**Abstract**

**Introduction:** Health literacy is a key factor underpinning health behaviours and effective use of health information. Optimising health literacy in adolescents and young adults (AYA) is critical as they transition from childhood to adulthood, changing health-related behaviours alongside physical, emotional, and cognitive change. In South African AYA, with unplanned pregnancy common, poor health literacy may impact multiple generations. However, to create culturally and contextually appropriate health literacy interventions, co-development with AYA is essential.

**Aim:** Our aim was to explore health perceptions and priorities of South African AYA as the first stage in the co-development of contextually relevant health literacy intervention design.

**Methods:** Through purposive sampling of youth registered at a youth development centre in Soweto, South Africa, AYA (n=39, 18-25y) were recruited to form an advisory Youth Health Council (YHC). Focus group discussions were recorded for inductive thematic analysis to inform AYA health literacy needs. Health literacy was assessed with the Health Literacy Test for Limited Literacy populations (HELT-LL).

**Findings:** Most AYA (85%) had suboptimal health literacy. Analysis showed that AYA perceived ‘health’ as a complex mix of indicators (physical, emotional, mental, spiritual) that formed a holistic view of health. However, lack of funds and factors inherent in their local environment (food systems, family hierarchy, crime, vandalism, limited healthcare services) frequently challenged beneficial health behaviours. Stress was a common feature in the lives of AYA associated with multiple health domains.

**Conclusion:** Stress-focused health literacy interventions are needed for youth in challenging environments. Understanding the complex constructions and the core tenets of health that young people hold can inform contextually relevant intervention co-creation for improved health literacy as youth transition into adulthood.

**Keywords**

Health engagement; health promotion; health literacy; young adults; South Africa

**Introduction**

The health of youth as they enter adulthood remains a major public concern at a global level. The burden of illness and disease among young adults has been reported to be particularly heavy in low- and middle-income countries (LMICs), where young adults make up more of the population in comparison to higher-income countries (1). In South Africa, young adults (15-34 years of age) form one third of the total population (2). Adolescence and young adulthood (AYA) is a critical time to ensure optimal health literacy as youth pass through developmental stages that influence their health and contribute to the adult burden of disease later in life, impacting life expectancy and health and wellbeing throughout the life course (3-5).

Health literacy is understood as a construct acquired through a life-long learning process, starting in early childhood (6) and is a key factor underpinning health behaviours and the effective use of health information (7). Individuals with low health literacy are less likely to engage in health screening, and more likely to experience hospitalization, higher medical expenses, and higher mortality rates (8). Lower health literacy scores have been associated with poor health behaviours, including in AYA, such as smoking, alcohol use, poor dietary choices, and high risk sexual behaviour (9). Furthermore, investments in AYA health can return what has been referred to as a triple dividend i.e. the potential to realise benefits for youth today, for youth in future as tomorrow’s adults and for the next generation for whom they will be parents (10, 11). Within South Africa, one in five female adolescents (age 12-19y) have had their first pregnancy which is frequently unplanned predominantly due to lack of knowledge (12). In this context, health literacy interventions may be especially critical for family planning and to support parenting self-efficacy and practices (13).

However, research conducted with AYA to understand health literacy gaps is lacking, especially outside of chronic disease populations (14). This is particularly the case in LMICs, where, for example, low mental health literacy among children and young people resulted in perpetuation of stigma and poor recognition of mental illness (15). Furthermore, low health literacy for menstrual health in LMICs, combined with practical challenges and cultural taboos, resulted in young women being absent from school for longer than their high-income country counterparts (16).

There are examples of effective health literacy interventions in LMICs for adults, children and adolescents for various health outcomes, incorporating various learning strategies such as technology feedback, interactive learning or art-based learning (17). For example, a peer-mentorship health literacy intervention was shown to increase HIV knowledge and improve attitudes to HIV prevention among Ugandan adolescents who engaged with the intervention (18). Attitudes to HIV prevention were also improved among adolescents in South Africa through community health literacy and drama classes (19). A study in Uzbekistan showed that including oral hygiene technology in an oral health literacy intervention improved both oral health literacy and oral hygiene status among school-going adolescents (20).

The school setting may be an ideal location to deliver health literacy interventions, with a recent review suggesting several important elements - multicomponent design, cross-curricula integration, professional development for teachers, inclusion of parents, and of community (21). An example of a successful health literacy intervention co-delivered through schools and embedded in the statutory curriculum is LifeLab UK, proven to increase health literacy levels and subjective evaluations of health behaviours in British adolescents (22). The intervention consists of support and training for educators, curriculum-linked engagement modules and hands-on practical activities for young people in a hospital teaching laboratory, while drawing on psychological, public health and educational frameworks to support learning. However, in the South African context, integrating new programmes into government school curricula can be challenging due to lack of infrastructure and resources, inadequate teacher training and negative attitudes (23), with reports that more than 80% of children are failing to meet grades in core subjects such as mathematics (24).

There is guidance from the World Health Organization (WHO) for developing health literacy toolkits in LMICs including a case study to understand health literacy needs in a South African community (25). The findings suggest that there are critical components in establishing a health literacy intervention in this setting, including respecting local wisdom, encouraging self-determination, building local capacity, and promoting co-ownership. Furthermore, understanding the health needs and priorities of communities and engaging them in the co-creation of health literacy interventions can improve intervention relevance (26). The aim of the present study was therefore to establish a local AYA advisory group (the “Youth Health Council”) in Soweto, South Africa to explore health perceptions and priorities of South African AYA to inform the co-creation of a contextually relevant health literacy intervention for Sowetan youth (LifeLab-Soweto) utilising learnings from LifeLab-UK.

