ethnic background	1	2	3	4
I feel I belong at my school	1	2	3	4
My family stands by me during difficult times	1	2	3	4
I am treated fairly in my community	1	2	3	4
I enjoy my family's/caregiver's cultural and family traditions.	1	2	3	4
I enjoy my community's traditions.	1	2	3	4
I feel supported by the clinic/hospital staff	1	2	3	4
I feel like my doctor/nurse cares about me	1	2	3	4
I feel all alone in the world	1	2	3	4

Feedback:

Do the items listed capture the construct? Is there anything missing that you would recommend adding?

Please use the highlighter or tick mark to indicate which items you think are **most** relevant

Leisure activities	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
I am able to do the activities I enjoy most	1	2	3	4
I have enough time for myself	1	2	3	4
I am able to do the things I want to do in my free time	1	2	3	4
My daily life has been filled with things that interest me	1	2	3	4
My daily activities often seem boring and unimportant to me.	1	2	3	4
When I do an activity, I enjoy it so much that I lose track of time.	1	2	3	4
I get so involved in activities I enjoy that I forget about everything else.	1	2	3	4
It is important to me that I feel satisfied by the activities that I take part in.	1	2	3	4
Being HIV+ has not stopped me from doing the things I like	1	2	3	4
I have no energy to do the things I like	1	2	3	4

Feedback:

Do the items listed capture the construct? Is there anything missing that you would recommend adding?

Meaning (Motivational)

Please use the highlighter or tick mark to indicate which items you think are **most** relevant

Spirituality	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
When I feel lost, I look to my religious leader/elders/culture for help.	1	2	3	4
My faith or spiritual beliefs are a source of strength for me	1	2	3	4
I participate in organized religious activities	1	2	3	4
I feel a sense of peace within myself	1	2	3	4
I find comfort in my faith or spiritual beliefs	1	2	3	4
I find strength in my faith or spiritual beliefs	1	2	3	4
Being HIV+ has strengthened my faith or spiritual beliefs	1	2	3	4
I believe everything happens for a reason	1	2	3	4
Being HIV+ is part of God's plan for me	1	2	3	4

Feedback:

Do the items listed capture the construct? Is there anything missing that you would recommend adding?

Please use the highlighter or tick mark to indicate which items you think are **most** relevant

Hope	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
I will accomplish what I want to do in my life	1	2	3	4
I will find good work	1	2	3	4
I will achieve the level of education I want	1	2	3	4
I will find work I enjoy	1	2	3	4
My work will give me opportunities to feel proud of myself	1	2	3	4
When I grow up I will have a good family life	1	2	3	4
When I grow up, I will have the life I want	1	2	3	4
I will have good health	1	2	3	4
I will have a long life	1	2	3	4
I will be able to provide for myself	1	2	3	4
I will be able to provide for my family	1	2	3	4
I believe life has meaning	1	2	3	4
I believe	1	2	3	4
I don't know what my future holds	1	2	3	4
Thinking about the future scares me	1	2	3	4

I look forward to sharing my life with others	1	2	3	4
The future doesn't excite me	1	2	3	4
I will be successful when I grow up	1	2	3	4
I am optimistic about my future.	1	2	3	4
I think that good things are going to happen to me.	1	2	3	4
I believe that things will work out	1	2	3	4
When I think of being HIV+ I remind myself that I have a bright future	1	2	3	4
I do not have plans for my future	1	2	3	4
Being HIV+ has not changed my plans for the future	1	2	3	4
I think my life will never get any better because of my status	1	2	3	4
I will have many opportunities in life	1	2	3	4
Being HIV+ will not stop me from achieving my goals	1	2	3	4
I have nothing to look forward to	1	2	3	4

Feedback:

Do the items listed capture the construct? Is there anything missing that you would recommend adding?

Please use the highlighter or tick mark to indicate which items you think are **most** relevant

Purpose in Life	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
Getting an education is important to me	1	2	3	4
I think it is important to help out in my community	1	2	3	4
I have goals and plans for the future	1	2	3	4
I feel a sense of purpose in my life	1	2	3	4
I have a reason for living, even though I have HIV	1	2	3	4
My life has no meaning	1	2	3	4
I enjoy making plans for the future and working to make them a come true	1	2	3	4
I have a sense of direction in life.	1	2	3	4
I can say that I have found what I want to do in life	1	2	3	4
I am learning more about myself and who I want to be	1	2	3	4
I struggle to think of what I want in life	1	2	3	4
I have no goals or aims	1	2	3	4
My life feels empty	1	2	3	4

Feedback:

Do the items listed capture the construct? Is there anything missing that you would recommend adding?

APPENDIX C: Revised version of the Mental Wellness Measure for Adolescents Living with HIV (MWM-ALHIV) (After Delphi Study)

Mental Wellness Measure for Adolescents Living with HIV

In this section we want to know more about how you feel about yourself, your family, friends and life. Please read each question carefully. When you think about your answers, please try to remember how you felt in the **last week.** Tick the box that fits your answer the best. Remember, there are no right or wrong answers, this is all about you. You do not have to show your answers to anybody, and all your answers are private.

