Abstract

Despite growing evidence of the significance of health literacy in managing and coping with HIV, it is not yet an integrated part of HIV/AIDS-related health promotion research and practice in Africa. This article contributes to addressing the gap in research on health literacy and HIV in Sub-Saharan Africa. We aimed to assess health literacy-related needs of young people living with HIV (YPLHIV) and adapt existing health literacy frameworks to the context of HIV/AIDS in Malawi. We used focus group discussions to collect data from a sample of the membership of the national association of YPLHIV. Twenty-four HIV-positive youth (18-29 years) participated in focus group discussions. Participants came from three regions of Malawi. Additionally, we conducted three in-depth interviews with key informants. We used a thematic framework approach to analyse data in MAXQDA. We contextualised definitions of four dimensions of health literacy: functional, interactive, critical, and distributed health literacy, which we used as an a priori analytical framework. To further contextualise the framework, we revised it iteratively throughout the analysis process. We identified the need for comprehensive information about HIV and sexual reproductive health, skills to interact with healthcare providers and navigate the health system, and skills to appraise information from different sources, among others. The identified needs were translated into 9 action recommendations for the national association of YPLHIV, and with relevance within the wider HIV sector in Malawi and beyond. We found that the dimensions in our analytical framework operate on the individual, system and public policy levels.

Keywords: Health literacy, needs assessment, HIV, youth, Low-income countries.

Introduction

There is growing evidence to support the significance of health literacy in coping and managing HIV. (Reynolds et al., 2019). However, there is a shortage of research on health literacy and HIV and AIDS from low-income countries of sub-Saharan Africa where most people with HIV live. Additionally,
research tends to focus on a narrow definition of health literacy with predominant definitions that are focused on functional health literacy (Nutbeam, 2000). Various other dimensions, such as interactive and critical health literacy (Ibid) have received less attention. Most current research focuses on PLHIV in general and does not provide an understanding of the relevance of health literacy for health outcomes of YPLHIV specifically. However, several studies have shown a relationship between health literacy and adolescent health behaviours (Fleary et al., 2018). In addition, poor health literacy has been shown to be associated with adverse health outcomes in a review exploring the importance of health literacy on health outcomes in adolescents and young adults, although the results were mixed for the association between health literacy and medication adherence among chronically ill adolescents and young adults (Sansom-Daly et al., 2016). Most of the studies included in the review explored functional health literacy with only a few featuring other health literacy dimensions such as communicative and critical health literacy.

The sparse evidence of higher-order dimensions of health literacy is partly due to the shortfalls in existing health literacy measuring tools (Altin et al., 2014). A further constraint is that existing tools are survey-type and need to be validated for use in other contexts, which affects their use in resource-constrained environments. Some studies have assessed health literacy qualitatively in PLHIV, although few are among young people or adolescents specifically. The qualitative studies have also used a narrow operationalisation of health literacy as ‘information seeking’ or ‘information’ practices (Zukoski et al., 2011; Lindgren et al., 2018). Research is required to understand the health literacy needs of YPLHIV in Sub-Saharan Africa and how these fit into the existing health literacy frameworks.

As in other sub-Saharan African countries, HIV and AIDS are significant contributors to the burden of disease in Malawi, where around 10 per cent of the population are living with the infection (National AIDS Commission, 2014). The prevalence of HIV is 2.1 per cent among 15-19-year olds and 4.0 in the 20-24-year age group. Young people account for 50 per cent of new HIV infections in Malawi (Small and Weller, 2013) and are a key population in the national response to HIV (Ibid).
We set out to undertake a qualitative assessment and conceptualisation of the health literacy-related needs of YPLHIV in Malawi to achieve a holistic framework in that setting. We expected that YPLHIV in Malawi would face challenges due to low health literacy within the different health literacy domains: Functional, interactive and critical health literacy (Nutbeam, 2000). We also included the dimension of distributed health literacy proposed in (Wagner et al., 1986), due to the importance of community in the Malawian culture. The study was embedded in the organisational context of the National Association of YPLHIV, established in 2014 in recognition of the neglected plight of YPLHIV in Malawi. The mandate of the association is to advocate for the needs of YPLHIV in Malawi. The research questions addressed in this study are as follows:

Based on the views and experiences of YPLHIV and a few selected key informants:

- What health literacy-related knowledge and skills do YPLHIV in Malawi require to cope with life, take control of adverse social and environmental circumstances, and live healthy lives?
- How can the existing health literacy frameworks (functional, critical, interactive and distributed health literacy) be modified to incorporate the specific needs of YPLHIV in Malawi?