**Methods**

**Setting**

This first stage in the co-development of a contextually relevant health literacy intervention design took place at a community youth development centre located in Soweto, Johannesburg, South Africa. Soweto was selected as the focal area of study for several reasons. Firstly, Soweto is a historically disadvantaged and largely underprivileged high-density peri-urban area that lies on the outskirts of the city of Johannesburg and is home to an estimated 1.3 million people (27). Although there have been drives toward AYA-friendly healthcare services, utilisation remains low with reports of healthcare providers’ unsupportive attitudes and communication issues hindering healthcare access (28, 29). Secondly, the structural and social environment of Soweto (including high unemployment, gender-based violence, and food insecurity) frequently places pressure on AYAs to prioritise economic opportunity over health while presenting numerous barriers for AYAs to adopt healthier behaviours (30). At the end of 2022, almost half of South African youth were not in education, employment, or training (NEET) (31), a status shown to impact mental health (32). Lastly, previous research in Soweto showed that only one in five adults had adequate health literacy (33), supporting the need for health literacy interventions in the area.

**Participants and Recruitment**

We recruited AYA (18-25 years) residing in the area surrounding the community youth development centre, and who were NEET at the time of the study. The youth development centre was established as a direct response to the levels of NEET youth within this area, to promote skills development, and to bring employment and training opportunities to the AYA. Local NEET youth register at the centre and give permission to be contacted for any opportunities for learning or for compensation. All NEET youth aged 18-25 years were selected from the database, systematically called by telephone and invited to attend the focus group discussions (FGD). Up to three attempts were made to contact each AYA by telephone, after which the next AYA on the list was called. This approach was necessary as cell phone numbers frequently change as youth identify better deals and switch to different telecommunication providers, or handsets are passed between individuals, for example, youth who are in relationships (34). The aim was to recruit 30-40 AYA to establish the advisory Youth Health Council (YHC). The sample size was chosen as the topic was focused specifically on health perceptions and priorities among AYA in the immediate area (i.e., representing the intended beneficiaries of the health literacy intervention) with this sample size forming around 1% of the 18-25y youth that live in this subdistrict. Boddy (2016) suggests that samples as low as 12 may be appropriate for FGDs with in-depth qualitative research if the sample is relatively homogenous (35).

For each FGD session or co-creation workshop attended, participants were provided with lunch and drinks (typically a sandwich, fruit, and juice) and reimbursed 50 Rand for their time. For reference, the South African National Minimum Wage in 2023 is 25.42 Rand per hour (36). This study reimbursement did not include transport costs as all youth stayed within walking distance to the youth development centre, where data collection took place in a comfortable room that supported good audio recording with sessions not overheard by those not directly consenting to take part and participants not distracted during the sessions. There were no additional exclusion criteria applied.

**Data Collection**

Focus group discussions (FGDs) were conducted to understand AYA health perceptions and priorities and their experience in engaging with health services. Data collection sessions were conducted between March and June 2022. Six FGDs explored AYA health perceptions and priorities. Based on the discussions, a series of co-creation workshops were then conducted with the YHC to review prototype health literacy intervention materials, to reflect on the relevance of these materials to participants and to advise how the intervention should be modified. This process was conducted to ensure that the researchers had captured AYA health priorities and accurately interpreted their health literacy needs. This process of participants co-constructing and adding to interpreted qualitative data has been referred to as ‘synthesised member checking’(37). Each FGD or workshop included an average of 6 participants, with the FGDs following a FGD topic guide (Table 1). Discussions lasted 60-90 minutes and were conducted by an experienced multi-lingual facilitator and notetaker using English and other South African languages (primarily isiZulu, SetSwana, SeSotho) as needed. The facilitator and note taker were learners at the youth development centre of similar age and background to the participants who were employed by the study team and trained in qualitative data collection by senior researchers and postdoctoral research fellows. Notes were taken during each session to document the AYA key narratives. All FGD sessions were audio-recorded and transcribed verbatim with translation by the study team as needed prior to analysis. Translations were checked by multiple study team members to ensure consistency in interpretation. Health literacy was assessed prior to the FGD sessions using the Health literacy test for limited literacy populations (HELT-LL), previously created for and validated for use in South African populations, with health literacy categories defined as inadequate (0–10), marginal (11–20) or adequate (21–24) (38). This is a short 12-item questionnaire that assesses knowledge and functional health literacy, shown to have concurrent validity with the Multidimensional Screener of Functional Health Literacy (MSFHL) and good discriminatory abilities among participants with varying levels of education (38). The HELT-LL test was administered by the study team directly with participants and responses recorded on paper, then later transferred to electronic data capture.

**Ethical Statement**

Approval to conduct the study was granted by the Human Research Ethics Committee (Medical) based at the University of the Witwatersrand (M200941 and M220438). All participants gave written informed consent to participate and for the group discussions to be audio recorded prior to data collection.

**Data analysis**

An inductive thematic analysis approach was used to analyse the data, with MAXQDA software, [version 20; Verbi Software, Berlin, Germany] used to organise data and codes. Five steps were employed in the analysis, following the guidelines of Braun & Clarke (39). These included becoming familiar with the data through reading and re-reading the transcripts and listening to the recordings while taking notes. Then initial codes were generated by labelling and organizing participants’ narratives to form a complete meaning and these initial codes were sorted into initial themes through identifying relationships between them. The themes were then reviewed to identify coherent patterns and ensure sufficient data to support a theme. This also included collapsing overlapping themes and re-working and refining codes and themes. Lastly, themes were defined and named by linking each narrative to the appropriate theme. Initial analysis and coding were conducted by a multilingual research team member (KM). Initial codes were reviewed and discussed with a second team member (LJW) until agreement was reached on all codes. The combining or elimination of codes and identification of themes was conducted jointly by both coders in the focused coding stages (40). Member checking by participants was used to ensure the analysis was an accurate reflection of participants’ narratives.