Domain: Sense of Coherence

Sub-domains: Comprehensibility (Cognitive)

	Self-Acceptance	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
1	When I fail at something important to me, I remind myself that it is part of being human				
2	I'm kind to myself.				
3	Even when I am bad at something, I still love myself.				
4	When something upsets me, it does not change how I feel about myself				
5	I am a valuable person, even if there are parts of myself that I do not like.				
6	I am happy with the way I am				
7	I feel I am a valuable person even when other people don't like me.				
8	I am comfortable with who I am as a person				
9	Living with HIV does not define who I am				
10	Living with HIV is part of who I am, and I am okay with that				

	Self-Esteem	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	I feel good about myself.				
2	There are many things that I like about myself.				
3	I am proud of myself				
4	I can do things as well as other people my age.				
5	I do not have much to be proud of.				
6	I feel that I'm just as worthy as other people my age				
7	I wish I could like myself.				
8	I take a positive attitude toward myself.				
9	When I think about living with HIV, I feel bad about myself				

	Self-efficacy	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	I can do most things if I try				
2	There are many things that I do well				
3	I know my strengths				
4	Living with HIV has not affected my ability to do what I want in life				
5	I feel strong				
6	I have many talents				
7	There are many things I cannot do because I am living with HIV				
8	I don't try new things because I am scared, I will fail				
9	I doubt myself				

	Adherence Self-efficacy	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	Taking my treatment is part of my daily routine				
2	I find ways to take my treatment every day, even when I am around people who don't know that I am living with HIV				
3	I take my treatment every day even when there are changes in my daily routine (example travelling)				
4	I take my treatment every day even when I don't feel well.				
5	I take my treatment every day even when my eating habits have changed.				
6	I take my treatment every day even when it gets in the way of my daily activities				
7	I take my treatment every day even when I am having a bad day				
8	I take my treatment every day even when I have problems going to the clinic.				
9	I take my treatment every day even when people close to me tell me not to				
10	I take my treatment every day even when I feel like people will judge me				
11	I am confident that I can manage my treatment				
12	I try to attend all my clinic appointments even when I have problems going to the clinic				

13	I do other things to try and stay healthy (e.g., eat healthy foods, drink water, exercise)				

Manageability (Behavioural)

	Resilience	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
1	I can work out my problems without hurting myself or others (for example by using drugs and/or being violent).				
2	I know where to go in my community to get help				
3	I do things at school that make a positive difference (i.e. make things better)				
4	I do things at home that make a positive difference (i.e. make things better)				
5	I know where to go for help when I have problems				
6	In general, I feel I am in control of my life				
7	For me, life is about learning, changing, and growing despite my circumstances				
8	I am confident that I can overcome the challenges in life				
9	Living with HIV does not stop me from accomplishing what I want in life				
10	When life is challenging, I give up				

	Coping	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	I try to work out problems by talking about them				
2	I think it is important to have new experiences that challenge how you think about yourself and the world				
3	I am good at managing my responsibilities.				
4	When I have problems, I think about different solutions to solve the problem				
5	When I have problems, I take action to solve it				
6	I try to avoid difficult situations as much as possible				
7	When I think of living with HIV I remind myself that there are others who are like me				
8	I ask others for help when I need it				
9	When I feel sad or when something is bothering me, I try to think of something else				
10	When I feel sad, or when something is bothering me, I do activities I enjoy (e.g. playing games, listening to music, reading etc).				

	Connectedness	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
1	I talk to my family/caregiver(s) about how I feel				
2	My family has fun together				
3	I feel close to my sibling(s) or other family member(s) (leave blank if you have none)				
4	I feel comfortable around my family				
5	Someone in my family accepts me for who I am				
6	I have friends I'm really close to and trust				
7	I feel like I belong in my community				
8	My family stands by me during difficult times				
9	I feel supported by the clinic/hospital staff				
10	I feel all alone in the world				

	Leisure activities	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	I am able to do the activities I enjoy most				
2	I have enough time for myself				
3	I am able to do the things I want to do in my free time				
4	My daily life has been filled with things that interest me				
5	My daily activities often seem boring and unimportant to me.				
6	When I do an activity, I enjoy it so much that I lose track of time.				
7	I get so involved in activities I enjoy that I forget about everything else.				
8	It is important to me that I feel satisfied by the activities that I take part in.				
9	Living with HIV has not stopped me from doing the things I like				
10	I have no energy to do the things I like				

Meaning (Motivational)

	Spirituality	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	When I feel lost, I look to my religious leader/elders/culture for help.				
2	My faith or spiritual beliefs are a source of strength for me				
3	I participate in organized religious activities				
4	I feel a sense of peace within myself				

5	I find comfort in my faith or spiritual beliefs				
6	I find strength in my faith or spiritual beliefs				
7	Living with HIV has strengthened my faith or spiritual beliefs				