Methods

Participants and setting

HIV-positive young people aged 18 to 35 years were recruited to participate in mixed-gender focus group discussions through the National Association of YPLHIV in Malawi. We chose to undertake the study among the founding members of the association who were in a position to articulate the needs of YPLHIV as a whole. Thirty-five years was the upper age limit for National Association of YPLHIV membership. The organisational embeddedness was intended to facilitate the translation of the research findings into practice. A purposive sampling strategy (Patton, 2002) was applied to
ensure a range of experiences and perspectives amongst participants. The board members of the
association advised us to use mixed-gender groups for two reasons: to foster mutual support among
participants and to enable the association to understand and address non-gender specific issues.
Young men and women share common challenges, such as stigma, complex medication regimes, and
emerging sexuality, and the associated need for sexual reproductive health services and these were
the subject of our investigation. We chose focus group discussions because they could facilitate the
generation of rich data through discussions based on first-hand understanding and experiences
(Morgan, 1997). Focus groups also seemed suitable to capture group aspects from founding members
of a young association mandated to advocate for the rights of YPLHIV.

In addition, we conducted semi-structured one-to-one interviews with three key informants (KI). KI
is a term within social research that refers to “those whose social positions in a research setting give
them specialist knowledge about other people, processes or happenings that is more extensive,
detailed or privileged than ordinary people, and who are therefore particularly valuable sources of
information to a researcher (...).” (Payne and Payne, 2004). Key informants were purposively
sampled through local organisations that had a good local reputation in dealing with adolescent HIV
issues. The organisations repeatedly came up in conversations with various stakeholders in the local
HIV/AIDS sector and were recommended by NAYPLHIV. The selected interviewees were identified
through referrals from colleagues within the organisations. We did not aim for saturation as key-
informant interviews were intended to help to contextualise and interpret data collected from the
young participants. We aimed to interview KI representing different occupational backgrounds such
as clinical, research and civil society to achieve a holistic contextualisation. We also deliberately
conducted KI interviews after FGD with young people to explore some of the same issues raised.

_data collection tools_

We contextualised the definitions of four health literacy dimensions (functional, interactive, critical
and distributed health literacy) to ensure appropriateness to the topic of investigation, which was HIV
in Malawian youth. The contextualisation was based on our initial understanding of the health needs
of YPLHIV and a review of existing literature. We also drew insight from existing measuring tools including the Health Literacy Questionnaire (HLQ) (Osborne et al., 2013) and the Health Literacy Survey (HSL-EU-Q) (Sørensen et al., 2013). The initial conceptualisation was used to develop the discussion and interview guides. Both focus group interviews and in-depth interviews with KI were semi-structured (Morgan, 1997), and they had a similar focus. We used the internet-based SMOG calculator (NIACE 2009), which is a tool to improve the readability level of documents to achieve a readability level of 11-14-years. The low readability level of questions facilitated translation of our research tools into the two local languages of Chichewa and Chitumbuka. We developed a structured questionnaire to collect information on background characteristics (age, gender, marital status, sexual behaviour, self-management practices, contraceptive use and disclosure).

Data collectors

Questions were pilot tested with a board member of the national association of YPLHIV and amended before the actual data collection. A local research assistant facilitated the focus group discussions while a female research assistant, of a slightly older age to the study participants, took notes and ensured that all topic where covered. The facilitator was a primary school teacher with 20 years of teaching experience and 10 years of research experience involving young people. He was selected for his skills in interacting with young people. The note taker was a holder of a postgraduate diploma in gender equality studies and had 6 years work and research experience with YPLHIV. Induction for the research assistants entailed a review of the discussion guides and role play.