**Results**

Of the 76 AYA who were contacted by telephone to take part in the study, 65 (86%) verbally agreed to take part although 40% of these failed to attend the centre for data collection. Of the 39 AYA (51% male) who did attend the centre and completed informed consent, 62% (n=24) completed both the initial FGD and the subsequent cocreation workshop. The average participant age was 21.3 years, and the median health literacy score was 16.9 (**Table 1**). While women appeared to have a higher health literacy score than men, this was not significant. Overall, only 15% of the group were classified as having an adequate health literacy score (≥21/24).

Based on the inductive analysis approach, 3 major themes with 11 subthemes were identified (**Table 2**).

**Theme 1. Perceptions of good health**

The AYA had varying views and beliefs on their health status and general health. While they had no difficulties in articulating what health means to them, their narratives showed that there is not one unequivocal perception of health and that it varies depending on their subjective evaluations. Overall, AYA perceived health as being a holistic state that incorporated both physical and psychological wellbeing. The constituent parts of ‘health’ were demonstrated in the subthemes; 1. Health behaviours and self-care; 2. Appearance; 3. Emotional health and positive attitude; 4. Spirituality; 5. Problem solving and goal attainment; and 6. Financial and environmental restraints. In terms of health behaviours, some AYA perceived good health as engaging in positive lifestyle behaviours such as exercising and eating a healthy balanced diet.

 *“It is the ability to stay physically and mentally fit.”*

 “*Health means, like exercising, drinking lots of water and taking care of yourself through eating healthy food, fruits and veggies*”.

Health behaviours were seen as a way of practicing self-careand AYA related good health to prioritising one’s own self by taking action to preserve and improve health. This ranged from recognised health behaviours through to attitudes toward life and acknowledging their impact on the local environment.

 “*Taking care of yourself, being responsible, uhm… fruits and vegetables*”.

 “*Taking care of yourself. Like eating healthy food, exercising, always staying positive*”.

 “*Taking care of yourself is maintaining your health in a way that’s not going to be harmful for your future, even for your surroundings*”.

There were divided opinions amongst AYA as to whether physical appearance could be used as a metric for good health. While some suggested good health was associated with being aesthetically appealing in various ways, others thought that an individual’s health could not be determined by the way an individual looks.

  *“A person that looks healthy is a person which has high shoulders and chest up*”.

 “*Your appearance. Ok, you have a great physique, yes, yes. Healthy skin, strong hair, healthy hair, and you are also well presentable*”.

 “*Physically it shows that one is healthy and, I think the weight. Not being too thin or too fat. You must be fit*”.

 “*I don’t think you can just say - that one is healthy and that one is not healthy. […] You might look at them and think that the thin one is healthier than the fat one but only to find that the opposite is true. You cannot really tell you understand*?”.

The narratives of some AYA suggested that the relationship between emotional and physical health and attitudes toward life, including optimism, may be mutually reinforcing. They felt that possessing good emotional health and healthy thoughts and feelings translated into an increased ability to cope and a belief in one’s competency to pursue health and wellbeing related goals, subsequently resulting in better health.

“*When you're emotionally healthy eventually you’ll be healthy and physically because one thing about a person is you must be emotionally healthy for you to survive or deal with anything. Yah so I think physical health goes with emotional health*”.

 “*If your thoughts are healthy, you won’t eat unhealthy food, you won’t live an unhealthy lifestyle, so it starts spiritually, mentally then it translates to the body*”.

The concept of spiritual heath was echoed by several AYA, relating this to a sense of knowing oneself and one’s own needs amidst a sense of purpose, inner peace, hope, meaning or inner strength.

 “*It’s being free with yourself, knowing yourself, knowing…. The spiritual inner you, yes. If you are aware of your mindset, your spirituality and then you are healthy*”.

 “*Spiritual health, it’s like understanding yourself, being able to understand that you see now, I’m not fine. To allow yourself that you are not fine, whether emotionally, just understanding that I’m thinking a lot and when you overthink things, just know that it’s not a good thing, you should like to get to calm yourself and take things slow”.*

Good health was also seen as promoting concentration, including the ability to focus and to solve problems efficiently; this was seen as essential for supporting goals and plans.

 “*When you are healthy you are able to think and think fast and when you are looking for solutions you are quick to get them”.*

 “*How do I know that I’m healthy? I think that it’s when my concentration is there. Like I finish in time, and I obviously can reach my goal*”.

A distinctive feature emerging from the narratives of a few AYA was that, although they are aware of what good health requires, lack of funds and factors inherent in their local environment (food systems, family hierarchy, crime and vandalism) reinforced and promoted poor health behaviours. As such, AYA felt that some healthier options were not accessible or feasible within their daily lives or they had little power over making healthier choices, due to factors outside of their control. These restrictions were most frequently related to food choices, where abundant and cheaper ultra-processed, energy-dense, less nutritious foods such as kota and pap were routinely eaten.

 “*… the challenge we face when it comes to health, the nutrition we consume around the society we're in. Eish, the kota[[1]](#footnote-1) I no longer want it. Pap[[2]](#footnote-2), I don’t have a choice …*”.

 “*… health is important to me but in other instances you don’t have a choice, maybe you grew up in a family where they say today, we're eating pizza because you can’t provide for yourself you don’t have a choice*”.

 “*Health for me is a person’s lifestyle meaning it’s the way the person eats; how does one maintain their body to stay fit. However, where we come from, there are no training facilities […], even if they exist, the facilities end up being ruined by the community*”.

Several AYA perceived health as largely influenced by financial standing, while poor health also came at financial cost.

 “*Being healthy is being wealthy. Life insurance is much cheaper when you're healthier*”.

 “*When you start being sick, money is needed*”.

**2. Perceptions of poor health**

Being ‘unhealthy’ was related to an inability to perform both physically and mentally, with being unhealthy seen as both debilitating and a weakness. While AYA acknowledged that poor health could mean poor psychological or poor physical wellbeing, being unhealthy was more frequently related to poor psychological wellbeing, with some expressing elements of judgement about these ‘unhealthy’ individuals.