	Hope	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
1	I will accomplish what I want to do in my life				
2	I will find good work				
3	I will find work I enjoy				
4	When I grow up I will have a good family life				
5	When I grow up, I will have the life I want				
6	I will have good health				
7	I will have a long life				
8	I will be able to provide for myself				
9	I will be able to provide for my family				
10	I am optimistic about my future.				
11	I think that good things are going to happen to me.				
12	I believe that things will work out				
13	I am living with HIV, and I have a bright future				
14	Living with HIV will not stop me from achieving my goals				

	Purpose in Life	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
1	Getting an education is important to me				
2	I think it is important to help out in my community				

3	I have goals and plans for the future				
4	I feel a sense of purpose in my life				
5	I have a reason for living				
6	I enjoy making plans for the future and working to make them a come true				
7	I have a sense of direction in life.				
8	I can say that I have found what I want to do in life				
9	I am learning more about myself and who I want to be				
10	I struggle to think of what I want in life				
11	I have no goals or aims				

APPENDIX D: Final version of the Mental Wellness Measure for Adolescents Living with (MWM-ALHIV) (after Cognitive Interviews)

Mental Wellness Measure for Adolescents Living with HIV

In this section we want to know more about how you feel about yourself, your family, friends and life. Please read each question carefully. When you think about your answers, please try to remember how you felt in the **last week.** Tick the box that fits your answer the best. Remember, there are no right or wrong answers, this is all about you. You do not have to show your answers to anybody, and all your answers are private.

	Self-Acceptance	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
1	I'm kind to myself.				
2	I love myself even when I fail at something				
3	When something upsets me, I feel bad about myself				
4	I love myself, even if there are things about myself that I dislike				
5	I am happy with the way I am				
6	I feel I am a valuable person even when other people don't like me.				
7	I love myself just the way I am				
8	Living with HIV does not define who I am				
9	Living with HIV is part of who I am, and I am okay with that				

	Self-Esteem	**Strongly disagree**	**Disagree**	**Somewhat Agree**	**Strongly Agree**
1	I feel good about myself.				
2	There are many things that I like about myself**.**				
3	I am proud of myself				
4	I can do things as well as other people my age.				
5	I feel like a failure				
6	I feel that I'm just as worthy as other people my age				
7	I wish I could like myself.				
8	I take a positive attitude toward myself.				
9	When I think about living with HIV, I feel bad about myself				
10	There are many things I wish I could change about myself				
11	Other people like me				
12	I think I am good looking				

	Self-efficacy	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	I can do most things if I try				
2	There are many things that I do well				
3	I know my strengths				
4	Living with HIV has not affected my ability to do what I want in life				
5	I have what it takes to achieve my goals				
6	I have many talents				
7	There are many things I cannot do because I am living with HIV				
8	I don't try new things because I am scared, I will fail				
9	I doubt myself				
10	I am confident in myself				
11	I struggle to learn new skills				
12	I feel like other people my age are better than me.				

	Adherence Self-efficacy	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	Taking my treatment is part of my daily routine				
2	When I am around people who don't know my status, I will still try to find a way to take my treatment (e.g. go to the bathroom)				
3	I take my treatment every day even when there are changes in my daily routine (example travelling)				
4	I take my treatment every day even when I don't feel well.				
5	I take my treatment every day even when it gets in the way of my daily activities (e.g. playing sport)				
6	I take my treatment every day even when I am having a bad day				
7	I am confident that I can manage my treatment				
8	I try to make a way to attend my clinic appointment, even when I have problems going to the clinic				
9	I do other things to try and stay healthy (e.g. eat healthy foods, drink water, exercise)				
10	Sometimes I forget to take my treatment				

11	Sometimes I skip my treatment				

	Resilience	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	I can work out my problems without hurting myself or others (for example by using drugs and/or being violent).				
2	I know where to go in my community to get help when I have problems				
3	I work well with people my age				
4	I feel good when I am at school				
5	I do things at home to help out				
6	I feel like I have enough support				
7	I feel I am in control of myself				
8	I see life challenges as a chance for me to learn and grow				
9	I am confident that I can overcome the challenges in life				
10	I worry about my problems				
	Thinking about my problems stresses me out				
11	Living with HIV does not stop me from accomplishing what I want in life				
12	When life is challenging, I give up				

	Coping	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	I try to work out problems by talking about them				
2	I am good at managing my responsibilities.				
3	When I have a problem, I think about different ways to solve the problem				
4	When I have problems, I take action to solve it				
5	I avoid my problems				
6	When I think of living with HIV, I remind myself that there are others who are like me				
7	I ask others for help when I need it				
8	when I feel sad or upset, I try to think of something else				
9	When I feel sad, or upset, I do activities I enjoy (e.g. playing games, listening to music, reading etc).				

