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# A qualitative enquiry into the meaning and experiences of wellbeing among young people living with and without HIV in KwaZulu-Natal, South Africa

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## ABSTRACT

Young people in sub-Saharan Africa encounter health and livelihood challenges which may compromise their wellbeing. Understanding how young people's wellbeing is defined could strengthen wellbeing policies. We investigated perceptions and experiences of young people's wellbeing, and whether these aligned with Ryff's psychological wellbeing (PWB) model.

Data were collected between January–August 2018 through focus-group discussions (n = 12) and in-depth interviews (n = 16) with young people living with and without HIV, selected purposively from South African healthcare facilities. Key informant interviews (n = 14) were conducted with healthcare workers and subject-matter experts. Using a framework approach, we situated our analysis around dimensions of Ryff's PWB model: autonomy, self-acceptance, purpose in life, environmental mastery, positive relationships, personal growth.

Young people's wellbeing was rooted in family and peer relationships. Acceptance and belongingness received from these networks fostered social integration. HIV-related stigma, crime and violence reduced their perceived control and social trust. For males, fulfilling gendered roles made them feel socially valued. Self-perceived failure to uphold sexual norms undermined women's social contribution and autonomy.

Social integration and contribution framed young people's wellbeing. However, these dimensions were not fully captured by Ryff's PWB model. Models that consider relationality across socio-ecological levels may be relevant for understanding young people's wellbeing.

## 1. Introduction

In 2019, Africa accounted for almost one-fifth (221 million) of the 1.2 billion young people aged 15–24 years worldwide (UN, 2019). It is estimated that by 2065, the number of young people in sub-Saharan Africa (SSA) will increase by 89% (UN, 2019). However, this demographic transition signals a challenge to sustainable development in SSA (OECD, 2018), where currently young people's wellbeing may be threatened by HIV/AIDS (UNAIDS, 2018) and unemployment (ILO, 2016).

Wellbeing among young people is now a priority indicator in global health, in line with Goal 3 of the 2030 Sustainable Development Goals agenda (UN, 2018). Broadly, this construct refers to how well one is thriving across multiple life domains (Adler and Seligman, 2016). Econometric evidence has shown that wellbeing during adolescence predicts positive human capital and labour market outcomes, including

adult health outcomes (Layard et al., 2014). Maximisation of societal utility (wellbeing) is an important policy goal (McGregor and Pouw, 2016). Direct measurement of people's wellbeing is now recommended for policy evaluations (Clark et al., 2019; Stiglitz et al., 2009). Economic studies have highlighted the value in using wellbeing measures to evaluate the broader impacts of multi-sectoral interventions and policies (Dolan and Peasgood, 2008; Greco et al., 2016). If we can improve our understanding of young people's wellbeing then we can select appropriate measures to evaluate and guide policy investment decisions to effectively promote their wellbeing.

The choice of wellbeing models and measures to guide resource allocation decisions for young people in SSA requires careful consideration to ensure alignment with local perceptions and experiences of wellbeing (McGregor and Pouw, 2016). The lack of data on how to frame and measure young people's wellbeing is a barrier to health investments among this group (Azzopardi et al., 2019). Psychological

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wellbeing (PWB) models such as Ryff's PWB model may be suitable for assessing young people's wellbeing in SSA given its alignment with the conceptualisation of wellbeing in African settings (Delle Fave et al., 2016), particularly among young people (Van Schalkwyk and Wissing, 2010; Wissing et al., 2014). A deeper understanding of how young people's wellbeing is locally constructed could help identify wellbeing models and measures for application in evaluations of wellbeing policies or programmes.

In this paper we examine how wellbeing was locally perceived and experienced by young people living with and without HIV in KwaZulu-Natal South Africa, and whether or not these aligned with Ryff's PWB model.

## 2. Theoretical framework and literature

Ryff's PWB model is rooted in a eudaimonic approach to wellbeing which emphasises meaning-making, self-realisation and growth, relatedness and quality of relationships (Ryff, 2014). This model is built on the assumption that an individual strives to function fully and realise his or her talents. It encompasses six dimensions of positive functioning: 1) self-acceptance: a positive self-attitude, 2) positive relations: quality relationships, 3) environmental mastery: the capacity to effectively manage one's life and surrounding world, 4) autonomy: a sense of self-determination, 5) purpose in life: a belief that one's life is purposeful and meaningful, and 6) personal growth: a sense of continued growth and development (Ryff, 2014; Ryff and Keyes, 1995) (Appendix 1-Insert link to online file). Broader wellbeing models include Keyes's (1998) social wellbeing model which comprises six dimensions: social integration, social acceptance, social contribution, social actualisation and social coherence (Keyes, 1998). The more recent PERMA model, focuses on positive emotions, engagement, relationships, meaning and accomplishment (Seligman, 2012).

We chose the Ryff PWB model for the following reasons. First, this model emphasises meaningfulness and relationality, which are central to wellbeing in Africa populations (Delle Fave et al., 2016), particularly among young people (Van Schalkwyk and Wissing, 2010; Wissing et al., 2014). Second, our previous work suggests that experiences of wellbeing among young people living with HIV (YPLHIV) encompass supportive relationships, aspirations and coping, which align with the model's dimensions (i.e. positive relations, purpose and mastery) (Govindasamy et al., 2020). Third, the model's dimensions are informed by development stage theories (Erikson, 1994; Jahoda, 1958) which are used to understand adolescent development, specifically identity and relationships (Hightower, 1990; Lerner and Steinberg, 2004; Miller, 1989). Fourth, compared to the social wellbeing and PERMA model, the Ryff PWB model has been widely applied in adolescent studies (Bojanowska and Piotrowski, 2019; Gardner and Webb, 2019; Ryff, 2014).