Data collection process

Focus group interviews were conducted in Chichewa in Southern region (Blantyre) and Central region (Lilongwe) and Chitumbuka in the Northern region (Mzuzu). The discussions took place in classrooms at centrally located schools within the three cities. We held the discussions on weekends to ensure privacy. Contemporaneous notes were taken in English, and the interviews were recorded and supplemented with observational notes. The facilitator stressed the expert position of interviewees to encourage participants to share experiences from their life-worlds. Positioning
participants as experts in this manner helped to decrease the power asymmetry between participants and the interviewer.

**Data analysis**

Transcripts were entered into MAXQDA v.12 software (VERBI Software - Consult - Sozialforschung GmbH 1989-2016). We used a framework approach to manage and systematically analyse the data. Framework analysis entails the organisation and management of data using an a priori analytical framework consisting of a set of codes organised into categories that have been jointly developed by the researchers involved in the analysis (Gale et al., 2013). The same analytical framework that informed the development of the data collection tools was used to analyse data. The analysis identified the representation in data of knowledge and skill assets or deficits (both articulated and implied) and coded them within the categories making up our analytical framework. The lead researcher’s coding of data was validated through discussion of the data excerpts in each dimension among members of the research team. We revised the analytical framework iteratively as analyses proceeded until all data were coded. Table I depicts the final contextualised framework. We identified knowledge and skill assets, deficits and needs that were translated into nine improvement recommendations which were presented to participants in the same focus groups as a way of validating the analysis. The recommendations were a practice-oriented output of the research intended to inform the programming of the national association of YPLHIV. The validation was undertaken as part of a subsequent phase of the research which involved community participatory prioritising activities using the concept mapping approach (Trochim and Kane, 2005).

Table I [Insert - Table I Contextualised theoretical framework- about here]

**Ethical considerations**

Written informed consent was received from all participants. Despite taking necessary precautions, the study protocol was breached due to two participants being under 18 years. The breach was reported to the ethics committee, which advised us not to use data from the two participants.
Results

Table 2 presents the socio-demographic and clinical characteristics of the 24 focus group participants, with the two under-age participants excluded. The mean age of the participants was 22 years (range 18-29). Nine participants were male. Eighteen participants gave their medication status of whom 14 were on Anti-Retroviral Therapy (ART). Of these, nine reported having missed more than one dose of their medication within the previous month. Twelve participants were sexually active, of whom three reported not having used a condom during their last sexual encounter. The majority had a secondary school level of education or beyond, although five were out of school at the time of the interviews.

We interviewed three KI: a nutritionist and adolescent programme coordinator at an HIV clinic in the Central region, a former district health research coordinator from the Southern region who was working with sexual reproductive health in an NGO at the time of the interview, and a project coordinator of a youth sexual reproductive health rights project with a faith-based NGO. All had health professional backgrounds and had worked with YPLHIV for six, eight and fifteen years respectively.

The analysis and interpretation of the focus group data resulted in the emergence of a contextual model of health literacy, as depicted in Figure 1. We developed a data-led extension of the initial framework consisting of the four individual-level health literacy classifications: functional, interactive, critical and distributed health literacy (see Table 1) to include three additional overhead health literacy classifications showing areas or levels where it is necessary to intervene to promote the health of YPLHIV in Malawi. We classified them as Individual health literacy, System health literacy and Public health literacy. Nine action recommendations were generated from the analysis; three on individual health literacy, five on system health literacy and one on public health literacy.
Health literacy was necessary at the individual, system and public health levels. Individual and system-level skills complemented each other across the four health literacy dimensions. Public health level health literacy was related to the need for advocacy at a multi-sectorial policy level.

Figure 1 [insert figure 1- Display of results depicting the contextual health literacy model, central themes and selected supporting quotes – about here.]

Functional health literacy

*Individual-level*

The focus group participants demonstrated varying functional health literacy skills. While some were very knowledgeable, others had questions, especially regarding sexual reproductive health (SRH) issues in light of being HIV-positive. The indication was also that participants' families and communities had wrong or incomplete information: "*My guardians told me I should marry someone HIV-positive only. Is it true or a lie?*” Female, Northern region. Primary information sources were healthcare providers, support groups for HIV-positive youth, religious institutions and schools.

