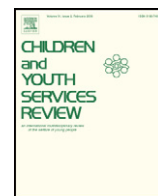




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Responding to adolescents living with HIV in Zambia: A social–ecological approach

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ABSTRACT

The number of adolescents living with HIV in Zambia is increasing, yet little is known about their experiences in a social context. Such knowledge could enable HIV programs to better respond to their needs. This qualitative study examined the experiences of adolescents living with HIV in Kitwe, Kalomo and Lusaka in Zambia. In-depth interviews were conducted with adolescents aged 10–19 living with HIV ($n = 58$) and their health care providers ($n = 14$). In addition, 13 focus group sessions were conducted with adolescents living with HIV ($n = 53$), health care providers ($n = 24$) and parents ($n = 21$). Thematic analysis was used to draw out the social–ecological determinants of adolescents' experiences. Results showed that a range of factors located at the individual, family and peer, community and structural levels determine the experiences of adolescents living with HIV. At the individual level, resilience and internalized stigma were found to shape adolescents' perception of an HIV diagnosis, and their ability to maintain a positive outlook and sustain relationships. Family and peers supported adolescents to adjust to new drug-taking routines, but these people occasionally disclosed adolescents' HIV status inappropriately. At the community level, stigma and discrimination in schools were found to negatively influence adolescents' experiences, suggesting that approaches to normalize HIV in schools are needed. The presence of non-governmental organizations provided an entry point for the provision of broad-based livelihood, nutritional and psychosocial services for adolescents living with HIV at the community level. At the structural level, poor flexibility of clinic opening hours, staff shortages and a lack of health policies related to adolescents living with HIV presented ongoing limitations to adolescents' ability to access relevant services. In conclusion, adolescents' experiences of living with HIV are influenced by factors located within and beyond adolescents themselves. Understanding these contextual factors, and adopting interventions that accentuate positive experiences while mitigating negative ones, could strengthen the provision of services tailored to the needs and circumstances of adolescents living with HIV in Zambia.

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1. Introduction

Through the empirical application of theoretical concepts linking health and social ecology (Stokols, 1996), the link between adolescents' health and their environment is becoming increasingly recognized. This recognition has emerged from the convergence of interrelated studies exploring the impact of social ecology on the health and development of young people (Gorman-Smith, Tolan, & Henry, 2000; Viner et al., 2012; Youngblade et al., 2007). The thrust of a social–ecological

approach to health is the recognition that individual experiences of health and illness are influenced by factors within and beyond the individuals themselves (Feldacker, Ennett, & Speizer, 2011; Stokols, 1996). As such, the social–ecological perspective has made distinctive contributions to advancing our understanding of adolescents' health by identifying determinants of their health located at the individual level as well as those located in the community, structural and socio-physical environments (Cook, Herman, Phillips, & Settersten, 2002; Viner et al., 2012).

A relativist's analysis typically identifies 'protective factors', 'assets' or 'resources' that promote adolescent health as well as 'risk factors and behaviors' that negatively affect their health at different levels of their social ecology (Anteghini, Fonseca, Ireland, & Blum, 2001; Youngblade et al., 2007). For example, studies have shown that individual assets such as personal competence, social factors such as adolescents' relationships with peers and parents, and community resources

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such as neighborhood schools could influence adolescents' sexual behavior (Magnani et al., 2002; Stanton et al., 2002), violent behavior (Haegerich, Oman, Vesely, Aspy, & Tolma, 2013), cigarette smoking (Lloyd-Richardson, Papandonatos, Kazura, Stanton, & Niaura, 2002) and other substance use (Griffin, Botvin, Scheier, Epstein, & Doyle, 2002).

In this paper, we argue that adopting an integrated social–ecological approach to understand the experiences of adolescents living with HIV could open up avenues for interventions that respond not only to their biophysical being, but also to their environmental circumstances. This is particularly relevant given that health practitioners often fail to consider the wider contexts of young people (Magnani et al., 2002). Indeed, Grzywacz and Fuqua (2000) assert that the consistent failure of health practitioners to consider the social environment when designing interventions – despite it being clear that individuals are inextricably connected to a larger social ecosystem – limits our ability to mitigate negative experiences and risk factors located at the family, community and wider societal levels. It may be argued that by concentrating on individuals' biophysical factors while ignoring their social contexts, practitioners achieve suboptimal health outcomes for individuals and perhaps entire communities.

Applied to adolescents at risk of HIV, a social–ecological analysis has implications relevant to practitioners. For instance, adolescents' ability to take up HIV prevention services in Zambia is heavily influenced by their family relations (Denison, McCauley, Dunnett-Dagg, Lungu, & Sweat, 2008) as well as by societal perceptions of HIV (Stephenson, 2009), suggesting that besides focusing on individuals themselves, interventions for adolescents at risk of HIV should also target their family and societal domains.