Qualitative studies which have applied a PWB framework, have identified positive relations with family members as a key dimension of adolescent wellbeing in the United States of America (Rose et al., 2016), and South Africa (Geldenhuys, 2016; Van Schalkwyk and Wissing, 2010). This current study extends this literature by contextualising psychological dimensions linked to relationships within Ryff's PWB model for young people. Whilst quantitative studies have reported differences in PWB scores between ages-groups and gender among young people in developing settings (Perez, 2012; Sun et al., 2016), it is unknown how and why these differ. We seek to narrow this evidence gap by examining how dimensions of Ryff's PWB model are shaped by socio-demographic factors. Furthermore, the voices of YPLHIV with regards to their wellbeing are missing in the literature. The unique and multiple issues that YPLHIV experience (e.g. stigma and disclosure) likely undermine their wellbeing (Bernays et al., 2017; Skovdal and Belton, 2014). Our study expands the wellbeing literature by adding to it the perspectives of YPLHIV and assessing how their experiences of wellbeing and illbeing differ to those not living with

HIV. Current evaluations of health policies aimed at promoting young people's wellbeing in SSA are based on narrow biomedical outcomes that ignore the lived experiences of young people. We seek to provide guidance on wellbeing models and measures that could be applied in surveys or monitoring and evaluation frameworks.

## 3. Methods

### 3.1. Study setting

South Africa is currently in the medium human development category, with a Human Development Index score of 0.705 and average life expectancy of 64 years (UNDP, 2019). It has one of the highest levels of income inequality with a reported Gini co-efficient of 0.63 (World The World Bank, 2015). This country ranks at 106 in the latest World Happiness Report, making it one of the least happy countries (Helliwell et al., 2019; Sachs et al., 2019). Furthermore, it has one of the largest HIV epidemics in the world, with an estimated 7.9 million people living with HIV (HSRC, 2018). The current HIV prevalence is 10.5% among 15-19 year-olds and 20.4% among 20-24 year-olds (HSRC, 2018). The country is divided into 9 provinces, with KwaZulu-Natal ranked as one of the poorest provinces, with a GDP per capita of 4507 USD (Stats SA, 2017). This province is further divided into 11 districts, with the eThekweni district, regarded as the epi-centre of South Africa's HIV epidemic (HIV prevalence 0->60 years: 14.5%, 95% CI: 11.2-18.6) (HSRC, 2014). This study was conducted in Umlazi, a peri-urban area within the eThekweni district that has an estimated population size of 404 811 (Stats SA, 2011).

### 3.2. Data collection

To gain an in-depth understanding of young people's wellbeing from a range of stakeholders, we conducted interviews with young people living with or without HIV, healthcare workers (HCWs), and subject-matter experts. Data were collected between January and August 2018. We purposively sampled young people and HCWs from two clinics within a public-sector hospital. We chose this hospital as it is the main referral hospital for our study community. Moreover, it operates two outpatient clinics, one for HIV treatment and the other for general health services, with dedicated delivery times for young people. Our fieldworker either approached patients during waiting times or HCWs directed potentially eligible patients to our recruitment room after their consult. Young people were sampled in line with the WHO definition of older adolescent (15-19 years) and young adult (20-24 years) (WHO, 2014). Experts were purposively sampled from academic institutions in South Africa or abroad.

The eligibility criteria for the following participant groups were as follows:

- Young person living with HIV**- aware of HIV status and clinically stable on antiretroviral therapy for more than six months with no other conditions (e.g. tuberculosis, pregnancy)
- Young person living without HIV**- no major self-reported health condition (e.g. HIV positive, tuberculosis, pregnancy etc.)
- HCW**- any HCW providing care to young people in the study clinic or catchment community
- Expert**-a researcher in the area of adolescent HIV or wellbeing

Topic guides were loosely mapped to Ryff's PWB model dimensions (Ryff and Keyes, 1995). This allowed us to ask questions that were relevant to each dimension and explore emergent issues outside this model.

Focus-group discussions (FGDs) (n = 12) were conducted with young people (5-10 participants per group) to obtain a wide range of perspectives on how wellbeing and illbeing were understood. We sought to create homogenous groups and thus grouped participants by

HIV-status, sex and age-range (15-19-year-olds, 20-24-year olds) in order to assess common experiences. FGDs were conducted until theoretical saturation was reached. We incorporated Draw-and-Tell Techniques in our FGDs (Crivello et al., 2008; Ferrari, 2016). We divided participants into two groups, and tasked each group with developing an image of a young person living a good or a bad life. Using the group's artwork, we explored what constituted a good and bad life for a young person in this community. We specifically asked participants the following questions: "how does this create a good life?", "what needs to be in place for you to have this good life?", "what can take this good life away?", "how does this create a bad life?". We probed elements in the drawings that were linked to Ryff's PWB model dimensions. Trust and confidentiality exercises were conducted to highlight the safe space for discussion, minimal disclosure of personal information and protection of participant information. Basic socio-demographic data were collected from each participant at the start of the FGD.