Traces of low individual health literacy on the part of the general public were also found in participant’s attribution of the stigma associated with HIV to insufficient information and low levels of knowledge about HIV and AIDS in the community: "*lack of information causes stigma and discrimination. The people should be told about the mode of HIV transmission. The mindset that PLHIV can't achieve anything needs to change.*” Female, Northern region. Among other things, stigma led to suboptimal adherence and care-seeking behaviours: “*Youths are being forced to go far [distance] because they are afraid of what people will say. They end up missing [clinic] dates.*” Female, Northern region. A key informant noted that the challenge that YPLHIV face is not understanding HIV itself, but not understanding how to cope with HIV and stigma and maintaining a positive future outlook: “*So generally they [young people] understand what HIV is. The challenge lies in their access to the information that can help them (...). Because they are supposed to fight stigma and discrimination, and they are supposed to understand how they are going to cope with the*
situation that they have HIV. They are looking at the future and how their future is going to be like.

So when they have to bring all those things together, it's a challenge.” KI, nutritionist, Central region.

System-level

According to our participants, the available information did not meet nor satisfy information needs of YPLHIV and communities: "The information is not enough; most of the information is about prevention, it targets people that are not infected." Male, Central region. This notion was echoed by a key informant: "(...) you know, the way the information is being relayed is different from now saying: now that you have HIV, these are some of the things you are supposed to be doing.” KI, nutritionist, Central region. Some of the information in circulation seemed to have an adverse effect of reinforcing both enacted stigma and self-stigma: “Sometimes, the teachers speak only negatively of HIV, instead of speaking encouraging words, like promoting testing and also healthy living.” Male, Northern region. One provider spoke of a culture of not distributing information to young people due to a belief that they were not capable of using information responsibly: “There are different areas where we need to improve, and one of the things is building the capacity, from the point of view of passing on knowledge by the various groups that are interacting with the youth, parents, the church leaders, teachers and community leaders such as youth. All those and the health care workers need to know the position and the potential of the youths to understand and build their health lives on their own. (...) I think treating the youths as people who have the potential to think and can make decisions about and for their own lives. Of course, as adults and as parents, we are there, we can, but we still need to understand in any other setting and in any other system, putting that element that the youths still have a potential to think on their own (...). Sometimes we have as a culture (...), told a lie in order to promote health and then when the youths start discovering that, that was not true, it has a negative impact.” KI, research governance, Southern region. A participant echoed the above sentiment but was convinced that young people were capable of acting responsibly if only they could be trusted: “(...) If Doctors help us, then we will be responsible.” Female, Northern region.
Interactive health literacy

**Individual-level**

Interactive health literacy skills were demonstrated by participants’ interest in safeguarding their health through proactive sharing of treatment defining information with health professionals: "When I go to the hospital or the ART clinic, I need to tell the doctor my status. That is if it is a new doctor, they need to prescribe me with medicine that is compatible with my ARVs." Female, Northern region.

Interactive skills were also related to demanding treatment and being able to navigate the healthcare system, including demanding services amidst harsh attitudes and non-confidentiality of providers:

“One day I went to the hospital with a rash. The doctor saw me and started shouting at me. I asked: "don't the rules say consultations are confidential?" and I got inside. I explained about my rash, but the doctor was not helpful, so I went to a nurse who told me to go to the health centre. I did not want to go to the health centre, so I proceeded to the central hospital and met a skin doctor who said this is an effect of the medication." Female, Central region. However, not all participants demonstrated the same level of skills as some noted that poor provider attitudes and being asked too many questions discouraged them from seeking services.

**System-level**

Failure in the healthcare system to accommodate the health literacy of YPLHIV was labelled lack ‘of youth-friendly health service' (YFHS), which is a policy within the Malawian healthcare system to promote young peoples’ access to SRH services (Ministry of Health, 2015). The participants’ reference to ‘young friendly services’ indicated that they were aware of the YFHS policy. Participants narrated that they did not experience ‘youth friendliness’ in their interaction with the healthcare system. Many explanations were given for this, e.g. poor attitudes and the older age of healthcare providers leading to intergenerational differences in perceptions. An additional complication was that HIV-status made it difficult to discuss SRH, and the impression was given that the providers were not sympathetic: “If you go to collect condoms, the nurses speak a lot, and this makes one think it is okay to do without a condom. This makes one use a new book [hand-held patient record] at the next
hospital visit so that the doctors should not know about one’s (HIV) status (...)” Female, Northern region. Some participants had experienced discrimination by health providers: “I went to [Name of the hospital], I had malaria, so I told the doctor my (HIV) status, I told him to give me the medicine which is compatible with my body. I overheard the doctor tell someone; "I cannot treat this girl; she is HIV positive". I had to go to the pharmacy and buy another (handheld record) book." Female Northern region. Provider attitudes made it difficult for participants to communicate and affected their willingness to volunteer treatment defining information, including their HIV status.