Similarly, we argue, understanding the link between the experiences and environmental circumstances of adolescents already living with HIV can help practitioners improve their response to this population. While each adolescent living with HIV has unique life circumstances, understanding the basic individual and environmental factors that influence their experience of living with HIV is a vital step towards surrounding them with 'protective factors' at the individual, community and structural levels (Bearinger, Sieving, Ferguson, & Sharma, 2007) and ensuring that they access services suited to their needs. However, many studies tend to focus on adolescents' sexual knowledge and behavior at the expense of their wider social contexts. In Zambia, where an estimated 80,000 adolescents (defined as young people aged 10–19) are living with HIV (UNICEF, 2011), 'less attention has been directed at understanding how protective factors operating at the family, school and community levels influence sexual risk taking' and 'broader experiences' of young people (Magnani et al., 2002). As a result, little is known about how environmental circumstances influence Zambian adolescents' experiences of living with HIV.

In response to this information gap, we undertook a qualitative study to explore the experiences of adolescents living with HIV in three Zambian districts: Kitwe, Kalomo and Lusaka. This study was the basis for a 2012 paper in which we reported that sexual, reproductive and HIV services in these locations were not adequately meeting the needs of adolescents living with HIV and suggested ways in which health systems could be strengthened to respond to them better (Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012). In 2013, we published additional study findings relating to how these adolescents were expressing their needs and recommended that interventions for adolescents living with HIV should match their evolving capacity and self-efficacy (Mburu et al., 2013).

In this paper, we focus on identifying factors that shape adolescents' experiences of living with HIV, with particular emphasis on the location of these factors in the social ecosystem. This encompasses the individual, home, school, neighborhood, community and societal or structural levels. Consistent with a relativist's social–ecological analysis, we identify factors that cause negative experiences as well as those that cause positive experiences or otherwise mitigate negative experiences, and we relate those factors to programmatic interventions. By identifying

multiple levels at which interventions should be delivered, this study has the potential to strengthen the provision of services for adolescents living with HIV, and to pave the way for integrated health programs that serve this population more effectively by taking into account the complex interaction between health and environmental determinants of their experiences.

2. Methods

2.1. Study setting

The study was conducted in one rural district (Kalomo) and two urban districts (Lusaka and Kitwe) in Zambia, a country where adolescents constitute 25% of the population (UNICEF, 2011). The three districts were selected to ensure a diversity of contexts in which a variety of interventions were being delivered through a combination of governmental and non-governmental organizations. In these districts, adolescents were accessing clinical services from government hospitals and clinics, and non-clinical support primarily from non-governmental organizations. In each district, we identified clusters of HIV clinics and surrounding community-based organizations that were collectively providing services; those clusters became the study's recruitment sites (Table 1).

2.2. Study participants

Study participants were 111 adolescents aged 10–19 living with HIV, together with some of their parents and guardians ($n = 21$) and health care providers ($n = 38$) (Table 2). In the adolescent group, 28 study participants were planning to have children in the future. Two sexually active adolescents reported having not disclosed their status to their sexual partners for fear of rejection. A small number of older adolescents were married and had children ($n = 6$). Further characteristics of the adolescents are shown in Table 2 below. The health care providers included medical doctors, nurses, counselors and administrative staff.

2.3. Study design

We used qualitative methodologies – in this case, semi-structured interviews and focus group discussions – to explore the experiences of adolescents living with HIV, and used findings from health care providers, parents and guardians for triangulation. Qualitative methodologies are particularly suited to identifying diverse perspectives and experiences (Esterberg, 2002). Data were collected between April and December 2010. The study was approved by the University of Zambia's Biomedical Research Ethics Committee.

2.4. Study procedures

Interview guides and topics for the focus group discussions were developed in reference to existing gaps in the literature and to the study objectives and questions. These included: 1) What were the sexual, reproductive, psychosocial and information needs of adolescents living with HIV? 2) What were the main sources of these services for adolescents living with HIV? 3) Were health (and psychosocial) services meeting the needs of adolescents living with HIV? 4) What were the experiences of adolescents in relation to HIV disclosure and living with HIV? Interview questions and topic guides were tailored to younger adolescents (10–14 years), older adolescents (15–19 years) and health care providers as appropriate. Focus group discussions were included to allow participants collectively share their varied perceptions and experiences.

In a pilot phase of the study, potentially ambiguous questions in the study tools were identified and modified accordingly. In addition, study tools were adjusted to take into account the cultural environment of the study setting. Final study tools were translated into vernacular versions. Researchers then back-translated the vernacular versions to ensure that the meaning of the questions was as intended.

Table 1
Study setting and illustrative range of services available at each setting.