Approximately 1–2 participants were purposively sampled based on age, gender and HIV-status from each FGD for participation in an in-depth interview (IDI) (n = 16). IDIs were 1.5–2 h in duration and explored personal experiences, how these experiences differed by groups and themes that emerged in the FGDs. We selected participants who appeared comfortable engaging with study staff in the FGDs, particularly those who appeared at ease with articulating their thoughts and opinions. Participants' experiences of wellbeing and illbeing were probed using a Life-course Timeline approach, as used in child wellbeing studies in developing studies (Crivello et al., 2008). Each participant was asked to draw a timeline from birth to present age, highlighting important happy and sad life events. The design was flexible, allowing participants to write or talk about their life history. We probed the following questions "describe yourself?", "who is your role model and why?", "why would you consider this a happy or sad event?", "what would you say to your younger self?", "how do you cope with stress?", "what would you consider important to you and why?".

Semi-structured KIIs (1–1.5 h) were conducted with HCWs (n = 9) and experts (n = 5). Interviews with HCWs sought to understand the psycho-social needs and health system barriers for young people living with and without HIV. Interviews with experts explored adolescent-centred wellbeing measures, constructions of wellbeing in developing settings, and ethical issues in wellbeing research. Key findings from the FGDs and IDIs were discussed further with HCWs.

Interviews were audio-recorded and conducted in the participant's preferred language (English or isiZulu). A facilitator conducted the FGDs, IDIs and KIIs. At each session the fieldworker made note of group dynamics or non-verbal communication. The first author conducted KIIs with English-speaking HCWs and all experts. Staff received regular debriefing from a social worker in order to manage difficult feelings or thoughts that may have arisen during data collection.

### 3.3. Data analysis

Audio recordings were transcribed and translated and checked for accuracy. A framework analysis approach was used (Ritchie et al., 2013). Two authors first read all transcripts and field notes, and examined participants artwork to gain a general understanding of each session and discuss the key themes that emerged. The first author then developed a list of codes, identified deductively or inductively. Examples of deductive codes included dimensions of Ryff's PWB model and themes identified in our wellbeing review (Govindasamy et al., 2020). The first author then applied the framework systematically to all data by coding transcripts using NVivo version 11. Data were independently coded by a co-author to assess inter-rater reliability. While there was good agreement between coders, a few differences emerged which were resolved through discussion to reach a consensus. A matrix was then developed by re-organising the data into relevant headings and categories. Using this matrix, data from the FGDs were compared

with IDIs and KIIs to explore convergence, complementarity, and discordance to enhance the validity of the results. We specifically sifted through the data to examine differences and similarities in wellbeing dimensions by age, sex and HIV status. DG conducted interpretations of the data, jointly with KM, GF and JS. We used the dimensions of Ryff's PWB model to order the data and facilitate the connection and representation of our data. We drew on the definition of each dimension (Appendix 1-insert online link here-) to interpret manifestations of wellbeing or illbeing in our data, and to identify experiences overlooked by this model.

### 3.4. Ethics approval

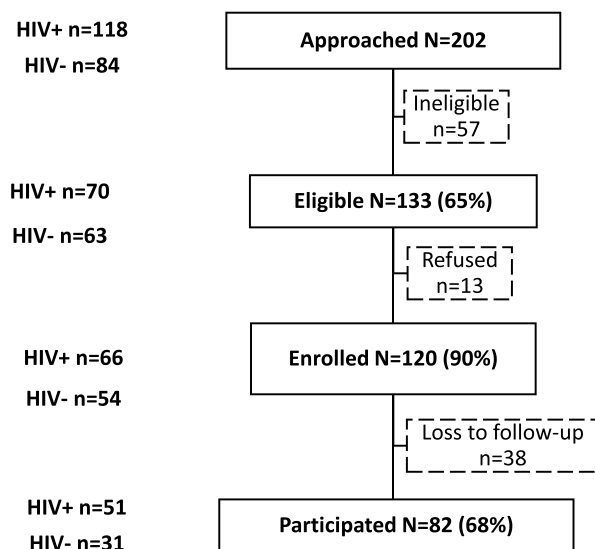
Ethical approval was obtained from the South African Medical Research (EC037-11/2016) and the London School of Hygiene and Tropical Medicine (13782-1). Approval to conduct this study within healthcare facilities was obtained from the KwaZulu-Natal Department of Health (Health Research and Knowledge Management Division) and hospital management. Written informed consent was obtained for participants aged 18 years and above. For minors, defined as individuals younger than 18 years in South Africa, written parental permission together with minor assent was obtained. All participants were assigned unique identification numbers. We used pseudonyms in this paper to maintain confidentiality. Participants who attended study interviews received a lunch pack and transport fare.

## 4. Results

### 4.1. Sample description

Overall, 202 young people were approached at the study clinics (Fig. 1). Of these, 133 (65%) met the eligibility criteria, and 120 were enrolled. Most refusals were among minors. YPLHIV who were unstable on treatment made up the majority of those who were ineligible to participate.

Of those enrolled, 82 (68%) participants attended one of the 12 FGDs conducted (Table 1). Of these, 8 FGDs were with YPLHIV (n = 51, approximately 6 participants per group) and 4 FGDs with young people



HIV+ = HIV-positive; HIV- = HIV-negative

Fig. 1. Recruitment flow of young people living with and without HIV.