	Connectedness	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree

1	I talk to my family/caregiver(s) about how I feel				
2	My family has fun together				
3	I feel close to my sibling(s) or other family member(s) (leave blank if you have none)				
4	I feel comfortable around my family				
5	Someone in my family accepts me for who I am				
6	I have friends I'm really close to				
7	I have friends that I trust				
8	I feel like I belong in my community				
9	My family stands by me during difficult times				
10	I feel supported by the clinic/hospital staff				
11	I feel all alone in the world				

	Leisure activities	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	I am able to do the activities I enjoy most				
2	I have enough time for myself				
3	I am able to do the things I want to do in my free time				
4	My daily life has been filled with things that interest me				
5	My daily activities often seem boring and unimportant to me.				
6	When I do an activity, I enjoy it so much that I lose track of time.				
7	I get so involved in activities I enjoy that I forget about everything else.				
8	I have hobbies that make me feel happy				
9	Living with HIV has not stopped me from doing the things I like				
10	I have no energy to do the things I like				

	Spirituality	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	When I feel lost, I look to my religious leader/elders/culture for help.				
2	My faith or spiritual beliefs are a source of strength for me				
3	I participate in activities that strengthen my faith or spiritual beliefs (e.g. going to church, meditating etc.)				
4	I feel a sense of peace within myself				
5	I find comfort in my faith or spiritual beliefs				
6	I find strength in my faith or spiritual beliefs				

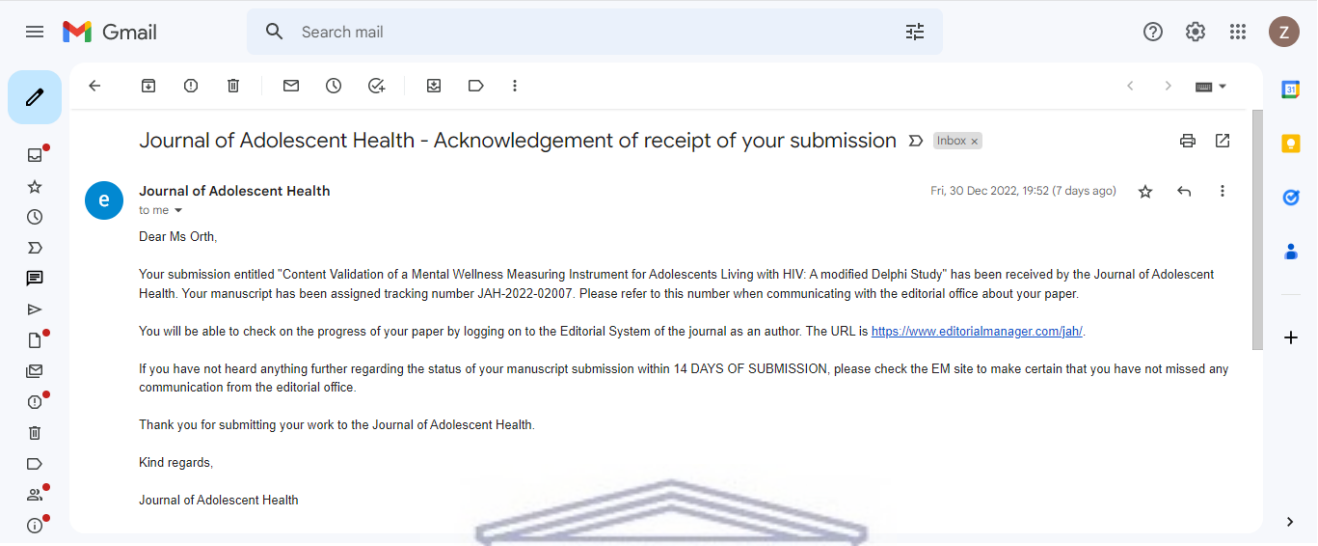
	Hope	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	I will accomplish what I want to do in my life				
2	I will find good work				
3	I will find work I enjoy				
4	When I grow up I will have a good family life				
5	When I grow up, I will have the life I want				
6	I will have good health				
7	I will have a long life				
8	I will be able to take care of myself				
9	I will be able to take care of my family				
10	I feel good about my future.				
11	I think that good things are going to happen to me.				
12	I believe that things will work out				
13	I am living with HIV, and I have a bright future				
14	Living with HIV will not stop me from achieving my goals				

	Purpose in Life	Strongly disagree	Disagree	Somewhat Agree	Strongly Agree
1	Getting an education is important to me				
2	I think it is important to help out in my community				
3	I have goals and plans for the future				
4	I know where I want to go in life				
5	I have a reason for living				
6	I enjoy making plans for the future				
7	I work hard to achieve my goals				
8	I can say that I have found what I want to do in life				
9	I am learning more about myself and who I want to be				
10	I struggle to think of what I want in life				

11	I have no goals				

APPENDIX E: Proof of Submitted Manuscripts

Manuscript 8: Content validation of a Mental Wellness Measuring instrument for Adolescents Living with HIV: a modified Delphi Study. Submitted to Journal of Adolescent Health (under review)



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Journal of Adolescent Health - Acknowledgement of receipt of your submission Inbox ×

Journal of Adolescent Health Fri, 30 Dec 2022, 19:52 (7 days ago)
to me

Dear Ms Orth,

Your submission entitled "Content Validation of a Mental Wellness Measuring Instrument for Adolescents Living with HIV: A modified Delphi Study" has been received by the Journal of Adolescent Health. Your manuscript has been assigned tracking number JAH-2022-02007. Please refer to this number when communicating with the editorial office about your paper.