Site (district)	Kalomo	Kitwe	Lusaka
Geographical location HIV clinics	Southern Province, 360 km from Lusaka Kalomo Hospital, Chilala Clinic, Kanchele Health Center	Copperbelt Province, 365 km from Lusaka Luangwa Clinic, Mopani Clinic, Wusakile Mine Hospital	Lusaka Province, capital of Zambia University Teaching Hospital, Chelstone Clinic
Typical services provided by HIV clinics	Clinical reviews, HIV testing and counseling, prescription of antiretroviral drugs, screening and treatment for opportunistic infections		
Non-governmental organization service providers	Kalomo Mumuni and interdenominational centers, Youth Christian Fellowship, Sikwazwa	Twafwane Christian Community Center, Catholic Multi-function Center, Mulenga	Network of Zambian People Living with HIV, Ng'ombe Home-Based Care Center
Typical services provided by non-governmental organizations	Nutrition support, youth-led peer support, vocational training for adults, adherence and psychosocial counseling, home visits, home-based care and community outreach activities		

Participants were recruited while accessing services at HIV clinics and at community centers run by non-governmental organizations. Researchers visited these sites and provided information about the study to managers and clinical staff. Following this, adolescents, their parents and guardians, and a number of their health care providers were invited to participate by the researchers. The researchers explained the aims and nature of the study to all prospective study participants in their local languages, and assured them that participation was voluntary. All adolescents in the study were aware of their HIV status and were accessing services. Adolescents were eligible to participate regardless of whether they were vertically infected or had acquired HIV later in life, and regardless of whether they were on antiretroviral therapy or not.

Robust strategies were employed to protect the confidentiality and privacy of participating adolescents and their parents and guardians during the entire research process. Adolescents aged 10–17 orally indicated their assent to participate, and their parents and guardians signed consent forms. Adolescents aged 18–19 signed their own consent forms in the presence of their parents and guardians. (The legal age of consent in Zambia is 18 years.) In addition, parents, guardians and health care providers who participated in the study signed their own consent forms. Participants were asked to choose a suitable private location at the clinics and community centers where they felt comfortable participating in the interviews and focus group discussions. Younger adolescents were interviewed while their parents and guardians waited in the vicinity of the clinic or community center. During the interviews, participants were guaranteed confidentiality and anonymity, and were informed of their right to end their participation at any time. Participation was voluntary with no direct benefits, but transport costs were reimbursed where appropriate.

HIV stigma is common in the setting where the study was conducted (Hodgson et al., 2012). In this context, research team encountered tensions between the ethos of protecting the privacy of adolescents and their families, and engaging local researchers who understood the study districts and knew some of the respondents. Thus, although the research team was already well versed in qualitative methods, researchers were further trained on privacy, confidentiality and child protection issues. Personally identifiable data were anonymized, and all data were held centrally in a password-protected computer at all times.

Most interviews were conducted in English by local researchers. In some cases, interviews were conducted in local languages (Bemba, Lozi or Nyanja) in accordance with the preference of participants. Each interview lasted 30–40 min. Focus group discussions were conducted with adolescents (8 sessions; $n = 53$), health care providers (3 sessions; $n = 24$) and parents and guardians (2 sessions; $n = 21$). Researchers who facilitated the discussions asked open-ended questions, used probes to guide the discussions and took brief notes. Each focus group discussion lasted about 50–60 min. Interviews and focus group discussions were audio-recorded and subsequently were

transcribed, and then transcripts in languages other than English were translated into English.

2.5. Data analysis

Transcripts were entered into QSR International's NVivo 7 so that emerging themes associated with different levels of factors affecting the experiences of adolescents living with HIV could be identified. An initial list of thematic codes was generated from a subset of the transcripts based on the study's overall objectives and conceptual framework. These codes were refined through inductive analysis (Silverman, 2001), and results were organized according to key themes that emerged from the data. Following the sorting and counting of themes, narrative thematic analysis was used to describe the factors that determined the experiences of adolescents living with HIV using a social-ecological framework.

3. Theoretical framework

This study used a social-ecological framework that has been employed by other scholars to understand individual, community and structural determinants of health (Mugavero, Norton, & Saag, 2011; Stokols, 1996). This framework recognizes that health experiences and outcomes are often influenced by factors situated within and beyond the individual (Feldacker et al., 2011; Stokols, 1996). Implicit in this model is the concept of a dynamic interaction between these various factors whose equilibrium ultimately defines the overall health experience – in this case that of living with HIV.

4. Results

4.1. Factors that influence the experience of adolescents living with HIV

The analysis identified a range of interrelated factors at the individual, family/peer, community and structural levels that determined the experiences of adolescents living with HIV (Fig. 1). While the opinions and emerging themes did not differ much between age groups or between same-sex groups, older adolescents elaborated more on their answers and tended to offer a more forward-thinking perspective, for instance in relation to plans to have children. In general, adolescents appeared to open up more in front of those of a similar age and gender during focus group discussions.

4.2. Individual-level factors

The most salient theme to emerge from the study in relation to individual-level factors that might influence adolescents' experience of living with HIV was their resilience, sometimes tempered by internalized stigma. Adolescents often reported that after learning of their HIV

Table 2
Study participants.