**Table 1**  
Socio-demographic characteristics- FGD participants.

	Total (N = 82) n (%)	HIV-negative (n = 31)	HIV-positive (n = 51)
<b>Total FGDs conducted</b>	12	4	8
<b>15–19-year-old</b>	6	2	4
Female	3	1	2
Male	3	1	2
<b>20–24-year-olds</b>	6	2	4
Female	3	1	2
Male	3	1	2
<b>Age (median, IQR<sup>a</sup>)</b>	19 (18–22)	20 (18–22)	18.5 (17–22)
<b>Age category</b>			
15–19 yrs.	44 (54)	13 (42)	31 (60)
20–24 yrs.	38 (46)	18 (58)	20 (40)
<b>Gender</b>			
Female	42 (51)	17 (55)	25 (49)
Male	40 (49)	14 (45)	26 (51)
<b>Race- Black</b>	82 (100)	31 (100)	52 (100)
<b>South African nationality</b>	82 (100)	31 (100)	52 (100)
<b>Current economic status</b>			
Enrolled in secondary education	35 (42)	7 (23)	28 (55)
Enrolled in tertiary education	19 (23)	10 (32)	9 (17)
Employed	6 (7)	4 (13)	2 (4)
Unemployed-searching for a job	22 (27)	10 (32)	12 (24)
<b>Completed compulsory education (Grade 9)</b>			
Yes	76 (93)	31 (100)	45 (88)
No	6 (7)		6 (12)
<b>Type of household</b>			
Formal	65 (79)	26 (84)	39 (76)
Informal	17 (21)	5 (16)	12 (24)
<b>Number of household members (median IQR<sup>a</sup>)</b>	5 (4–7)	4 (2–7)	5 (4–8)
<b>Biological mother lives in household</b>			
Yes	32 (40)	15 (48)	17 (33)
No	50 (60)	16 (52)	34 (67)
<b>Biological father lives in household</b>			
Yes	8 (10)	5 (16)	3 (6)
No	74 (90)	26 (84)	48 (94)
<b>Caregiver</b>			
Biological mother	22 (27)	10 (32)	12 (24)
Grandmother	16 (20)	1 (3)	15 (29)
Aunt	12 (15)	4 (13)	8 (16)
Other	32 (40)	16 (52)	16 (31)

<sup>a</sup> IQR = Interquartile range.

not living with HIV (n = 31, approximately 7 participants per group). The median age of participants in our FGD sample was 19.5 years, with 51% who were female. The majority FGD participants were black South Africans, who completed compulsory education (i.e. Grade 9), with 41% enrolled in secondary school. Nearly 80% of participants resided in formal households, without their biological parent/s.

From the FGDs, 16 participants were sampled for IDIs (n = 10 with YPLHIV, n = 6 with young people not living with HIV) (Table 2). Most IDI participants were aged 15–19 years (n = 8), with over two-thirds currently completing secondary school. More than 50% (n = 10) reported that their biological father was deceased.

Most key informants were HCWs (n = 10), mainly nurses (n = 4). Experts included social scientists with expertise in wellbeing or adolescent health research (n = 5), based mainly at South African institutions.

#### 4.2. Description of wellbeing

Using the dimensions of Ryff's PWB model, we describe how wellbeing was perceived and experienced in this context.

##### 4.2.1. Positive relations

When we asked young people and key informants what makes a good life for a young person in this setting, most accounts embodied a strong sense of relatedness, with a good life described as “*living together as a family*”, having a “*loving family*” and having “*trusting family members*” (Fig. 2). Family units were described by young people as groups with “*shared happiness and love*”. Supportive caregiver relationships appeared essential for wellbeing as this facilitated integration within family networks. The importance of supportive caregivers for a good life was more pronounced in FGDs with YPLHIV compared to those not living with HIV. Vertically HIV-infected participants expressed gratitude to their grandmothers' for their support with HIV status disclosure and medical adherence during childhood. Young people exhibited strong awareness of the reciprocal nature of relationships, which was often reflected in their desires to “*provide*” for their households.

Positive relations that extended beyond the family were also critical for cultivating social integration. For Sne, being part of a clinic-based adolescent HIV support group gave her a sense of belonging:

“there used to be a group we used to meet as young people ... who have HIV would learn from each other, and talk ... it was nice ... talking ... everyone felt comfortable ... because we spoke about anything regarding HIV ... we would talk and it was nice, .... you even develop friendships there” [Sne, 19-year-old female, HIV-positive]

In contrast, for 18-year-old Bongani belonging to a church group helped him develop friendships with other members.

Descriptions of sad life events were often linked to negative experiences and lack of integration within networks. From FGDs and IDIs with male participants living with and without HIV, it was evident that in a good life, biological fathers played a key role in fostering belonging. For Sanele and Nka, the lack of acceptance from the paternal family or not having a father in the household, made them feel “out of place”, and likely lowered their wellbeing by reducing a sense of belongingness.