You will be able to check on the progress of your paper by logging on to the Editorial System of the journal as an author. The URL is https://www.editorialmanager.com/jah/.

If you have not heard anything further regarding the status of your manuscript submission within 14 DAYS OF SUBMISSION, please check the EM site to make certain that you have not missed any communication from the editorial office.

Thank you for submitting your work to the Journal of Adolescent Health.

Kind regards,

Journal of Adolescent Health

APPENDIX F: Published Papers

BMJ Open

Adolescent mental wellness: a systematic review protocol of instruments measuring general mental health and well-being

Zaida Orth , Brian van Wyk

To cite: Orth Z, van Wyk B. Adolescent mental wellness: a systematic review protocol of instruments measuring general mental health and well-being. *BMJ Open* 2020;**10**:e037237. doi:10.1136/bmjopen-2020-037237

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School of Public Health, University of the Western Cape, Bellville, South Africa

Correspondence to
Zaida Orth;
zaidaorth@gmail.com

ABSTRACT

Introduction The promotion of mental health well-being among global adolescent populations is of great public health and social significance. This is particularly true for adolescents living with chronic illnesses as studies have shown that these populations are at higher risk for developing mental health problems. There is vast recognition of the need for age and culturally appropriate interventions to promote mental well-being and prevent mental health problems. In stark contrast, there is a dearth of relevant measures of mental well-being for adolescents. Our proposed systematic review aims to identify measures of mental well-being and to assess content, psychometric properties and relevance to adolescent populations.

Methods and analysis The systematic review methodology will be guided by the seven steps proposed by Eggar, Davey and Smith. Documents will be sourced from electronic databases (Academic Search Complete, Educational Resource Information Center, Medical Literature Analysis Retrieval System Online, Cumulative Index of Nursing and Allied Health Literature plus, PsyArticles, SocIndex and Sabinet). All documents will be exported to Mendeley and two reviewers will independently screen the titles, abstracts and full texts for inclusion. Any discrepancies will be resolved by a third party. We will include studies published in all languages from 2000 to 2020, that use an instrument(s) that measure mental well-being among adolescent populations. Studies reporting on clinically significant mental illnesses or disorders will be excluded. A descriptive meta-synthesis approach will be used to identify and describe the mental health instruments used among adolescent populations, and to report on the psychometric properties.

Ethics and dissemination Ethical approval is not required. The results of this review will be disseminated through a peer-reviewed publication as well as conference presentations.

Strengths and limitations of this study

- This study contributes to the knowledge around the available and appropriate measures used to measure adolescent mental well-being, which are necessary to develop interventions and inform health policy.
- The search strategy comprises of seven electronic databases to search for peer-reviewed and grey literature.
- A descriptive meta-synthesis approach will be used to describe the mental health well-being components being measured and to assess the psychometric properties of the measurements in the study.
- The limits of this study are related to the time span of the search strategy (2000–2020).

INTRODUCTION

In recent years, mental health has been identified as a key public health concern, particularly for children and adolescents.[1 2] According to WHO,[3] mental health conditions account for 16% of the global burden of disease and injury for adolescents aged 10–19 years, with depression being identified as the leading cause of disability and illness among this population. Evidence suggests that half of all lifetime mental disorders will start during adolescence, yet the majority of these will go unrecognised and untreated.[4] There are various factors which hinder the effective treatment of adolescent mental health. These include lack of resources, lack of communication between parents and healthcare practitioners, lack of policies aimed at child and adolescent health, and the ways in which mental health problems are diagnosed. According to Wissow *et al*,[4 5] many children and adolescents have functional problems related to emotions or behaviour, but do not meet the criteria for diagnosis of a mental health disorder. It is critical though that such at-risk children and adolescents be identified so that appropriate prevention be put in place. This is concerning as adolescence represents a crucial period of development, where exposures, learnt behaviours and experiences can set the trajectory for an individual's mental and physical health in adult life.[3 4] The life course approach advocates for effective interventions during adolescence to

BMC Psychology

RESEARCH

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Measuring mental wellness among adolescents living with a physical chronic condition: a systematic review of the mental health and mental well-being instruments

Zaida Orth* and Brian van Wyk

Abstract

Background: Globally, promoting mental health and well-being among adolescents has become a public health priority, especially for adolescents living with a physical chronic condition (CC), as research suggests they may be more at risk of developing mental health co-morbidities. Valid and reliable instruments are needed to measure and better understand mental health and mental well-being among adolescents living with a CC. To this end, we reviewed studies reporting on mental health and well-being instruments used in adolescent populations living with a chronic physical condition/disease globally.