 “*An unhealthy person feels depressed all the time*”.

 “*Unhealthy people are insecure.*”.

 “*When you’re unhealthy mentally you’re always seeking pity*”.

*“I think an unhealthy person that cannot take care of themselves spiritually, mentally, emotionally, body and mind, financially… unable to take care of themselves*”.

*“You don’t want to see other people. You want to be alone. You don’t want other people to let you know what’s up”.*

Similarly, being unhealthy was related to poor physical wellbeing and some quite extreme views of the limited physical capacity of unhealthy individuals.

 “*If you are not healthy, you can’t do anything, you can’t stand*”.

 *“Someone who is not healthy is always tired, they don’t have energy, no energy whatsoever. When you ask them questions, they take time to answer*”.

Several AYA voiced how poor health was related to ‘living in the moment’ with a focus on image and popularity taking priority. This was seen as potentially creating a negative impact on the future of the country.

 “*An unhealthy person lives impulsively, they don’t have priorities, they just live because they are alive, it’s fun…”*

 “*Some people don’t enjoy good things they rather go the route of living unhealthy, looking fancy and impressing. So unhealthy people yoh, youth, the youth is lost, and we say we are the future of our country. We, ourselves, don’t listen to each other*”.

Despite this view, the perceptions of ‘unhealthy’ individuals often suggested that AYA did not see themselves in this category or identify with the condition, with ideas that those classed as unhealthy suffered significant restrictions in daily living. However, stress was a central feature influencing health for many AYA and to which they could relate, either in terms of their health effecting their ability to cope with stress or the role of stress in altering their health.

 *“A healthy person, they do things and think positively and doesn't let stress put him under pressure because he is healthy”.*

 *“They (unhealthy people) are the kind of people that are always stressed, always thinking about a lot of things, they just feel stressed”.*

 *“When you are stressed, when I am stressed, I lose weight”.*

 *“When you are unhealthy you doubt everything. You feel like you are stressed. Because you are not healthy inside”.*

**3. Health awareness and engagement**

Good health was seen to involve both being health conscious and engaging in healthy behaviours, including those for managing stress in everyday life.

 “*For my future, I think I should exercise and prevent illnesses and live a long life, be fit, for my mentality; be able to think outside the box and not have stress*”.

 “*I'm a regular exerciser. I keep fit. People will be saying like, why do you exercise, you're not going to be tough, you're skinny? No, it's not about that. It’s for my own health, blood pressure you know, also to balance my body*”.

 “*You need to be healthy as a person because you avoid diseases, dangerous diseases. I feel like when you keep healthy, your mindset also changes. The way you view things outside also changes so yah, I feel like that’s why health is important*”.

Perceptions held around chronic disease and what that may mean for AYA were often quite extreme, with several suggesting this motivated them to engage in health behaviours or seek information to prevent disease. This was, however, not the case for everyone, with others reporting different motivations to engage in health behaviours.

 “*I'm always keeping healthy, and it takes that feeling that what if I get sick… what am I going to do? Like I'm on that safe side*”.

 “*Heart attacks. It can hit you at any moment even when you think you are healthy*”.

 “*We are concerned. Diabetes, your limbs can get cut off! We are not as concerned now, that’s why we are here, we want to learn more and do more*”.

 “*I don’t think a lot about my health. I’m the kind of person that I go to the gym when the thought pops in my mind or if there is a [soccer] club we are playing against and I want to show them that I’ll score, that’s when I’ll go to the gym*”.

With regards to health screening, two very clear groups emerged. The first consisted of those who firmly believed it is better to know about one’s health status and were curious about their results for themselves and for the protection of others, even though the process was described as scary.

 “*You go for yourself you don’t need to be forced. And when you are pricked you get knowledge on whether you have HIV or not which is if you have it they are able to prescribe medication for you so that they can help you and not pass it on to others.*”.

 “*You see when you go and check you might not be worried but once the results come out you will know how to take care of yourself*”.

 “*I’m curious about what’s going on in my body. It’s better to get used to it at a young age, to go to the clinic and check how I am doing*”.

 “*I feel that tests are important because you know where you stand regarding your health, even though they are scary yes, but it’s very important to know.*”.

 “*You have to know how your body works*”.

In contrast, the second group expressed a firm lack of interest in any health screening or services, including for obtaining vaccines. This was not articulated out of fear, but rather from a belief that they lacked the need for such services.

 “*Sometimes I feel like things like that are for people who are ignorant about their health. When you are healthy you know where you stand and know that you are not HIV positive because you live a healthy lifestyle. You don’t sleep around and don’t drink alcohol and eat well. If your body is sore, it’s because you didn’t sleep well. You need not stress about going to have checked. It helps though for those that don’t care about their health*”.

 “*They tell you to vaccinate. I don’t believe in vaccinating. I've never been hospitalized in my life; my life is fine why must I be vaccinated*?”

 “*I don’t believe I’ll get those things [non-communicable diseases]. Even at home no one has…*”

The quality of available health services was recognised as a deterrent for engaging with healthcare, and AYA hoped that through participating as a Youth Health Council member they could make a difference.

 “*For me health is a huge priority in the community. In our clinics the treatment given to patients who are sick are not the same. They take time to attend to them and people just give up and leave without receiving what they came for and when they come back the next day they are told to come back in the next month. If I can change that situation... that’s what I want, to prioritize health*”.

**DISCUSSION**

The aim of this study was to explore how AYA living in an urban African setting understand and construct health to inform the co-creation of a contextually relevant health literacy intervention. Our findings suggest that in this context health is perceived by AYA as a complex mix of physical, psychological, and emotional indicators. Additionally, our findings suggest that AYA perceptions of health do not exist in a vacuum. These perceptions are influenced by their broader social environment as well as a complex interplay of factors that operate at a micro and macro level including families, peers, social norms, physical environment and access to services or lack thereof. Stress appeared a central tenet in their lives in this context, with poor health associated with stress and health behaviours seen as modifying stress and enabling AYA to cope with everyday challenges. Overall, only 15% of the AYA had adequate health literacy levels as defined by their HELT-LL scores.