Experiences of HIV-related stigma characterised sad life events for YPLHIV. Stigma encountered within family networks impaired wellbeing by reducing their self-esteem and ability to build positive relationships. For example, Owethu tried to re-connect with his father who rejected him because of his HIV-positive status:

“Yes and then my father said “okay you have HIV”, he started to reject me but then he said if you come to visit me you are not going to take your pills ... not understanding that I am ... not understanding that I am at this level that where I might even get AIDS ... I'm not going.” [Owethu, 18-year-old male, HIV-positive]

The internalised stigma that Sne harboured negatively affected her self-worth and ability to be in an intimate relationship

“Who will accept condition I am in now .... Because everyone is scared of HIV ... that means I should not date .... I must stay like this .... be myself .... and not have a boyfriend. Because if he can ever be sick obviously it will be me .... then I realised that no I should not commit myself.” [Sne, 19-year-old female, HIV-positive]

Similarly, perceptions of a bad life echoed a sense of lowered social trust and exclusion among male participants:

“The sports grounds should be close to where black young people live, young people should not travel long distances, they should not travel long distances going to these grounds because those who are poor might end up not being part of this because of long distance they would travel to go to these grounds to play.” [FGD, 15-19-year-old males, HIV-positive]

“You have a degree then you're sitting at home doing nothing, the government is supposed to fight for that because there are no job opportunities, not at all, I don't want to lie.” [FGD, 20-24-year-old

**Table 2**  
Sample characteristics- IDI participants (N = 16).

IDI participant	HIV status (mode of HIV infection)	Age	Gender (parental status)	Current economic status	Completed compulsory education (Grade 9)	Highest Grade completed	Type of household	Number of people living in household	Biological mother lives in household	Biological father lives in household	Primary caregiver
Sinothando	HIV-positive (vertically infected)	15	Female	In secondary education	Yes	Grade 10	Formal	4	No	No-deceased (HIV/AIDS related)	Aunt
Thandi	HIV-positive (vertically infected)	18	Female	In tertiary education	Yes	Grade 12	Formal	5	Yes	No-deceased	Biological mother
Sne	HIV-positive (vertically infected)	19	Female	In secondary education	Yes	Grade 11	Informal	17	No-lives and works in the city	No-deceased	Grandmother
Busi	HIV-positive (vertically infected)	20	Female	In tertiary education	Yes	Grade 12	Formal	3	No-deceased	No-deceased	Aunt
Thembeke	HIV-positive (sexually infected)	24	Female, (mother)	Unemployed searching for a job	Yes	Grade 12	Formal	10	Yes	No-deceased	Biological mother
Khewsi	HIV-positive (vertically infected)	15	Male	In secondary education	No	Grade 7	Formal	10	Yes	No- does not know who father is	Biological mother
Bongani	HIV-positive (vertically infected)	18	Male	In tertiary education	Yes	Year 1- university	Formal	6	No-deceased (HIV/AIDS-related)	No-disowned by father	Grandmother
Owethu	HIV-positive (vertically infected)	18	Male	In tertiary education	Yes	Grade 12	Formal	4	Yes	No-disowned by father	Biological mother
Andile	HIV-positive (vertically infected)	22	Male	Unemployed searching for a job	Yes	Grade 11	Formal	Unknown	No-deceased	No-deceased	Sister
Sanele	HIV-positive (vertically infected)	22	Male	Unemployed searching for a job	Yes	Grade 10	Formal	5	No-deceased (HIV/AIDS-related)	No-deceased (gun-related)	Aunt
Mandisa	HIV-negative	18	Female	In secondary education	Yes	Grade 12	Formal	3	Yes	Yes	Biological mother
Zanele	HIV-negative	23	Female, (mother)	In tertiary education	Yes	Grade 12	Formal	2	No-deceased	No-deceased	Grandmother
Hlengiwe	HIV-negative	24	Female, (mother)	In tertiary education	Yes	Grade 12	Informal	1 (Lives on her own)	No	No-deceased	Herself
Sipho	HIV-negative	16	Male	In secondary education	Yes	Grade 10	Formal	4	Yes	Yes	Biological mother
Ayanda	HIV-negative	20	Male, (father)	In secondary education	Yes	Grade 11	Formal- hostel	2	No	No	Himself
Nka	HIV-negative	21	Male	Unemployed searching for a job	Yes	Grade 11	Formal	2	Yes	No-deceased	Biological mother



Fig. 2. FGD, 15-19-year-old females, HIV-positive. This drawing highlights the importance of a supportive family networks for young people's wellbeing.

males, HIV-positive]

#### 4.2.2. Purpose in life

When we asked young people living with and without HIV what mattered most in their lives, salient in responses was the attainment of education and career goals such as passing high school, obtaining a tertiary qualification and attaining employment. Importantly, these goals appeared to promote wellbeing by providing a sense of purpose and making them feel socially valued as illustrated below:

"... you see when you're educated, they even respect you at home ... back home if you're uneducated they'll say things like "what does she know, she's uneducated". So, if you are educated, even the community respects you" [FGD, 15-19-year-old females, HIV-positive]

Finding meaning in negative life experiences also generated purpose in life. When we asked a doctor what mattered most to the wellbeing of YPLHIV, she indicated it was knowing they could have a future and their lives had meaning:

"... believing that they can have a family, they can get a job, and that they will be well..that HIV is not going to lead to AIDS and it's not going to lead to an early death" [HIV clinical specialist]

For Zanele, defining herself as a mother and granddaughter exemplified how fulfilment of social roles instilled purpose.

"I always say I live for him (referring to her child) and my grandmother. I come last, they are my priority, I study for them." [Zanele, 23-year-old female, HIV-negative]

Improving one's living standards, often depicted as displays of wealth and material possession in drawings (Fig. 3) and being able to provide for one's family or "give back to community" dominated accounts of a good life among males living with and without HIV.

Religious and spiritual beliefs often helped bring meaning to tragic life events. For instance, Busi, a 20-year-old HIV-positive female, explained that her faith taught her that "everything that happens on earth has a reason".