Methods: We used a systematic review method guided by PRISMA to identify assess mental health and mental well-being instruments used in adolescents living with a CC. In this instance, mental health instruments were defined as those representing negative domains of mental health (i.e. depression and anxiety) while mental well-being instruments included positive aspects of mental health (i.e. self-concept and resilience).

Results: We identified 22 articles, which included 31 instruments that were used to measure either mental health (n = 8) or mental well-being (n = 15) or both (n = 8) in adolescents living with a CC. Of these, thirteen studies used a Health-Related Quality of Life (HRQoL) scale to measure mental health and/or mental well-being. The KIDSCREEN questionnaires and the Strengths and Difficulties Questionnaire were identified as being frequently used across the 22 studies. Additionally, 7 out of the 31 instruments were disease specific, with 3 focusing on adolescents with diabetes. All the instruments were developed in high income countries and adapted for use in lower- and middle-income countries (LMICs). Adolescents with Type 1 Diabetes (n = 7) and HIV (n = 4) were researched in 11 out of 22 studies. Only eight studies were conducted in LMIC, of which four were in Africa.

Conclusions: HRQoL instruments are useful in measuring mental health and well-being in adolescents living with a CC. However, relatively few valid measures of mental health and mental well-being for adolescents living with a CC exist, which accentuates the paucity of research on mental health and mental well-being of adolescents who are living with a CC. Specific measures need to be developed in and for LMICs where cultural contexts affect mental well-being in unique ways.

*Correspondence: zaidaorth@gmail.com
School of Public Health, University of the Western Cape, Robert Sobukwe Rd, Bellville 7535, South Africa

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REVIEW
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Measuring Mental Wellness of Adolescents: A Systematic Review of Instruments

Zaida Orth[1]†, Faranha Moosajee[2]† and Brian Van Wyk[1]†*

[1] School of Public Health, Faculty of Community and Health Sciences, University of the Western Cape, Bellville, South Africa, [2] Division for Postgraduate Studies, University of the Western Cape, Bellville, South Africa

Objective: Mental health is critical to the healthy development of adolescents. However, mental health encompasses more than the absence of mental illness; and should include indicators of mental wellness. A critical review of available mental wellness instruments for adolescents were conducted to identify operational definitions of mental wellness concepts for this population group.

Method: A systematic review of literature published between 2000 and 2020 was done to identify mental wellness instruments for adolescent populations. The review followed the PRISMA operational steps.

Results: We identified 2,543 articles from the search strategy and screened titles and abstracts for eligibility. After appraisal, 97 studies were included in the qualitative synthesis; of which, 79 mental wellness instruments were identified. Most studies did not provide a definition for mental wellness. We identified thirteen mental wellness concepts from 97 studies, 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.*

Conclusion: The review reflected previous research identifying a lack of consensus around the definitions of mental health, mental wellness, and mental wellbeing. This has implications for developing instruments for adolescents that adequately measure these constructs. Most of the instruments identified in the review were predominantly English and from developed countries. This indicates a need for instrument that are explicitly conceptualised and operationalised for adolescents in all their varied contexts.

Keywords: mental wellness, measurement, systematic review, adolescent, mental wellbeing

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Laura Galiana,
University of Valencia, Spain

Reviewed by:
Mohd Faizul Hassan,
Universiti Teknologi MARA Puncak Alam, Malaysia
Lynn Rew,
University of Texas at Austin, United States

***Correspondence:**
Zaida Orth
zaidaorth@gmail.com

†ORCID:
Zaida Orth
orcid.org/0000-0002-2895-0417
Faranha Moosajee
orcid.org/0000-0002-1156-4472
Brian Van Wyk
orcid.org/0000-0003-1032-1847

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BACKGROUND

Adolescents are prioritised in the global public health agenda because they play a central role in achieving the 2030 Sustainable Development Goals (SDGs) (World Health Organization, 2017; Guthold et al., 2019; Patalay and Gage, 2019). In 2019 UNICEF estimated that there were 1.2 billion adolescents (aged 10–19 years), which represents approximately 16% of the global population (UNICEF, 2020a). It is further estimated that approximately 50% of all mental disorders have their onset during adolescence (Patalay and Gage, 2019; Peters et al., 2019; UNICEF, 2020b). According

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A Facility-based Family Support Intervention to Improve Treatment Outcomes for Adolescents on Antiretroviral Therapy in the Cape Metropole, South Africa

Zaida Orth[1] **and Brian van Wyk**[1]

Abstract

Adolescents living with human immunodeficiency virus (HIV) (ALHIV) globally, report worse treatment outcomes compared to adults and children on antiretroviral therapy (ART). We conducted a photovoice study with eighteen ALHIV to explore experiences and challenges of being on ART, and individual interviews with 5 health workers to describe the challenges in treating ALHIV. The facility implemented the *Family club* intervention to facilitate caregivers (parent/guardians) supporting ALHIV on treatment. The health workers revealed that "*disclosing HIV status*" to children was the biggest challenge for caregivers and health workers. Participating ALHIV reported that *family support* and having a *positive mentality* were instrumental for continued treatment adherence. However, *disclosure* of HIV status to friends remained a challenge due to pervasive community stigma. *Treatment fatigue* and *side-effects* were also barriers to adherence. Family support was instrumental in facilitating adherence support for ALHIV. However, this (intervention) should include peer support to improve positive mental well-being in ALHIV.