Critical health literacy

Individual-level

The data revealed three alternative healing systems: prayer, traditional/herbal medicine and modern/biomedical treatments, including ART. The information stemming from the alternative systems was found to be contradictory. For instance, some preachers claimed to cure HIV through prayer and would ask people to stop taking treatment. One of the providers complained that many young clients were mixing ART with herbal medicines from traditional healers with unknown effects. A discussion on faith healing was insightful on how challenging it can be for some youth to critically appraise information when the source and content are compelling like in the case of faith healing: “The danger with that [people praying for you] is that they tell you that you are healed, and yet you are not.” Female, Southern region. Participants narrated that some youths would take a suppressed viral load due to medication as a confirmation of their healing and stop taking their medication, only to become severely ill.

System-level

Similarly to the individual level challenges described by the YPHIV, KI concurred that the healthcare and education systems, as well as cultural and religious institutions, were providing conflicting information. Conflicting information was not only in the public sphere but was likely to be present in the consultation room as well: “For example, if I work in the hospital, and at church, I happen to be
a church elder. And say that I have this young boy who is a member of my church, and he comes to
the hospital. I tell the person: "use protection when having sex." Whenever I meet the same individual
at church; I tell him/her: “abstain from sex.” KI, research coordinator, Southern region. Involving
multiple sectors and players in the HIV response was seen by KI as critical in reaching most YPLHIV
including the ones that do not yet know that they are HIV-positive: “(...) there is no suitable system
which can mobilise them [the out of school youth]. However, some of them are members of a
particular religious community.” KI, Faith-based NGO, Northern region.

Distributed health literacy

Individual-level

Stigma and discrimination constituted barriers to distributed health literacy in that our participants
were afraid to disclose their status to family and friends: “I cannot tell my parents; they can say I am
a prostitute if they are negative.” Female, Southern region. Similarly, many participants had
difficulties disclosing to their partners:” Some boyfriends will say it is okay, but they leave you slowly.
This makes me not disclose my status. Sometimes you are forced to lie.” Female, Northern region.

Generally, young people noted that self-stigma led to isolation: “I used to stigmatise myself, I isolated
myself..., and I felt alone, no future.” Female, Central region. Participants identified meeting other
YPLHIV as an important determinant of health and a coping strategy. For some, the time-period
around when they first found out they were HIV-positive was characterised by self-stigmatisation.
Having social support was critical to coming to terms with being HIV-positive, and for many, real
support came through the YPLHIV support groups.

System-level

The teen clubs at clinics and community support groups were also a source of support for the young
people and helped them break the isolation by enabling the young people to meet others in the same
situation. “I went to [Name of hospital], and they told me to go to a Teen Club, I did not want to
attend the club at all. One day I met a friend at the hospital, and she encouraged me to attend, and
that is when I started learning more and associating with friends (...).” Female, Northern region.

Accepting the diagnosis was described as crucial to adopting appropriate health behaviours: “If you accept your status and you take care of yourself, life becomes easier.” Female, Southern region. It was also clear that support from carers was essential for accepting and managing seropositive status.

The family was also a source of information as well as material and emotional and care support. Despite this, participants reported that counselling was mainly offered to the infected young people alone and not to carers. It was evident from some of the information shared by our participants that carers were doing their best but that they sometimes were misguided in their actions. Misguided actions include giving special treatment to the HIV-positive client and exposing them to stigma in the process: “I stayed with my aunt at one time, and she used to give me lots of food, the other people used to wonder why I had lots of food, which was also not good.” Male, Northern region.

Public Level health literacy

Unlike the health literacy ‘domains’ described above, the need for ‘public health literacy’, identified and defined as "The degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community.” (Freedman et al., 2009), emerged as the analysis progressed. According to Freedman, the primary aims of Public health literacy are to engage more stakeholders in public health efforts; and address social and environmental determinants of health.