#### 4.2.3. Self-acceptance

Many of the HCWs highlighted the lack of psycho-social support services to support young people with managing difficult life events such as HIV disclosure, death of a family member, an unplanned pregnancy or experiences of gender-based violence. Hence, this challenged young people's ability to accept their situation and build positive identities, and likely comprised their wellbeing, as explained by one of the HCWs':

"A lot have siblings that are negative ... they feel like obviously they're discriminated against ... why am I positive?"

Expressions of self-acceptance in this setting embodied a sense of relatedness as it was dependent on acceptance from others within close relationships. When Bongani was asked whether he accepted his HIV-positive status, he responded:

"... her (referring to his girlfriend) accepting me really changed the way I looked at myself ... also the family members that knew about my status, telling me that it is okay ... they are supporting me in every way." [Bongani, 18-year-old male, HIV-positive]

However, in Bongani's life timeline, he depicted himself as a tree that was dying "cos of the virus" and referred to himself and his deceased mum as the "black sheep of the family". This suggested that even in the context of acceptance by close contacts, internally he experienced challenges with coming to terms with his HIV-positive identity and felt socially excluded.

Expressions of self-acceptance were often inter-twined with elements of internalised stigma.

"I have accepted that I am a human being who has a disease like this, I am HIV positive. Yeah, and I must live with it (referring to HIV) for the rest of my life. Until there is a cure for it." [Sinothando, 15-year-old female, HIV-positive]

#### 4.2.4. Environmental mastery

When we asked young people living with and without HIV how they managed some of their complex lived experiences (e.g. disclosure, death of a parent, bullying) most responses suggested that they



Fig. 3. FGD (20-24-year-old males, HIV-negative). This drawing depicts the importance of social status for young people's wellbeing, particularly for males.

employed negative coping strategies such as suppressing thoughts via sleep, which corroborated HCWs accounts. However, a few young people, specifically YPLHIV, practiced more positive forms of coping such as “writing down” one's thoughts which may have promoted wellbeing.

It appeared that positive relations facilitated positive coping. For instance, when Sne felt overwhelmed with anxiety she and her grandmother would draw on their religious beliefs and practices.

“then Gogo (her grandmother) says “never, never, never” ... you let's say, I have a problem, I'm writing exams and I'm lost ... Gogo just says “no, no, no, the devil is playing games”, she pulls out her bible ... and really we would read it ... After that I feel like something has been lifted from me ... even when I start with my exams ... I know I am that person who is always sick you know ... so if I keep praying every day it's like even sickness goes away, it's that thing .... It's like there's a breeze, I feel fresh.” [Sne, 19-year-old female, HIV-positive].

Several YPLHIV exhibited a strong sense of perceived control in their efforts to prevent inadvertent HIV disclosure to peers mainly via avoiding social interaction, as illustrated below:

“...so I have to go to the ... to the appointment (referring to his HIV clinic appointment) ... so when I come back they like “where were you?” and I'm like okay ... each and every month I have to think of a lie ... so instead I stick to being by myself.” [Bongani, 18-year-old male, HIV-positive]

There was a great awareness of surrounding opportunities (e.g. government bursaries, grants and tenders). Several young people exercised agency in pursuit of these opportunities.

“In 2016, second semester I didn't go to school because I didn't get NSFAS (government bursary scheme), there was not enough money at home. I didn't want to put pressure on them, I stayed. 2017, I went back until this year, I finally got NSFAS this year.” [Zanele, 23-year-old female, HIV-]

Common in all drawings of a bad life were depictions of crime and violence in their communities (Fig. 4). Discussions linked to these drawings revealed young people's fears around their lack of perceived control. For example, the multiple house robberies that Siphos family

endured may have undermined his wellbeing by reducing his perceived control and societal trust as suggested below:

“Eh you don't cope well if you see a person pointing a gun at you that happened in (area X). You get there and you end up suffering abuse under hands of strangers because they rob you and you cannot identify them and then they come back to you and ask for your help because you don't know who robbed you honestly ... it is hard to cope under criminal conditions ...” [Siphos, 16-year-old male, HIV-negative]

#### 4.2.5. Autonomy

Attainment of financial independence was salient in accounts of a good life among young women living with and without HIV. Financial independence appeared to enhance wellbeing via building one's sense of autonomy and ability to contribute to their homes and communities. Several young women exhibited a strong sense of self-determination and self-efficacy in pursuit of financial independence.

“so, study agriculture ... Then I can start having farms ... you see, have my own business. I really want to be independent” [Sne, 19-year-old female, HIV-positive]

Resistance to community norms and practices (e.g. dress code for women in religious institutions) also embodied a sense of autonomy for young women:

“yes, I come from a strict family ... yes, my grandparents attend a church ... at home a girl doesn't wear pants they don't like it ... yes, I do wear jeans but then they ... they don't like.” [Thandi, 18-year-old female, HIV-positive]

For Zanele and Hlengiwe, their accounts of falling pregnant echoed a sense of loss of independence and rejection for failing to meet their caregivers' expectations. Thus, their pursuit of academic success may have been linked to the need to regain their autonomy and social value, and ultimately enhance their wellbeing.

Peer pressure was often described in the context of a bad life, particularly for young men living with or without HIV. Whilst conforming to peer norms may have increased their sense of integration within peer networks, it may have negatively affected wellbeing by reducing their autonomy.