The Health Literacy Skills Framework illustrates how the relationship between health literacy and other health-related outcomes operates at the individual level, though largely influenced by broader macro level characteristics such as family, local community, and the healthcare system (41). Our findings generally agree with this framework and suggest broader societal factors are likely to exert an influence on the health perceptions and behaviours of AYA. These may influence how they develop, acquire, and apply health literacy skills which may subsequently influence their ability to make informed health choices that influence subsequent health-related outcomes (41).

Our finding that AYA attach both judgement and a sense of distance to disease and unhealthy individuals in part speaks to earlier studies showing individuals who make social judgements tend to overlook critical information (42). For example, around one in five children across Africa exhibit elevated blood pressure (43). As such it is likely that several participants would also have elevated BP, although they may be less likely to engage with health information or services if they do not recognise this vulnerability or if they sense that they will face discrimination or stigma when accessing health services.

Alternative (non-clinical) centres for health promotion may be more acceptable to youth. Schools are becoming an increasingly important setting for implementing health promotion strategies in communities (44). While the school environment can contribute significantly to young people’s academic success (45), there is also a growing interest by schools in contributing to the health of youth (46, 47). Health education in schools can shape young people’s perceptions of health and health behaviours by adopting strategies that put them at the heart of health activities or decisions around positive health behavioural changes (48). In LMICs, school-based interventions have been implemented to promote AYA health and health behaviour. Countries such as Cambodia, China, Malaysia, the Philippines and others have employed educational activities to improve specific health and behavioural outcomes as well as change the knowledge and attitudes of young people on a range of health topics and risk behaviours, noting student participation was critical to success (49). However, within the South African context, such school-based initiatives may be hampered by poor management and leadership infrastructure, resources and staff (47). Additionally, once youth leave school, it is not clear where this health promotion support can be found.

Certainly, it seems from the AYA narratives that there is a disconnect between current available health services and their health needs and perceptions about using health services. Previous research in South Africa showed that AYA from 13 years of age were largely attended to in the adult health care system by health professionals who lack specialised training to handle the needs of young adults (50). The Youth Friendly Services (YFS) Program in South Africa, implemented and led by non-governmental organisations and the South African Department of Health, includes the training of healthcare providers and the accreditation of healthcare facilities (51). However, evaluations suggest less than ideal implementation of YFS in primary healthcare (PHC) (52), with staff highlighting a lack of training in young adults’ health (53). With many AYA having not experienced YFS and unaware of the initiative, they remain reluctant to access health services at local Department of Health (DOH) PHC facilities (54). Successful models of healthcare delivery that support AYA to access care (typically in high income countries) show the importance of including AYA in the creation, implementation and evaluation of such services (55). Although, this review by Anderson and Lowen (2010) acknowledged that school and community-based centres may be better placed than PHC to meet the health needs of AYA (55). Additionally, previous research suggests that health literacy interventions for diet and physical activity health behaviour change may be more effective when delivered in the community than in PHC (56). Further increasing PHC service provision for AYA may still result in a misalignment with AYA health needs.

The results should be viewed within the limitations of this study. For example, prior to the informed consent process, the study team did not collect any data on the NEET youth, so that comparison of the 60% of youth that did attend and the 40% that did not attend the data collection sessions was not possible. Previous research has explored the development, history, persisting high prevalence and marginalizing effects of NEET status on South African youth, with a considerable number disengaging from society (57). Furthermore, unemployment acts as a driver to engage with infrequent and often insufficient earning opportunities in the informal economy (58), such that youth may agree to take part in a study but then have an alternative economic opportunity that may present itself. This non-attendance rate among NEET youth is perhaps then not surprising within this context but may have resulted in selection bias. A further limitation is that we did not collect data on the years of education from NEET youth that did attend the sessions, as this may be associated with the health literacy scores recorded (38). However, it is likely that most if not all of the participants had less than tertiary education as among South Africa’s over 6 million NEET youth, only around 6% have completed tertiary level education (59).

Lastly, with focus group discussions, there is a risk that participants chose to report socially desirable data, creating a social desirability bias. This may be particularly problematic when the data collectors are from outside of the community participating in the research, necessitating strategies to identify and overcome such bias (60). A strength of this study was that the data collection team were employed from among NEET youth in the local community and trained in research methodology and qualitative data collection.

Our findings suggest that health is viewed holistically by AYA encompassing all aspects of physical, psychological, and mental wellbeing. Thus, offering health information or services based on a medical model of delivery only to AYA, may well create a disconnect between service providers and the intended users. Youth-focused spaces where AYA can engage in health conversations and feel comfortable discussing sensitive issues related to their holistic health and well-being will likely result in the development of positive attitudes towards health and greater uptake and engagement with health services. Importantly, with only 15% of our AYA showing adequate health literacy levels, future research should evaluate youth-focused spaces outside of ’medical’ health infrastructure that can support interventions to improve AYA health literacy. With the weight of evidence showing health literacy influences health behaviour and health outcomes across the lifespan, contextually relevant health literacy interventions located within safe spaces for youth and acknowledging the environmental stresses in which youth operate are urgently needed. Within this paper, we present one approach to co-creating relevant health literacy interventions with NEET youth recruited to form an advisory Youth Health Council. The next step is to feasibility test the intervention with NEET youth from the same environment who were not involved in the intervention creation, and to capture their feedback on its relevance and potential utility to improve health literacy prior to broader pilot testing and evaluating the intervention generalisability. Future research is needed to identify the most effective methods for co-creating contextually relevant health literacy interventions with NEET youth in LMICs, considering the challenging social and cultural contexts in which they live.