Public health literacy manifested as a significant issue. Many informants identified the need for collective action in addressing stigma by correcting misconceptions about HIV in the community Table 1: “If we are in a group of people and the discussion is on HIV, we tend to be reserved, but this is the time to jump into the conversation, (and) even correct misinformation.” Female, Central region. Participants also highlighted the necessity of policy-level action, including policy development in the area of HIV and AIDS, which entails high-level critical health literacy skills (See Table 1). However, the most pressing matter for participants was the need to advocate for youth-friendly health services: “I feel that for things to change, that youths can access health services, there
is a need for advocacy.” Male, Northern region. Public health literacy aspects were also stressed in the participants' views from the validation workshop. For example, participants emphasised the need for both top-down and bottom-up approaches: "There is no way youth can change things without investing their 'own' effort. Nothing for us without us." Mzuzu Validation workshop. “Government must do the best in helping youths living with HIV so we can achieve the zero HIV infection.” Blantyre Validation workshop.

Discussion

We set out to assess the health literacy-related needs of YPLHIV in Malawi and adapt existing conceptual frameworks to the study’s context. We used qualitative methods in an attempt to produce a holistic assessment of different dimensions of health literacy (functional, interactive, critical and distributed health literacy). Through a framework approach, we identified health literacy-related assets and deficits within these four dimensions. We also identified that the assets and deficits could be categorised according to whether they were related to individual, system or public health literacy. We developed a preliminary model to depict the relationship between the three hierarchical health literacy levels and the four dimensions of health literacy based on the findings of this study (see Figure 1).

Our study corroborates with the World Health Organisation’s current definition, which stresses the role of health literacy as an empowerment tool that enables individuals and communities to take an active role in bettering their own health (World Health Organization, 1998). However, the study also supports the push by the US National Academy of Medicine towards definitions that do not solely perceive health literacy as an individual characteristic (Pleasant et al., 2016). The National Academy of Medicine advocates for a definition that places more responsibility for improving health literacy on systems (ibid). Systems health literacy is predominantly concerned with the role of health systems in western contexts. (World Health Organisation, 2013;DeWalt et al., 2011;World Health Organisation, 2015). By contrast, we identified the need to examine system health literacy at multiple
levels (functional, interactive, critical and distributed levels), and across multiple systems important
for young people in all aspects of their lives (that is widening beyond the health system to systems
such as social care and education as well as cultural and religious institutions). We developed a
definition that captures this contextual understanding of system health literacy as follows: ‘The
capacity and willingness of health and social systems, including cultural institutions, to accommodate
the functional, interactive and critical health literacy needs of people and communities in the planning
and delivery of services of relevance to health’. In other words, the impact of policy and practice
across multiple sectors on health literacy (and HIV literacy in particular) should be considered
through mainstreaming.

Our study confirmed that, where system health literacy is low, more effort, and more complex skills,
are required from patients (Nutbeam, 2000; Sørensen et al., 2012). The study suggests that YPLHIV
face more difficult challenges than most young people. For example, the study’s participants reported
discrimination and non-confidentiality by health workers, which had adverse effects on their mental
health and health-seeking behaviour. Trust in healthcare professionals and patient-provider
communication are central to health literacy (Ibid) and essential for adherence to ART (Nachega et
al., 2012). Initiatives to improve ‘YFHS’ should, therefore, strive to address these and other issues
particular to YPLHIV. Improvements in system health literacy can potentially lead to a decrease in
health inequalities by supporting systems to accommodate young people living with HIV, who are
vulnerable to low health literacy.

The concept of public health literacy was first introduced by (Freedman, et al., 2009), and although
we initially had not included it in our theoretical framework, the study provided empirical evidence
in support of the concept. Public health literacy needs were shown to operate on an individual and
group level as the need to influence the development of health literacy enhancing policies as well as
policy enforcement.