Interviews	Adolescents (n = 58)	Health care providers (n = 14)
Age range	10–19 years	32–47 years
Mean age	16 years	36 years
Rural	21%	36%
Urban	79%	64%
Male	50%	35%
Female	50%	65%
In sexual relationship	50%	-
Focus group discussions		
<i>Adolescents</i>		
Female sessions	4 sessions; n = 18	
Mixed sessions	4 sessions; n = 35 (female = 48.6% in mixed sessions)	
Total	8 sessions; n = 53	
<i>Health care providers</i>		
Urban	2 sessions; n = 16	
Rural	1 session; n = 8	
Total	3 sessions; n = 24	
<i>Parents and guardians</i>		
Urban	1 session; n = 8	
Rural	1 session; n = 13	
Total	2 sessions; n = 21	

status, they had undergone a transformation in which they became progressively more capable of withstanding difficulties associated with having the disease. Adolescents, especially older ones, described their individual efficacy and ability to maintain positively adaptive behavior in the face of being diagnosed with a life-long condition. One study participant attributed this to his own desire to “enjoy life like any other person” (interview, 16-year-old male, Kalomo). Adolescents valued their own personal relationships and strived to sustain them:

Being HIV-positive has not had an effect on my relationships. I try to do the things I used to do before I knew.... I am very positive about everything in my life; I try not to be sad.

[Interview, 15-year-old female, Lusaka]

Often, adolescents' ability to respond flexibly to their HIV status was linked to their own personal aspirations. For instance, one study participant aspired “to be a manager so that [he could] bring [his] family together” (interview, 17-year-old male, Lusaka). Older adolescents referred to and looked forward to social-role transitions from adolescence into adulthood. They also thought positively about marriage and childbearing, with 28 out of 58 interviewed (48%) adolescents planning to have children in the future:

One day I would also like to get married and have children. I would like to have two children.

[Interview, 16-year-old female, Lusaka]

Adolescents were motivated and had a sense of purpose. Some adolescents described carrying out an expanded range of duties, such as caring for their own children or younger siblings who were or were not living with HIV, with resilience, a deep sense of responsibility, hope for the future and optimism that eclipsed any sense of living with a chronic disease.

However, there were instances in which adolescents had internalized HIV stigma, and were “shy and ashamed” (interview, 16-year-old female, Kitwe). This was often associated with notions of self-pity and low self-esteem:

I was low, I wasn't talking to people, and I didn't want people to know about my status.

[Interview, 17-year-old female, Kitwe]

Although some adolescents reported that internalized HIV stigma had affected their ability to engage socially, many of these adolescents said that they were able to accept their situation eventually, regain their self-esteem, and interact with their families and peers, which in turn strengthened their self-efficacy and resilience.

4.3. Family and peer-level factors

Three major themes emerged relating to family and peer-level factors affecting adolescents living with HIV: adherence, disclosure and social support.

4.3.1. Adherence

The importance of family members was prominent as a regular source of adherence support to adolescents, often through verbal reminders to take medicine and encouragement when experiencing side effects. Adolescents, especially younger ones, cited numerous cases in which their initial difficulties with and anxieties about initiating antiretroviral therapy were mitigated by encouragement from their close relatives:

My mother and father support me so that I can adhere to my treatment. They support me all the time and I feel that that the support that they give me is enough.

[Interview, 14-year-old female, Lusaka]

My grandmother always makes sure that I take my medicine. She always supports me.

[Interview, 11-year-old female, Lusaka]

Family members frequently accompanied adolescents to clinics and helped them to adjust to new routines of taking medications.

4.3.2. Disclosure to adolescents of their positive HIV status

Study data suggested that the circumstances relating to how parents and guardians informed adolescents of their positive HIV status had important consequences. In particular, poor or delayed disclosure often created tensions and emotional difficulties for adolescents:

I used to come to the hospital to [collect] medicine without knowing the reason why, until I finally confronted my father and he told me the truth in 2008. My mother did not want to tell me. Every time I asked her what was wrong with me she would not tell me. When I found out about my status I was shocked and I felt very sad.

[Interview, 14-year-old female, Lusaka]

Sometimes disclosure was made difficult by cultural traditions and taboos:

Most of our adolescents don't have access to information because of tradition – us parents don't like discussing such issues because sexuality is something sensitive ... so my view is that we [need to] change the perspective of dealing with this as a taboo.

[Focus group discussion, parents, Lusaka]

4.3.3. Disclosure of adolescents' HIV status to others

While some participants reported having disclosed their HIV status to their boyfriend or girlfriend, others had not disclosed because they feared abandonment or other negative consequences:

I have a boyfriend at the moment but it is not a sexual relationship. He does not know about my status. I am scared of telling him because he might leave me.