**CONCLUSION**

The health needs of young adults appear frequently poorly addressed by the existing health care system. With typically low health literacy levels, and many young adults viewing health screening as irrelevant in their lives, there is a need to deliver contextually relevant health literacy interventions within dedicated youth spaces. Moreover, interventions must place youth holistic perspectives of health at their core and involve young adults in intervention co-creation. Health promotion and disease prevention efforts should consider young people’s construction of health which can inform public health policies and programmes.

**Conflict of Interest**

None to declare.

**Acknowledgements**

The authors thank the youth that gave their time for this research and the focus group facilitators, Mr Lethukuthula Ndwande, Ms Hazel Moraka, and Ms Delisile Kubheka.

**Funding**

This research was funded through a grant from the DSI-NRF Centre of Excellence in Human Development [OPP2021008], hosted at the University of the Witwatersrand, South Africa. KMG is supported by the National Institute for Health Research (NIHR Senior Investigator (NF-SI-0515-10042), NIHR Southampton 1000DaysPlus Global Nutrition Research Group (17/63/154) and NIHR Southampton Biomedical Research Centre (NIHR203319)) and the European Union (Erasmus+ Programme ImpENSA 598488-EPP-1-2018-1-DE-EPPKA2-CBHE-JP). For the purpose of Open Access, the author has applied a Creative Commons Attribution (CC BY) licence to any Author Accepted Manuscript version arising from this submission.

**REFERENCES**

1. Sawyer SM, Afifi RA, Bearinger LH, Blakemore S-J, Dick B, Ezeh AC, et al. Adolescence: a foundation for future health. The lancet. 2012;379(9826):1630-40.

2. Mid-year population estimates. Pretoria: Statistics South Africa; 2022.

3. Wood D, Crapnell T, Lau L, Bennett A, Lotstein D, Ferris M, et al. Emerging adulthood as a critical stage in the life course. Handbook of life course health development. 2018:123-43.

4. Due P, Krølner R, Rasmussen M, Andersen A, Trab Damsgaard M, Graham H, et al. Pathways and mechanisms in adolescence contribute to adult health inequalities. Scandinavian journal of public health. 2011;39(6\_suppl):62-78.

5. Woods-Townsend K, Hardy-Johnson P, Bagust L, Barker M, Davey H, Griffiths J, et al. A cluster-randomised controlled trial of the LifeLab education intervention to improve health literacy in adolescents. PLoS One. 2021;16(5):e0250545.

6. Zarcadoolas C, Pleasant A, Greer DS. Understanding health literacy: an expanded model. Health promotion international. 2005;20(2):195-203.

7. Diviani N, van den Putte B, Giani S, van Weert JC. Low health literacy and evaluation of online health information: a systematic review of the literature. J Med Internet Res. 2015;17(5):e112.

8. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Annals of internal medicine. 2011;155(2):97-107.

9. Fleary SA, Joseph P, Pappagianopoulos JE. Adolescent health literacy and health behaviors: A systematic review. Journal of adolescence. 2018;62:116-27.

10. Patton GC, Sawyer SM, Santelli JS, Ross DA, Afifi R, Allen NB, et al. Our future: a Lancet commission on adolescent health and wellbeing. The Lancet. 2016;387(10036):2423-78.

11. Norris SA, Lakeb L, Drapera CE. Child health matters: A life course perspective. 2019.

12. McHunu G, Peltzer K, Tutshana B, Seutlwadi L. Adolescent pregnancy and associated factors in South African youth. Afr Health Sci. 2012;12(4):426-34.

13. Lee J-Y, Murry N, Ko J, Kim MT. Exploring the relationship between maternal health literacy, parenting self-efficacy, and early parenting practices among low-income mothers with infants. Journal of health care for the poor and underserved. 2018;29(4):1455.

14. Sansom-Daly UM, Lin M, Robertson EG, Wakefield CE, McGill BC, Girgis A, et al. Health literacy in adolescents and young adults: an updated review. Journal of adolescent and young adult oncology. 2016;5(2):106-18.

15. Renwick L, Pedley R, Johnson I, Bell V, Lovell K, Bee P, et al. Mental health literacy in children and adolescents in low- and middle-income countries: a mixed studies systematic review and narrative synthesis. European Child & Adolescent Psychiatry. 2022.

16. Holmes K, Curry C, Ferfolja T, Parry K, Smith C, Hyman M, et al. Adolescent menstrual health literacy in low, middle and high-income countries: a narrative review. International Journal of Environmental Research and Public Health. 2021;18(5):2260.

17. Meherali S, Punjani NS, Mevawala A. Health Literacy Interventions to Improve Health Outcomes in Low- and Middle-Income Countries. HLRP: Health Literacy Research and Practice. 2020;4(4):e251-e66.

18. Nabunya P, Ssewamala FM, Mukasa MN, Byansi W, Nattabi J. Peer mentorship program on HIV/AIDS knowledge, beliefs, and prevention attitudes among orphaned adolescents: an evidence based practice. Vulnerable Children and Youth Studies. 2015;10(4):345-56.

19. Hanass-Hancock J. Tangible skill building and HIV youth prevention intervention in rural South Africa. African Journal of AIDS Research. 2014;13(3):229-35.

20. Khudanov B, Jung HI, Kahharova D, Lee J-W, Hamidov I, Lee E-S, et al. Effect of an oral health education program based on the use of quantitative light-induced fluorescence technology in Uzbekistan adolescents. Photodiagnosis and Photodynamic Therapy. 2018;21:379-84.

21. Nash R, Patterson K, Flittner A, Elmer S, Osborne R. School‐based health literacy programs for children (2‐16 Years): An International Review. Journal of School Health. 2021;91(8):632-49.