The study was undertaken with the intent of informing the work of the national association of
YPLHIV in Malawi. We developed nine action recommendations based on the assets and deficits that
we identified. On the individual-level, needs were identified within all domains. Functional health literacy emerged as a lack of knowledge about HIV and sexual reproductive health in light of being HIV-positive. The need for communication skills and skills to navigate the systems were demonstrated by variation in the ability of participants to interact with systems shaping their everyday lives. For critical health literacy, informational critical appraisal skills were needed due to the contradicting information in circulation. Support groups for YPLHIV were found to be a suitable platform for collective empowerment of YPLHIV in Malawi through distributed health literacy-enhancing initiatives. Support groups were seen as vital for coping and self-management, in line with previous research (Chen and Shi, 2015; Lan et al., 2015; Martinez and Chakraborty, 2014). Support groups also acted as a buffer against stigma and discrimination. Supporting carers with guidance and counselling could further improve distributed health literacy. These results demonstrate that health literacy has the potential to make significant contributions to the fight against AIDS. Investments should not only focus on functional health literacy, but also on higher-order dimensions which entail the application of knowledge and information.

Limitations

Our study was undertaken among a sample of youths whose membership of the new and evolving national association of YPLHIV indicate likely empowerment and activist traits (Brashers et al., 2002). Additionally, the majority of the study’s participants had high school level education so it is not known to what extent the results of this study would apply to YPLHIV who are not members of the association or have lower educational attainment. We assume that less empowered or less educated YPLHIV in Malawi experience more challenges than those identified in our study.

As a qualitative study only involving 24 young people with HIV and three key informants, we could not capture the entirety of the complex social and cultural Malawian context. However, the study gives a valid view of YPLHIV from the perspectives of the participants, and can inform more regional, district or setting specific studies within the context of intervention development.
The fact that the focus groups involved both sexes may have influenced our findings. Discussions seemed relaxed and wide-ranging, including sensitive issues, although girls were generally more vocal than boys. It is likely that single-gender interviews might have given rise to different, gender-specific findings.

Another weakness of this study is that the data collected only had a few examples of critical health literacy. An explanation could be that our discussion guide was not good at capturing critical health literacy, which raises questions about the appropriateness of the questions used to explore critical health literacy. Another reason may be that there is a need for greater clarity in the definition of critical health literacy than we were able to achieve in this study, to distinguish it more from functional and interactive health literacy. Future research should explore more appropriate ways of exploring health literacy qualitatively. The study findings call for more nuanced and distinct definitions of health literacy dimensions. For example, an outline of where functional health literacy ends and critical health literacy begins, or the differences between the dimensions more generally would be helpful. Our iteratively generated contextualised framework, refer to Table 1, is an initial approach to achieve this. A recent meta-review of scoping and systematic reviews examining literacy conceptualisations generated representative concept definitions (Elliott et al., 2019), which seems to provide an alternative framework with which health literacy may be explored qualitatively. The meta-analysis identified three skill categories (information acquisition, information analysis, and the application of information) and three categories of desired consequences (knowledge, attitudes and behaviours).

**Conclusion**

Our study found that health literacy among YPLHIV in Malawi should be viewed in a much broader context than the hitherto principal focus on individual-level health literacy in the literature. We identified health literacy-related needs within four health literacy dimensions: functional, interactive, critical and distributed. Furthermore, we found that the needs of YPLHIV could be addressed on three
levels: the individual patient, the system and the public policy levels. System health literacy extended its scope beyond the healthcare system and incorporated the education system and some cultural institutions which were playing a vital role in conditioning and supporting the development of health literacy and promotion of health. The model shows that efforts to address individual-level health literacy needs of YPLHIV in Malawi in the absence of broader reinforcing and enabling measures at the system and public health literacy levels are likely to fail. The study also gave rise to contextualised definitions of the four health literacy dimensions and three health literacy levels. Furthermore, the study generated nine concrete action recommendations intended to inform interventions, programmes and policy at the grassroots level within the national association of YPLHIV and the wider HIV sector in Malawi. The need to impart YPLHIV with information critical appraisal skills and skills to interact and navigate the healthcare system were among the nine recommendations which can be found as part of the supplementary material. Although the study results primarily apply to Malawi, the results may also be transferable to neighbouring countries with similar contexts.