Fig. 4. FGD 20-24-year-old males, HIV-positive. This drawing highlights the high levels of crime and violence that young people in this community are exposed to. Crime and violence framed young people's understanding of a bad life.

“one of the major problems with the youth is peer pressure others end up smoking especially at school not because you want to but because your friends are smoking.” [FGD, 15-19-year-old males, HIV-negative]

#### 4.2.6. Personal growth

When we asked young people what advice they would provide to their younger selves, accounts encompassed a sense of enhanced self-knowledge and continued development which may have promoted wellbeing. Bongani's life journey reflected a continuous process of change and self-awareness. Self-reflection of his behavior, thoughts and feelings during adolescence was pronounced in his interview:

“now I have life goals and relationship goals ... and then this is me facing life, and then .... is that all you got to pull me down, like it isn't over yet ... don't compare yourselves to other people .... You don't want to be a jack of all trades ... Because there was a time where I wanted to experiment every single thing ... know your strength and weaknesses ... because there is stuff that you think you might handle ... But cannot handle” [Bongani, 18-year-old male, HIV-positive]

Personal growth was pronounced among young mothers' accounts as they reflected on their life journey pre- and post-pregnancy. For example, Zanele's acceptance of her pregnancy and new role as a mother gave her the motivation to improve her situation and move forward with life:

“I grew under poverty. I lost my two parents when I was young. Ah ... and I fell pregnant at a young age, I wasn't, I wasn't mature enough to be a mother ... when I first held my baby with my own hands welcoming him on earth. Yeah, I realised that it was painful, but he is here I must love him, protect him, accept him. And I am also moving on with my life, I am studying, and I can see a bright future ahead of me. I am not like others; others don't get the opportunity to continue with school. I have to be grateful and see it as a golden ticket that I am moving on with my life.” [Zanele, 23-year-old female, HIV-negative]

## 5. Discussion

In health economics, there is a growing movement towards the application of wellbeing measures for policy evaluations (Clark et al., 2019; Dolan and Peasgood, 2008). It is recommended that these measures should be grounded in wellbeing models that are aligned with how wellbeing is locally understood to improve the effectiveness of wellbeing policies and programmes. Our study aimed to explore how young people's wellbeing was perceived and experienced in South Africa and whether or not these aligned to dimensions of Ryff's PWB model. Whilst accounts in our study embodied psychological elements within Ryff's PWB model, it appeared that these were rooted in integration and contribution, social dimensions that extend beyond this model.

When we asked young people to describe a good life or happy life events, most responses encompassed eudaimonic components (e.g. social support, belonging, acceptance, social contribution). Whilst Ryff's PWB model was useful for capturing elements that shape wellbeing at an intra-personal level (e.g. self-worth, self-acceptance, autonomy, personal growth), it did not fully capture inter-personal factors at various socio-ecological levels which affected young people's wellbeing (e.g. family belonging, community-level HIV-related stigma, acceptance from networks, neighbourhood crime and violence). Our findings differ from a previous multi-national study which found that wellbeing was derived mainly from close relationships and did not extend to community or social issues (Delle Fave et al., 2011). The broader socio-cultural context influenced young people's wellbeing in our setting, which concurs with studies from developing and developed countries (Dunlop-Bennett et al., 2019; Hong and Goh, 2019; Liamputtong and Kurban, 2018; Moosad, 2019), specifically African studies on adolescent wellbeing (Camfield and Tafere, 2009; Meyer et al., 2019; Van Schalkwyk and Wissing, 2010; Wissing et al., 2014).

We found that young people's wellbeing was described in terms of connections and role-relationships with others, in line with a relational construal of self in this setting (Adams and Dzokoto, 2003; Brewer and Gardner, 1996). Hence, dimensions within Ryff's PWB model such as purpose, mastery and self-acceptance were mainly described in the context of social networks. However, as shown in our data and a Kenyan study (Goodman et al., 2018), family networks play a key role



in facilitating belonging, a facet overlooked in Ryff's PWB model. For example, shared beliefs and values within family or church networks promoted a sense of shared identity and belonging for young people, which in turn promoted social connectedness and engagement (Lim and Putnam, 2010). In the social wellbeing model, a key dimension is social integration, which denotes the degree to which an individual feels a sense of belongingness in their social networks (Keyes, 1998). This suggests that this model may be more appropriate than Ryff's PWB model for understanding young people's wellbeing in this context.

In mainstream economics, social networks are mainly considered beneficial for wellbeing (Helliwell and Putnam, 2004). However, in our study, young people experienced several forms of negative relationality which compromised wellbeing. Similar to a previous study in eSwatini (Shabalala et al., 2016), we found that the negative relationships between fathers and sons decreased a sense of belongingness among young men. Unique to the lived reality for YPLHIV, was the negative effects of stigma encountered within networks on social exclusion and self-acceptance as reported in previous studies (Goudge et al., 2009; Hutton et al., 2013). Furthermore, fear and experiences of crime and abuse was a common theme in our data, probably due to the high prevalence of crime and violence in our study community (Stats SA, 2018). These experiences likely reduced wellbeing by limiting one's perceived control and social trust (Martínez et al., 2019; Powdthavee, 2005) or by impeding group membership and social engagement, as suggested in a South African youth study (De Wet et al., 2018). Whilst Ryff's PWB model does focus on environmental mastery it fails to capture the link between negative relationality on social integration. However, in the social wellbeing model, the impact of rejection and lack of community trust on social integration is explicit (Keyes, 1998). This further highlights the appropriateness of using the social wellbeing model as a key lens for understanding wellbeing in this context.