22. Woods-Townsend K, Leat H, Bay J, Bagust L, Davey H, Lovelock D, et al. LifeLab Southampton: A programme to engage adolescents with DOHaD concepts as a tool for increasing health literacy in teenagers–a pilot cluster-randomized control trial. Journal of developmental origins of health and disease. 2018;9(5):475-80.

23. Dube BA, Nhamo E, Magonde S. Factors affecting ICT integration in the teaching and learning of physical education in South Africa: A case of Johannesburg East cluster primary schools in the Gauteng Province. International Journal of Sport, Exercise and Health Research. 2018;2(1):88-92.

24. Spaull N, Kotze J. Starting behind and staying behind in South Africa: The case of insurmountable learning deficits in mathematics. International Journal of Educational Development. 2015;41:13-24.

25. Dodson S, Good S, Osborne RH. Health literacy toolkit for lowand middle-income countries: a series of information sheets to empower communities and strengthen health systems. New Delhi: World Health Organization, Regional Office for South-East Asia, 2015.

26. Boateng MA, Agyei-Baffour E, Angel S, Asare O, Prempeh B, Enemark U. Co-creation and prototyping of an intervention focusing on health literacy in management of malaria at community-level in Ghana. Research Involvement and Engagement. 2021;7(1):55.

27. Britannica, The Editors of Encyclopaedia. "Soweto". Encyclopedia Britannica, 30 Sep. 2020, <https://www.britannica.com/place/Soweto>. Accessed 7 February 2023.

28. Lince-Deroche N, Hargey A, Holt K, Shochet T. Accessing sexual and reproductive health information and services: A mixed methods study of young women’s needs and experiences in Soweto, South Africa. African journal of reproductive health. 2015;19(1):73-81.

29. Otwombe K, Dietrich J, Laher F, Hornschuh S, Nkala B, Chimoyi L, et al. Health-seeking behaviours by gender among adolescents in Soweto, South Africa. Global health action. 2015;8(1):25670.

30. Ware LJ, Prioreschi A, Bosire E, Cohen E, Draper CE, Lye SJ, et al. Environmental, social, and structural constraints for health behavior: perceptions of young urban black women during the preconception period—a healthy life trajectories initiative. Journal of Nutrition Education and Behavior. 2019;51(8):946-57.

31. Quarterly Labour Force Survey. Quarter 3: 2022 STATISTICAL RELEASE P0211. Statistics South Africa. <https://www.statssa.gov.za/publications/P0211/P02113rdQuarter2022.pdf> [Accessed 07 February 2023].

32. Garman EC, Avendano M, Araya R, Evans-Lacko S, McDaid D, Zimmerman A, et al. Understanding the complex relationship between multidimensional poverty and depressive symptoms among young South Africans: A cross-sectional study. Journal of Affective Disorders. 2022;319:352-60.

33. Calvert C, Kolkenbeck-Ruh A, Crouch SH, Soepnel LM, Ware LJ. Reliability, usability and identified need for home-based cardiometabolic health self-assessment during the COVID-19 pandemic in Soweto, South Africa. Scientific reports. 2022;12(1):1-9.

34. Porter G, Hampshire K, Abane A, Munthali A, Robson E, De Lannoy A, et al. Mobile phones, gender, and female empowerment in sub-Saharan Africa: studies with African youth. Information Technology for Development. 2020;26(1):180-93.

35. Boddy CR. Sample size for qualitative research. Qualitative Market Research: An International Journal. 2016;19(4):426-32.

36. New earnings threshold and National Minimum Wage – Effective 1 March 2023 [press release]. <https://www.ccma.org.za/labourlaws/new-earnings-threshold-and-national-minimum-wage-effective-1-march-2023/#:~:text=The%20Department%20of%20Employment%20and,for%20workers%20in%20certain%20sectors>.: South African Department of Employment and Labour: Commission for Conciliation, Mediation and Arbitration2023.

37. Birt L, Scott S, Cavers D, Campbell C, Walter F. Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? Qual Health Res. 2016;26(13):1802-11.

38. Marimwe C, Dowse R. Health literacy test for limited literacy populations (HELT-LL): Validation in South Africa. Cogent Medicine. 2019;6(1):1650417.

39. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.

40. O.Nyumba T, Wilson K, Derrick CJ, Mukherjee N. The use of focus group discussion methodology: Insights from two decades of application in conservation. Methods in Ecology and Evolution. 2018;9(1):20-32.

41. Squiers L, Peinado S, Berkman N, Boudewyns V, McCormack L. The health literacy skills framework. J Health Commun. 2012;17 Suppl 3:30-54.

42. Lord CG, Lepper MR, Preston E. Considering the opposite: a corrective strategy for social judgment. Journal of personality and social psychology. 1984;47(6):1231.

43. Crouch SH, Soepnel LM, Kolkenbeck-Ruh A, Maposa I, Naidoo S, Davies J, et al. Paediatric Hypertension in Africa: A Systematic Review and Meta-Analysis. eClinicalMedicine. 2022;43:101229.

44. Buijs GJ. Better schools through health: Networking for health promoting schools in Europe. European journal of education. 2009;44(4):507-20.

45. Wang M-T, Holcombe R. Adolescents’ perceptions of school environment, engagement, and academic achievement in middle school. American educational research journal. 2010;47(3):633-62.

46. Basch CE. Healthier students are better learners: high‐quality, strategically planned, and effectively coordinated school health programs must be a fundamental mission of schools to help close the achievement gap. Journal of School Health. 2011;81(10):650-62.

47. Shung-King M, Orgill M, Slemming W. School health in South Africa: Reflections on the past and prospects for the future. South African health review. 2013;2013(1):59-71.

48. Pulimeno M, Piscitelli P, Colazzo S, Colao A, Miani A. School as ideal setting to promote health and wellbeing among young people. Health promotion perspectives. 2020;10(4):316.