**Abbreviations**

- HIV: Acquired Immune Deficiency Syndrome
- ART: Antiretroviral treatment
- KI: Key informant
- YFHS: Youth Friendly Health Services
- (Y)PLHIV: (Young) People Living with HIV
References


### Individual Health literacy (HL)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
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<tbody>
<tr>
<td>Functional</td>
<td>Ability to access or extract and understand information from various sources (both oral and written) according to individual need. In HIV context: Ability to access and understand available information about HIV and how to lead a healthy life in light of being HIV-positive.</td>
</tr>
<tr>
<td>Interactive</td>
<td>Ability to derive meaning from various forms of communication and to apply it and the ability to communicate about HIV in clinical and social settings, e.g. ability to interact with healthcare providers and navigate the healthcare system.</td>
</tr>
<tr>
<td>Critical</td>
<td>The ability to evaluate or critically appraise the accessed information in making appropriate informed decisions about health that apply to specific contextual and or situational circumstances and having self-efficacy and confidence in implementing decisions made and thereby exerting greater control over one’s life and the impact of being HIV-positive.</td>
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<tr>
<td>Distributed</td>
<td>Entails skills related to accessing social support in coping through help in accessing, evaluating and understanding information and in decision making for health from people in one’s social network. In HIV context this includes the ability to disclose HIV status to one’s family and friends and the level of knowledge and skills of family and friends to offer the support needed.</td>
</tr>
</tbody>
</table>

### System HL

The capacity of systems to accommodate the individual HL needs of clients and communities in the planning and delivery of services. Systems refer not only to health services but all systems or institutions of relevance to health such as education, social care, religious institutions, and others as relevant to local contexts. Because the systems’ roles are to accommodate and develop HL of the clients, system HL may also be categorised into the four domains as with individual HL above: Functional, interactive, critical and distributed as demonstrated by this study.

### Public HL

“*The degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community. Public HL targets the public with the purpose to improve the health of the public. The primary aims of Public HL are to engage more stakeholders in public health efforts; address social and environmental determinants of health*” (Freedman et al. 2009). This dimension of HL was depicted in participant’s eagerness to engage in collective advocacy to influence policy and public knowledge of HIV.
Table 2 Social-Demographic and health characteristics of focus group participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Categories</th>
<th>Number of people/ Mean(range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>9</td>
</tr>
<tr>
<td>Age</td>
<td>Overall</td>
<td>22 (18-29)</td>
</tr>
<tr>
<td></td>
<td>Blantyre (Southern region)</td>
<td>22 (14-29)</td>
</tr>
<tr>
<td></td>
<td>Mzuzu (Northern region)</td>
<td>21 (18-25)</td>
</tr>
<tr>
<td></td>
<td>Lilongwe (Central region)</td>
<td>23 (19-29)</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>6 people</td>
</tr>
<tr>
<td>Education¹</td>
<td>Secondary (9-12 years)</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Tertiary (Over 12 years)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Out of school²</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>2</td>
</tr>
<tr>
<td>Can read and write</td>
<td>English</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Chichewa only</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>English and Chichewa</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>English, Chichewa and other</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>5</td>
</tr>
<tr>
<td>Study site</td>
<td>Mzuzu (Northern region)</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Lilongwe (Central region)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Blantyre (Southern region)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>2</td>
</tr>
<tr>
<td>Awareness of positive status (years)</td>
<td>Under 5</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>5-10</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Over 10</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>1</td>
</tr>
<tr>
<td>Knows/remembers CD4 from the previous check-up</td>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>4</td>
</tr>
<tr>
<td>On medication</td>
<td>Yes</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>6</td>
</tr>
<tr>
<td>Adherence: missed dose(s) in the last 30 days</td>
<td>Yes (more than one)</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>No (One or less)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>8</td>
</tr>
<tr>
<td>Sexual experience</td>
<td>Yes</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>4</td>
</tr>
<tr>
<td>Condom use</td>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>13</td>
</tr>
<tr>
<td>Disclosure outside of the healthcare system</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Partially²</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Totally³</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>2</td>
</tr>
<tr>
<td>Living with</td>
<td>Parent(s)</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Relatives/guardians</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Husband/wife</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Alone</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Missing data</td>
<td>5</td>
</tr>
<tr>
<td>Children</td>
<td>Yes</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>HIV+</td>
<td>1</td>
</tr>
</tbody>
</table>

¹ Categories include participants who were still attending school or had left school within the category.
²Captures participants who had disclosed their status to one or more of the following: family, friends, school colleagues and in their community.
³Participants who were fully open about their HIV status.