[Interview, 19-year-old female, Lusaka]

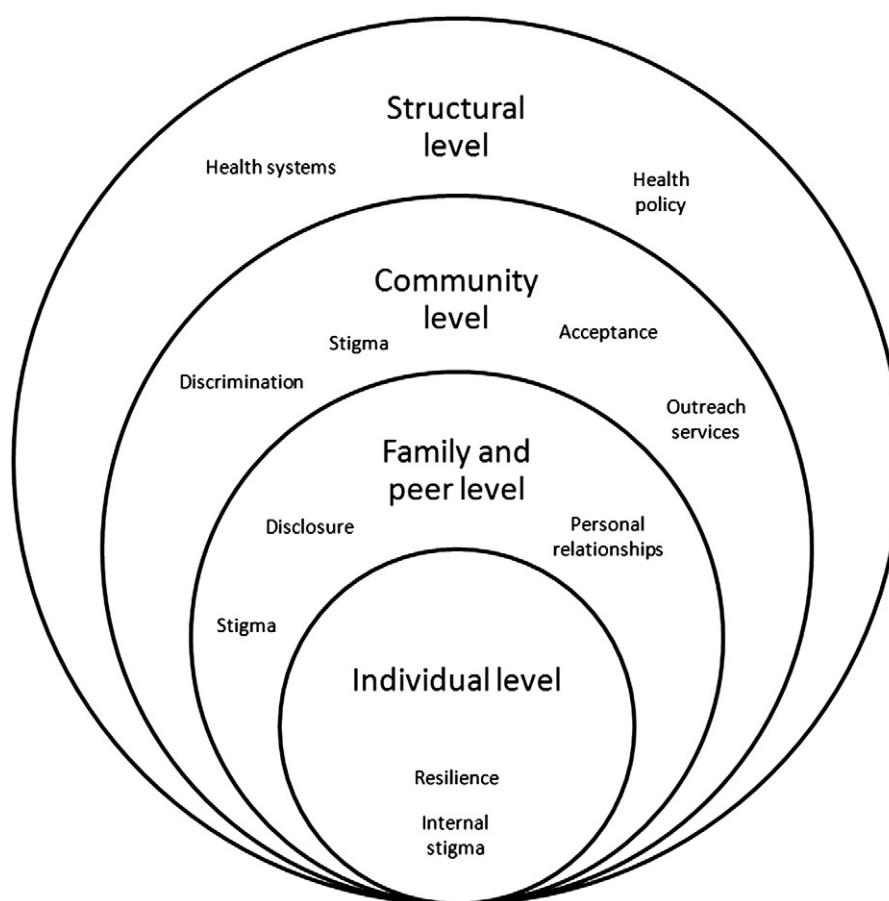


Fig. 1. Factors influencing the experience of adolescents living with HIV identified in this study, illustrated using a social–ecological framework.

A few adolescents expressed disappointment when either confidentiality was breached by third-party disclosure. For example, one adolescent narrated an incident in which her status was disclosed by her auntie to other people outside her family without her knowledge:

This was very painful for me because I thought that it was my right to disclose to people about my status. I felt that my rights were violated. I actually cried.

[Focus group discussion, 16-year-old female, Lusaka]

Adolescents, regardless of their age or gender, grappled with their apparently limited control over when and how to disclose their HIV status, as well as whom to disclose to, and resented the high level of control over disclosure of their status exerted by parents, guardians and older relatives.

4.3.4. Social support – families and peers

Families were perhaps the most important social structure that made adolescents feel accepted and valued:

My outlook on life is usually optimistic. I usually wake up looking forward to a new day but there are days when I feel sad. When I feel sad I talk to my niece and that makes me feel happy again.

[Interview, 14-year-old female, Lusaka]

Yet there were instances where adolescents, especially older ones, felt that their families had become over-protective of them since their HIV diagnosis:

I'm like an egg now and I'm wondering when I became one... When I was told I was HIV-positive, we went home and everyone was informed, but [since] then I'm being treated like an egg.

[Interview, 18-year-old male, Lusaka]

Along with family members, peers who were also living with HIV featured prominently as a source of psychosocial support and friendship. Adolescents reported that through such peer connections, they could share coping strategies, make each other feel valued and offer each other a sense of identity:

Here at the center I get to meet people who are my age ... I am able to talk to my friends [who are also HIV positive] because they are going through the same things that I am going through.

[Interview, 15-year-old female, Lusaka]

This representation of HIV-positive peer groups as a form of citizenship was often constructed in the context of peer support programs and youth clubs run by community-based organizations or structured around HIV clinics. Asked about the meetings at the youth clubs, one study participant responded:

They make us feel like we are normal children and are not sick. I enjoy these meetings very much and would like to have more of these meetings.

[Interview, 14-year-old female, Lusaka]

Thus many participants seemed to derive hope and support from spending time with other adolescents living with HIV, learning from one another and finding a community where living with HIV was no longer stigmatizing.

4.4. Community-level factors

The main community-level factors that influenced adolescents' experiences were stigma and discrimination, as well as the availability of community-based services for HIV education, nutritional support and other material support.