In our study we found that manifestations of Ryff's PWB model dimensions e.g. positive relations, purposeful living and personal growth, were underpinned by the need to uphold socio-cultural norms and values such as respect for elders and contributing to one's family and community. This converges with the concept of Ubuntu, a social philosophy that encapsulates values embedded within African culture such as building and maintaining positive relationships and showing empathy (Nussbaum, 2003; van der Walt, 2010). Furthermore, the need to uphold these norms were rooted in the desire to feel socially valued. For instance, young men emphasised the importance of having a job in order to financially contribute to the household and improve living standards. Contributing to one's community and attainment of high social status facilitated the portrayal of young men as vital members of society, and thus promoted their wellbeing, similar to findings from a Zambian study (White and Jha, 2018). Social contribution is not an explicit element within Ryff's PWB model yet it is a key dimension within the social wellbeing model. This again suggests that the social wellbeing model may be more appropriate for capturing the socio-cultural reality of young people's wellbeing.

Our findings could be taken further through longitudinal ethnographic research to deepen our understanding of wellbeing and illbeing experiences as young people transition from adolescence to young adulthood, using a social wellbeing lens. Psychometric evaluations and cognitive interviewing studies of measures unpinned by the social wellbeing model such as the Mental Health Continuum-Short Form scale (Keyes, 2009) are also needed.

Our study makes the following contributions to the literature: 1) we involved young people directly and sought to assess their wellbeing experiences; 2) we add to the literature on the cultural meanings of social and psychological wellbeing dimensions in the Global South, particularly from the perspectives of vulnerable populations such as YPLHIV; and 3) we expand Ryff's PWB model, by adding to it the contribution of community and society to young people's wellbeing.

Our findings suggest the following lessons for policy and practice in this setting. First, Keyes's social wellbeing model as opposed to Ryff's

PWB model may be more relevant for understanding the pathways to young people's wellbeing. Second, the application of a battery of wellbeing scales grounded in the PWB and social wellbeing model such as Ryff's PWB scale (Ryff, 2014), the Mental Health Continuum-Short Form (Keyes, 2009) and the Warwick-Edinburgh Mental Wellbeing Scale (Tennant et al., 2007) may be appropriate for policy evaluations. Together, these scales encompass a range of dimensions that frame young people's wellbeing in this setting. Third, we highlight that programmes focused on strengthening social integration at various socio-ecological levels (e.g. family functioning programmes, clinic-based HIV support groups, community-based stigma or crime and violence prevention programmes) could be effective in promoting young people's wellbeing. Lastly, our findings suggest that policies which build young people's human capital via increasing educational attainment and employment, could promote wellbeing by enhancing one's sense of social contribution. The main strengths of our study include the use of a theoretically informed wellbeing model and multiple data collections, which may have helped improve the credibility of our data.

Our findings are subject to the following limitations. We used the Ryff's PWB model to structure our analysis. This model was originally developed using data from American adults and thus may not be valid for use among younger populations in developing settings. The data from young people and HCWs were generated from one peri-urban healthcare facility and community in South Africa. Thus, it is unknown if the meaning ascribed to wellbeing in this study are transferable to other socio-cultural contexts in South Africa or other developing settings. Our study did not include perspectives from caregivers and other family members, a group that played a critical role in shaping dimensions of young people's wellbeing. The 20-24-year-olds preferred to talk as opposed to draw in the IDIs. Social desirability bias may have likely influenced our results. For example, reflecting on the responses from YPLHIV, we found that most YPLHIV described how they excluded themselves from certain networks. Self-exclusion may have been the narrative they shared to make it less painful for themselves and to exhibit a sense of agency. In addition, most young people portrayed themselves as goal driven, with groups acknowledging the importance of religious practices and respect for elders. This might have been their way of showing that they conform to the socio-cultural identity of a "good" young person. Furthermore, whilst KIIs highlighted the treatment and acceptance issues that YPLHIV experienced, few of our participants living with HIV mentioned difficulties related to this. Perhaps as they wanted to fit in with the socio-cultural messaging on living positively. Voices from young fathers, immigrants, LGBTQBI populations, sex workers and young people not engaged with health services were missing in our data.

## 6. Conclusion

Our findings indicate that wellbeing for young people living with and without HIV is primarily cultivated within social networks. Whilst perceptions and experiences of young people's wellbeing encompassed intra-personal elements included in Ryff's PWB model (i.e. self-acceptance, self-worth, autonomy), these were more strongly rooted in social integration and social contribution, dimensions aligned with the social wellbeing model. Further evaluations of social wellbeing models and measures underpinned by this model are needed in this setting.

## Authors contribution statement

Darshini Govindasamy: Conceptualisation, Methodology, Project administration, Software, Formal analysis, Investigation, Data curation, Writing - original draft, final. Giulia Ferrari: Supervision, Conceptualisation, Methodology, Validation, Resources, Writing-critical review of all drafts. Kealeboga Maruping: Investigation, Data curation, Validation, Writing - original draft, Paidamoyo Bodzo: Software, Validation, Writing - original draft, Catherine Mathews:

Funding acquisition, Validation, Writing - original draft. Janet Seeley: Supervision, Conceptualisation, Methodology, Validation, Resources, Writing-critical review of all drafts

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## Appendix A. Supplementary data

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