49. Xu T, Tomokawa S, Gregorio Jr ER, Mannava P, Nagai M, Sobel H. School-based interventions to promote adolescent health: A systematic review in low-and middle-income countries of WHO Western Pacific Region. PloS one. 2020;15(3):e0230046.

50. Stefan C, Van Der Merwe P-L. Treating adolescents in South Africa: Time for adolescent medicine units? SAMJ: South African Medical Journal. 2008;98(3):184-7.

51. Ashton J, Dickson K, Pleaner M. The evolution of the national adolescent friendly clinic initiative in South Africa. Geneva: World Health Organisation. 2009.

52. 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 services research. 2018;18(1):1-10.

53. Geary RS, Gómez-Olivé FX, Kahn K, Tollman S, Norris SA. Barriers to and facilitators of the provision of a youth-friendly health services programme in rural South Africa. BMC Health Services Research. 2014;14(1):259.

54. Schriver B, Meagley K, Norris S, Geary R, Stein AD. Young people’s perceptions of youth-oriented health services in urban Soweto, South Africa: a qualitative investigation. BMC Health Services Research. 2014;14(1):625.

55. Anderson JE, Lowen CA. Connecting youth with health services. Systematic review. 2010;56(8):778-84.

56. Taggart J, Williams A, Dennis S, Newall A, Shortus T, Zwar N, et al. A systematic review of interventions in primary care to improve health literacy for chronic disease behavioral risk factors. BMC Family Practice. 2012;13(1):49.

57. Swart I, Hallstein Holte Br, Hiilamo H. Chapter 2: NEET as a Comparative Conceptualisation of Youth Marginalisation. A South African?Nordic European Exchange of Perspectives. Stuck in the Margins? Research in Contemporary Religion. Volume 31: Vandenhoeck & Ruprecht; 2021. p. 31-48.

58. Etim E, Daramola O. The Informal Sector and Economic Growth of South Africa and Nigeria: A Comparative Systematic Review. Journal of Open Innovation: Technology, Market, and Complexity. 2020;6(4):134.

59. Grice J. Why are so many young people NEETs? South African Journal of Science. 2019;115:1-.

60. Bergen N, Labonté R. “Everything is perfect, and we have no problems”: detecting and limiting social desirability bias in qualitative research. Qualitative health research. 2020;30(5):783-92.

**Table 1. Focus Group Discussion Topic Guide**

|  |  |
| --- | --- |
| **Section 1 – Health and everyday life** | What does health mean to you? What does a healthy person look like? What does an unhealthy person look like?What does it feel like to be unhealthy? What does it feel like to be healthy?What impact does your health have on your daily life? How often do you think about your health? What makes you think about your health? |
| **Section 2 – Concerns about health** | When it comes to your health, what are the things you think about most?What are the things that worry you most about your health? What are the biggest concerns you have about your health for the future? |
| **Section 3 - Interactions with health services** | Where do you go to check or discuss your health? How often do you go to this place or these places?What happens at these places? Can you tell us about times you remember when you have gone that were really good or really bad?How do you feel when you leave? How satisfied were you? How much did your level of worry or concern for the health issue change? |

**Table 2. Age, sex, and health literacy results of the Adolescent and Young adults (AYA)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **All** **(n=39)** | **Men****(n=20)** | **Women (n=19)** |
| Age | 21.3 ± 2.4 | 21.9 ± 2.7 | 20.6 ± 2.0 |
| Health literacy score | 16.9 ± 3.7 | 16.4 ± 3.7 | 17.5 ± 3.9 |
| Health literacy category, n (%) Adequate Inadequate or marginal | 6 (15)33 (85) | 2 (10)18 (90) | 4 (21)15 (79) |

*Mean ± SD unless otherwise indicated.*

**Table 3. Themes and subthemes**

|  |  |  |
| --- | --- | --- |
| **Theme** | **Sub-theme** | **Open Codes** |
| 1.Perceptions of good health | 1.1. Health behaviours and self-care | Knowledge/perceptions of healthy eating, balanced diet, exercise, physical or mental fitness; role of health behaviours in self-care |
| 1.2. Appearance | Body shape, size, or posture; healthy skin, hair; overall presentation |
| 1.3. Emotional health and positive attitude | Positivity, optimism, self-affirmation; association with independence |
| 1.4. Spirituality | Spirituality as part of identity, links with mental and emotional health. |
| 1.5. Problem solving & goal attainment | Concentration, focus, maintaining attention, finding solutions, having direction; links to health, resilience to stress, coping skills and reaching goals. |
| 1.6. Financial and environmental restraints | Funds needed to stay healthy (healthy food, gym access, health insurance); costs associated with being sick. Broader environmental influences on health - food systems, food availability, food choices at home and family hierarchy, crime, safety, and vandalism of facilities. |
| 2. Perceptions of poor health | 2.1. Poor psychological wellbeing | Poor health from stress, overthinking or thinking too much, depression. Impact on behaviour. |
| 2.2. Poor physical wellbeing | Limitations in activities of daily life, impact on relationships. |
| 3. Health awareness and engagement | 3.1. Engagement in health behaviours | Engagement in healthy behaviours (regular exercise, keeping fit, avoiding fast food); motivations (having fun, finding balance, promoting mental, emotional, or physical health including good blood pressure, avoiding disease, better complexion); enablers (planning, discipline, prompts and cues)  |
| 3.2 Health screening perceptions | Desire for knowledge, understanding of health status, seeking support to manage health; Poor quality services; Clinic screening need – not needed by youth as healthy, health information from other sources – family, traditional medicine. |

1. Kota: Sandwich typically made from a quarter loaf of white bread filled with fried potatoes, processed meat, and cheese. [↑](#footnote-ref-1)
2. Pap: porridge made from maize meal with sugar or salt usually added. [↑](#footnote-ref-2)