4.4.1. Stigma and discrimination

Adolescents identified the stigma and discrimination they encountered in many community settings as a significant factor affecting their quality of life. They described both actual experiences of discrimination based on their HIV status, as well as how their fears of potential discrimination affected their decisions regarding disclosure of their status:

You have to face challenges here and there, like stigma and discrimination. To my surprise it's not [always from] someone outside the family.

[Interview, 16-year-old female, Kitwe]

There is no one I trust. If I tell them [about having HIV], they may start discriminating [against] me because there are still some people that have a misconception and don't have the right information about HIV.

[Interview, 18-year-old male, Lusaka]

In particular, discrimination at school greatly affected the experiences of adolescents. Instances were reported of teachers hinting at the presence of students living with HIV in a manner that was interpreted as a warning not to associate with them:

Sometimes some teachers would start saying all sorts of things like, 'You should be aware, you have friends who are HIV-positive in this class, you should just be aware', so sometimes it hurts me to listen to what they are saying ... hearing them say bad things.

[Interview, 16-year-old female, Kitwe]

Discrimination at school was also a frequent cause of absenteeism:

I thought everyone who looked at me knows my status. For this reason I stopped going to school for about three months. When I went back to school my friends would ask me where I had been and I would tell them that I had pneumonia. I could not tell them the truth.

[Interview, 19-year-old female, Lusaka]

4.4.2. Community-based services

Care and support provided through non-governmental and church centers also influenced the experiences of adolescents. Services included nutritional, psychosocial and adherence support delivered through home visits, as well as through general outreach activities designed to increase the reach of youth-friendly services in the community:

Sometimes they give us food here [at Twafwane], when they also receive [it] and we feel good because they help us. When you are taking these [antiretroviral] drugs, you need to have food [and] eat so that you have strength.

[Interview, 19-year-old female, Kitwe]

However, some community services such as nutritional support were not always available:

[For a] long time they used to give us some food like soya beans.... Now they don't.

[Interview, 19-year-old female, Kitwe]

Youth-friendly services, youth clubs, youth centers and youth corners in HIV clinics provided an environment where adolescents could

speak privately with peers, community members and health care providers, and with the help of those allies begin to develop a better understanding their own needs and challenges. The variety, complementarity, organization and reach of community-based and outreach services seemed to be transformative, providing a conducive setting where small but incremental changes in attitudes about HIV were starting to take place:

Here at the center we have workshops and they teach us a lot of things such as the 'adventure of life'. They teach us that life does not end just because you are HIV-positive. There are still a lot of things that we can do and achieve in life. I enjoy such things because they encourage us.

[Interview, 15-year-old female, Lusaka]

At the hospital we have a peer support group.... They also give us information on HIV/AIDS. They also tell us that it is possible to have children even though we are [HIV-] positive.

[Interview, 14-year-old female, Lusaka]

Similarly, schools were an important source of information on safer sex:

I get my information on prevention of pregnancy and safe sex from school. The teachers teach us about it and give us books to read.

[Interview, 15-year-old female, Kitwe]

Some participants suggested that such information should be more broadly disseminated:

The number of people that will be teaching us should be a lot and not only in school but in the community; they should increase those people to come and sensitize us, because most of the people really don't know.

[Interview, 16-year-old female, Kitwe]

In some communities, services were available in other settings, including churches:

We have got this class where our parish priest would invite all those people working in clinics to come and help us out, [and] to give us all the information we need about sexually transmitted infections and other diseases.

[Interview, 16-year-old female, Kitwe]

Experiences of discrimination negatively affected adolescents, whereas community outreach services were viewed positively in terms of providing safe spaces, tackling stigma and discrimination, and providing material support when possible.

4.5. Structural-level factors

At the structural and policy level, two major sets of factors shaped adolescents' experiences: health system-related factors and health policies.

4.5.1. Health system-related factors

Besides the issue of stigma, which was reported to be common even within HIV clinics, adolescents described the impact on their personal lives of frequent visits to the clinics. Poor access to health facilities was a constant source of frustration:

When going to the clinic my auntie puts me on her back then we walk to the clinic ... because I cannot manage to walk all the way to the clinic because it is very far.

[Interview, 10-year-old female, Lusaka]

Attending HIV clinics for routine clinical review or to collect antiretroviral drugs often interrupted adolescents' daily routines. Participants

indicated a need for clinics to be more flexible, for example, by extending their opening hours:

Sometimes you find you don't want to miss school but you have to because the doctor needs to see you. If only they could say we [could] go on Saturday or Sunday.

[Interview, 12-year-old male, Kitwe]

Key informants working in clinics acknowledged the need for and challenges of providing adolescent-friendly services:

We used to have a youth-friendly corner, but due to lack of funding it has died a natural death. There needs to be a full-time person trained specifically to deal with adolescents. But there isn't.

[Focus group discussion, health care provider, Kalomo]

Sometimes we have a lot of pressure, especially with adult clients, so you find that you lose your temper. Adolescents become victims of that due to the fact we attend to them at the same time.