Keywords

photovoice, adolescents living with HIV, adherence, family club

Introduction

The increased availability of antiretroviral therapy (ART) combined with the scaling up of health care services and programmes aimed at supporting adherence to treatment has increased the life expectancy of people living with human immunodeficiency virus (HIV) (PLHIV), including perinatally infected children who are now surviving into adolescence.[1,2] The increased survival rates of perinatally infected children along with the growing number of behaviorally infected adolescents have resulted in adolescents being identified as the fastest-growing population of PLHIV. As such, adolescents have been identified as one of the key populations in the fight against HIV. According to UNAIDS 2019, the global population of adolescents living with HIV (ALHIV) was estimated at 1.7 million.[3] In South Africa the number of ALHIV was estimated at 360,000 (230,000-500,000), with 31,000 (8100-62,000) new infections reported in 2019.[3]

Globally, it is estimated that there has been a 45% increase in AIDS-related deaths among adolescents between 2005 and 2015.[4] This is of great concern, as it stands in contrast to the decrease in AIDS-related deaths reported for all other age groups.[5] The increase in AIDS-related deaths among ALHIV suggests lapses in treatment and successful engagement. Evidence suggests that this lapse in treatment may be associated with the type of care and the quality of support that ALHIV receive.[6] Adolescence is a unique developmental period in which individuals experience significant physical, psychological and social changes.[7-9] Our report from an exploratory study of ALHIV on ART in a low socioeconomic setting in Cape Town also revealed that; school versus health facility conflicts, negative household dynamics and finding the health facility as an unfriendly place, as reported barriers to adherence.[10] Therefore, the World Health Organization (WHO) recommended that public health care facilities establish adolescent-friendly health services which include age-appropriate treatment programmes to provide psychosocial support, sexual and reproductive health

[1] School of Public Health, University of the Western Cape, Bellville, South Africa

Corresponding Author:
Zaida Orth, School of Public Health, University of the Western Cape, Robert Sobukwe drive, Bellville 7535, South Africa.
Email: zaidaorth@gmail.com

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ORIGINAL RESEARCH

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

Zaida Orth, Brian van Wyk

School of Public Health, University of the Western Cape, Bellville, Western Cape, 7535, South Africa

Correspondence: Zaida Orth, Tel +27728718490, Email zaidaorth@gmail.com

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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Systematic Reviews

PROTOCOL

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Rethinking mental wellness among adolescents: an integrative review protocol of mental health components

Zaida Orth* and Brian van Wyk

Abstract

Background: Adolescents have been overlooked in global public health initiatives as this period is generally considered to be the healthiest in an individual's life course. However, the growth of the global adolescent population and their changing health profiles have called attention to the diverse health needs of adolescents. The increased attention toward adolescent health has accentuated existing gaps as global health reports have emphasised that there is a continued need for valid and reliable health data. In this context, evidence has shown that mental health issues constitute one of the greatest burdens of disease for adolescents. This integrative review aims to unpack the meaning of mental wellness among adolescents and its associated constructs by analysing and synthesising empirical and theoretical research on adolescent mental wellness. In doing this, we will develop a working definition of adolescent mental wellness that can be used to develop an instrument aimed at measuring adolescent mental wellness.

Methods: The integrative review is guided by the five steps described by Whittemore and Knafl. A comprehensive search strategy which will include carefully selected terms that correspond to the domains of interest (positive mental health/mental wellness) will be used to search for relevant literature on electronic databases, grey literature and government or non-governmental organisations (NGO) websites. Studies will be included if they describe and/or define general mental wellness in adolescent populations aged 10–19. The screening and reporting of the review will be conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Data from the integrative review will be analysed using narrative framework synthesis for qualitative and quantitative studies.

Discussion: This integrative review aims to search for and synthesise current research regarding adolescent mental wellness to identify how wellness is being described and conceptualised. We aim to identify gaps and to contribute to a more comprehensive definition of mental wellness which can aid in the development of an age- and culturally appropriate measure of adolescent mental wellness.