[Focus group discussion, health care provider, Kalomo]

Adolescents also noted the negative impact of these human resource constraints on their ability to interact with health care providers:

People [health care providers] come and do things so fast because they want to go back fast — they talk fast, write drugs, and then say, 'Next'.

[Interview, 16-year-old male, Kalomo]

The requirement for health facilities to respond better to adolescents' needs was nearly universally acknowledged.

4.5.2. Health policies

With regard to the policy environment shaping the delivery of HIV-related services for adolescents, study participants highlighted various impediments to the quality of services. The slow implementation and decentralization of adolescent-friendly services were acknowledged as areas that require further attention:

Another recommendation would be about policy. At the moment, adolescents are being sidelined. Adults are able to talk for themselves and children are also represented but no one represents the adolescents.

[Focus group discussion, health care provider, Lusaka]

These services should be made national. As it is, we have had instances where adolescents come from other provinces to University Teaching Hospital for treatment. But when they go back their [local] facilities, [similar] services are not available in their provinces or where they live so they are lost [to follow-up].

[Focus group discussion, health care provider, Lusaka]

Attention was also drawn to the need to better incorporate the HIV response into other health services to lessen the persisting sense of HIV being exceptional:

We need national policy and guidelines that support these institutions to begin normalizing [the HIV response].

[Interview, health care provider, Network of Zambian People Living with HIV, Lusaka]

5. Discussion

There is a growing imperative to understand the experiences and contextual circumstances of adolescents living with HIV and to respond to factors that impede their uptake of services and general well-being (Hodgson et al., 2012). Some of these factors may relate directly to the

adolescents themselves, while others may be embedded within the environment in which they live (Menon, Glazebrook, Campaign, & Ngoma, 2007; Siziya, Muula, Kazembe, & Rudatsikira, 2008). Results from this study indicate that experiences of adolescents living with HIV are shaped by a variety of factors across individual, family and peer, community, and structural domains. Results identify both positive and negative factors at each of these levels.

First, our results suggest that a positive self-concept and a strong locus of control, which link with Blum's (1998) components of resilience, are important factors that shape the perception of an HIV diagnosis at the individual level. Resilience refers to 'the process of overcoming the negative effects of risk exposure, coping successfully with traumatic experiences, and avoiding the negative trajectories associated with risks' (Fergus & Zimmerman, 2005). This individual attribute enabled adolescents to come to terms with an HIV diagnosis, maintain a positive outlook and sustain external relationships. Positive self-concept, communicative ability and self-efficacy have been shown to promote the health of adolescents living with HIV in other settings, for instance rural Tanzania (Carlson, Brennan, & Earls, 2012). However, individual resilience and positive self-concept are also influenced by social learning and context and family and social networks (Blum, 1998). Skovdal and Daniel (2012) call for recognition and understanding of children's interaction with their social environment as a way of conceptualizing resilience among children affected by HIV in sub-Saharan Africa. In this paper we have shown how adolescents' resilience is an outcome of their interaction with aggregative external rings of support, which in this context were provided by families, peers and community organizations.

Second, family and peers were noted to influence adherence by creating an environment that enabled adolescents to adjust to new drug-taking routines and cope with side effects. This is consistent with other studies showing that support from trusted adults (including and in addition to parents and guardians) as well as peers has a positive impact on adolescents' adherence to treatment and uptake of other services (Hodgson et al., 2012; Menon et al., 2007) as well as on coping strategies (Midtbø, Shirima, Skovdal, & Daniel, 2012). In our study, family members often controlled disclosure of HIV status to adolescents themselves as well as to others, often with negative consequences. Similar consequences resulting from parental control over disclosure of adolescents' HIV status have been documented in Uganda (Siu, Bakeera-Kitaka, Kennedy, Dhabangi, & Kambugu, 2012). These findings suggest that approaches which promote appropriate disclosure, as well those that empower adolescents to choose if, when and how to disclose, and who to disclose to, could help to mitigate negative outcomes of poor disclosure, such as financial and emotional neglect, stigma, discrimination and rejection (Menon et al., 2007; Mburu et al., 2014; Siu et al., 2012). Better recognition of adolescents' evolving capacity and self-efficacy could be a first step towards allowing them to have some autonomy over disclosure to others (Mburu et al., 2013; Mburu et al., 2014).

Third, similar to studies conducted among adolescents in general (Viner et al., 2012; Waters, Cross, & Runions, 2009), this study found that the school environment was important in defining the experiences of adolescents living with HIV. In particular, our findings support calls to strengthen approaches that normalize HIV and tackle discrimination in schools. Our results also underscore the concept of connectedness, including attachments, friendships and networks at school, as an important determinant of adolescents' experiences (Waters et al., 2009). Yet our study shows that school attendance was threatened by HIV-related discrimination and by frequent weekday appointments to attend clinics. This is particularly relevant given that education and school attendance are recognized as protective factors that promote safer sexual behavior (Magnani et al., 2002).