Keywords: Adolescent mental health, Mental wellness, Integrative review, Positive psychology

Background

In 2016, adolescents (10–19 years) were estimated at 1.2 billion (18%) of the world population, making them the largest population of adolescents in history [1, 2]. Adolescents have been largely overlooked in global health and social policies, because this period is generally considered to be the healthiest in an individual's life-course [2], and the unique health problems associated with

*Correspondence: zaidaorth@gmail.com
School of Public Health, University of the Western Cape, Bellville 7535, South Africa

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EDITED BY
Fang Lei,
University of Minnesota Twin Cities, United States

REVIEWED BY
Siaw Leng Chan,
Universiti Putra Malaysia Bintulu Sarawak Campus, Malaysia
Jessy Fenn,
Rajagiri College of Social Sciences, India

*CORRESPONDENCE
Zaida Orth
zaidaorth@gmail.com

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Rethinking mental health wellness among adolescents living with HIV in the African context: An integrative review of mental wellness components

Zaida Orth* and Brian Van Wyk

School of Public Health, Faculty of Community and Health Sciences, University of the Western Cape, Bellville, South Africa

Objective: Adolescents living with HIV (ALHIV) are considered to be at heightened risk for developing mental health problems in comparison to their peers due to the burden of living with a stigmatized condition and managing a chronic condition. Poorer mental health outcomes among ALHIV are associated with lower rates of adherence to anti-retroviral therapy (ART). It is necessary to improve mental wellness among ALHIV as this acts as a buffer against developing mental health problems which, if left untreated can evolve into mental health disorders. Research on mental wellness concepts among ALHIV is underdeveloped which is associated with a lack of appropriate measures of mental wellness. We conducted an integrative review to conceptualize mental wellness and consider the critical components for measuring mental wellness in ALHIV.

Method: An integrative review of published literature focusing on mental wellness of ALHIV in the African context was conducted. The process was guided by the PRISMA operational steps. As part of our problem identification phase, we drew on findings from a previous systematic review of mental wellness instruments and a qualitative photovoice study on exploring the experiences of ALHIV, to develop an initial framework of 13 mental wellness concepts and behaviors which informed the search strategy.

Results: The review included 17 articles from which we identified six mental wellness concepts: Connectedness, Sense of Coherence (SOC), Self-esteem, Self-acceptance, Hope for the Future and Spirituality as well as six behaviors facilitating mental wellness: Coping, Resilience, Purpose in Life (goals), Self-efficacy, Adherence Self-efficacy, and Leisure Activities. All of these concepts and behaviors have been noted in our previous research (systematic review and qualitative work), with the exception of adherence self-efficacy. Based on the findings from this review and our previous work, we adapted the Salutogenic Model of Health developed by Antonovsky in 1987, to propose a Salutogenic Model of Mental Wellness (SMoMW) for ALHIV in the African context. This SMoMW may be used to develop an age and culturally appropriate measure of mental wellness for ALHIV.

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Article

Asking the Experts: Using Cognitive Interview Techniques to Explore the Face Validity of the Mental Wellness Measure for Adolescents Living with HIV

Zaida Orth * and Brian Van Wyk

School of Public Health, Faculty of Community and Health Sciences, University of the Western Cape, Robert Sobukwe Rd., Bellville 7535, South Africa
* Correspondence: zaidaorth@gmail.com

Abstract: There has been an increased focus on the mental health of adolescents living with HIV (ALHIV), because evidence shows that poor mental health outcomes are associated with lower rates of adherence and retention in HIV care. However, the research to date has predominantly focused on addressing mental health problems and reducing symptoms of mental illness rather than strengthening mental wellness [positive mental health]. Consequently, little is known about the critical mental wellness indicators that should be targeted in services for ALHIV. There is a need for valid and appropriate measures of mental wellness to drive research and provide evidence on the mental wellness needs of ALHIV that would inform service delivery as well as the monitoring and evaluation of treatment outcomes. To this end, we developed the Mental Wellness Measure for Adolescents Living with HIV (MWM-ALHIV) for ALHIV in the South African context. In this paper, we report on the findings from a cognitive interview study with nine ALHIV aged 15–19 years receiving treatment at a public healthcare facility in the Cape Metropole, South Africa. Through interviews, participants identified key issues related to the wording, relevance and understanding of the items and provided suggestions to improve the instrument's overall face validity.

Keywords: adolescents living with HIV; instrument development; mental wellness; cognitive interviewing

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1. Introduction

Mental wellness (positive mental health) has been identified as a significant driver of adolescent health and well-being [1]. This is evidenced in the inclusion of mental health (wellness) in the Sustainable Development Goal (SDG) target 3, which highlights mental health promotion as a critical factor in reducing premature mortality from non-communicable diseases and ensuring good health for all by 2030 [2]. This target is especially relevant for adolescents living with HIV (ALHIV), as they learn to navigate living with a highly stigmatized chronic condition and other challenges and health risks associated with adolescence [3]. Research aimed at understanding the lived experiences of ALHIV has shed light on the various biopsychosocial challenges face, including delayed disclosure, stigma, dysfunctional families, community violence, substance use, poverty, gender inequality and bullying, to name but a few [4–7]. Their exposure to these various stressors places them at greater risk of developing mental health disorders in comparison to their peers who do not have HIV [4–7]. Various studies have reported high prevalence rates of mental health disorders such as anxiety, depression, and post-traumatic stress disorder (PTSD) [7–9]. Moreover, poor mental health has been significantly associated with low adherence to antiretroviral therapy (ART) and retention in care (RiC) among ALHIV [10,11]. Consequently, the low rates of adherence to ART and RiC are associated with higher AIDS-related deaths among ALHIV in comparison to children and adults living with HIV [12,13].