Fourth, in relation to the community level, our study reinforces existing evidence demonstrating that community-based interventions can contribute to enhancing positive experiences while meeting the needs of adolescents with HIV. Evidence of community participation

in providing care for adolescents from our study setting suggests that community-based services can form 'transformative social spaces' (Campbell & Cornish, 2010), changing negative community perceptions, increasing the competence of adults in relation to adolescent issues, and creating a positive environment overall for the promotion of adolescents' health (Carlson et al., 2012). In our study, youth-friendly centers created an environment where adolescents could speak privately with their peers who were facing similar circumstances. Other studies from Zambia show that peer and other social support is important in helping adolescents to take up services and remain positively engaged in care (Menon et al., 2007), and that peer education targeting adolescents by both governmental and non-governmental organizations can improve their HIV literacy and knowledge (Denison et al., 2012).

Finally, our study suggests that structural factors are equally important in determining the experience of HIV among adolescents. The structural level of analysis, which is actionable within and beyond conventional programming, requires additional action at a health policy level (Baryamutuma & Baingana, 2011; Binagwaho et al., 2012; Gruskin & Tarantola, 2008). In the setting of our study, health system factors, such as insufficient staff specifically trained on adolescent health, and inadequate provision of consultation rooms at HIV clinics, have been reported as preventing adolescents from accessing appropriate services (Hodgson et al., 2012; Mburu et al., 2013). In addition, although relevant health policies in Zambia address HIV prevention among young people, these do not highlight the needs of adolescents already living with HIV (Kalibala & Mulenga, 2011; Mburu et al., 2013). This gap could become more apparent as more adolescents get tested for HIV in line with current recommendations (WHO, 2013).

Besides access to health services, structural determinants can also affect health-related behaviors as well as vulnerabilities of adolescents living with HIV (Rudy, Murphy, Harris, Muenz, & Ellen, 2009). Noting the need for appropriate structural interventions, Sawyer et al. (2012) highlight the detrimental impact on adolescent health of structural barriers to their autonomy and access to sexual education and contraceptives. Our study included adolescents who had children of their own, suggesting that an exploration of how gender and gender responsibilities may have modified their experiences of HIV could form the basis for appropriate gender-sensitive interventions. In light of the diversity of adolescents' situations, considerations related to age, gender, domicile and other contextual circumstances should become a cornerstone of adolescent programming.

In summary, our findings show that experiences of adolescents living with HIV in Zambia are shaped by a variety of factors across individual, family and peer, community and structural domains, all of which practitioners should consider when designing interventions for this population. Since adolescents are often disadvantaged by structures, policies, health services and their social environment, 'surrounding young people with protective factors' (Bearinger et al., 2007) should be the objective of every HIV program. To promote the quality of life of adolescents living with HIV, attention is required to all of these domains. In light of the explicit and implicit tensions and conflicts contained within these domains, our study suggests that the experiences of adolescents form an area of multilateral negotiation between the adolescents themselves and their families, peers, communities and environment. This interplay defines adolescents' roles in response to one another and also imposes a set of references whose equilibrium ultimately defines adolescents' distinct individual experiences of living with HIV.

These findings lead us to make a number of recommendations. These include the need to increase support to parents and guardians to help them navigate issues around disclosure; expand adolescent-centered HIV services with sufficient appropriately trained staff and flexible clinic hours; and strengthen adolescents' access to peer support groups.

In interpreting these findings, a number of limitations should be noted. First, findings from this study, which were generated through a

convenience sample, may not be generalizable to a wider population of adolescents in Zambia and beyond. Second, these findings reflect the perspectives of adolescents who were accessing HIV-related services, and this group's experiences could differ from those of adolescents not accessing such services. Despite these limitations, our study provides new insights into the experiences of adolescents living with HIV in Zambia.

6. Conclusions

Adolescents' experiences of living with HIV are determined by factors located *within and beyond* adolescents themselves, including factors at the family and peer level, community level and structural level. Creating supportive environments for adolescents to initiate and remain in HIV care requires approaches that accentuate positive experiences while mitigating negative ones. However, such approaches are inherently complex, since they can have diverse outcomes in different settings, especially given that adolescents are a heterogeneous group, varying according to age, social environment, gender vulnerabilities, and religious and economic background (Braeken, Otoo-Oyortey, & Serour, 2007). These contextual factors should inform adolescent-centered services and interventions at multiple levels of the social-ecological framework. Understanding these contextual factors is an indispensable strategy for strengthening services tailored to the needs and circumstances of adolescents living with HIV, as well as a mechanism for facilitating the fulfillment of adolescents' health-related rights in Zambia.

Authors' contributions

GM conceptualized the study and drafted the manuscript. MR and GM performed data analysis and participated in the interpretation of the findings. DO contributed to the literature review and the writing of the manuscript. CH coordinated the primary data collection and reviewed drafts. KI and LF participated in the critical review of the manuscript. All authors read and approved the final manuscript.

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