Rethinking the Family in the Context of Care for Adolescents living with HIV in Swaziland

Shabalala, F.; De Lannoy, A.; Moyer, E.; Reis, R.

DOI
10.1080/09540121.2016.1195482

Publication date
2016

Document Version
Final published version

Published in
AIDS Care

License
CC BY

Citation for published version (APA):
Rethinking the family in the context of care for adolescents living with HIV in Swaziland

Fortunate Shabalala, Ariane De Lannoy, Eileen Moyer & Ria Reis

To cite this article: Fortunate Shabalala, Ariane De Lannoy, Eileen Moyer & Ria Reis (2016) Rethinking the family in the context of care for adolescents living with HIV in Swaziland, AIDS Care, 28:sup4, 8-17, DOI: 10.1080/09540121.2016.1195482

To link to this article: https://doi.org/10.1080/09540121.2016.1195482
Rethinking the family in the context of care for adolescents living with HIV in Swaziland

Fortunate Shabalala\(^a\)\(^b\), Ariane De Lannoy\(^c\), Eileen Moyer\(^a\) and Ria Reis\(^a\)\(^d\)\(^e\)

\(^a\)Amsterdam Institute for Social Science Research, University of Amsterdam, Amsterdam, The Netherlands; \(^b\)Faculty of Health Sciences, Department of Community Health Nursing Sciences, University of Swaziland, Mbabane, Swaziland; \(^d\)Poverty and Inequality Initiative, Southern Africa Labour and Development Research Unit, University of Cape Town, Cape Town, South Africa; \(^e\)Department of Public Health and Primary Care, Leiden University Medical Centre, Leiden, The Netherlands; \(^c\)The Children’s Institute, University of Cape Town, Cape Town, South Africa

ABSTRACT
Drawing from 18 months of ethnographic fieldwork in one urban and one rural setting in Swaziland, involving 13 case studies of adolescents living with HIV, in this article we explore the meaning of the family as it applies to Swazi adolescents’ everyday life. Our findings suggest that the meaning of the family is constantly evolving and transforming based on changing needs of, and expectations by, adolescents in different contexts and moments of the care continuum. Central to the meaning of the family is a strong desire for belonging — that is, being accepted, welcomed and appreciated. Traditional institutions that used to regulate where children belong still shape adolescents’ perceptions, hopes and desires, but may also prevent their realisation. Support groups are important but do not substitute for the familial belongings adolescents living with HIV have lost, and long for. Policymakers, programme managers and health providers working with adolescents living with HIV need to embrace the complexity and dynamism of the meaning of family and base their policies, programmes, standards and guidelines not only on the factual care arrangements that adolescents find themselves in, nor on legal definitions of rights and responsibilities, but also on what adolescents want.

KI: We are all affected; no one can say he or she has not been affected. Everyone has a brother, a sister, a child, a parent, a friend, a relative, a work colleague, a neighbour … we have all experienced HIV… at home at school, in church, in the community…
FS: When you say “we”, who are you referring to, who is “we”?
KI: I am referring to you and me, us, every Swazi…
Our roots are traced back to the same forefathers… we belong together… we are all sick with HIV directly or indirectly… We are family and we must care for one another. (Key informant interview, August 2012)

The extract above is from a conversation with the headman of the rural site in Swaziland where the first author carried out fieldwork. The topic was the staggering number of vulnerable children in the area. According to official data, this rural site had 4000 households – defined by the Swaziland Central Statistics Office as a person or group of people residing together and eating from the same pot – representing approximately 2% of the households in the country (Central Statistics Office [CSO] & United Nations Population Fund [UNFPA], 2010). Of the 4000 households, 240 (6%) were headed by children, and 440 (11%) were skipped generation households where grandparents assume the role of primary caretakers for their orphaned grandchildren (Ortner, 2015; Reijer, 2013, p. 17) – some living with HIV. At the time of the study in 2012, there were 120,000 orphans in the country and 78,000 of these were due to losing parents to AIDS (United Nations International Children’s Emergency Fund [UNICEF], 2013).

The fieldwork formed part of the doctoral research of the first author on adolescent experiences of HIV/AIDS in different family contexts in Swaziland, a small landlocked country in southern Africa lying between South Africa and Mozambique. The country has a total surface of 17,364 square kilometres and a population of 1.2 million in 2014 (World Population Review, 2016). Approximately 25% of the country’s population are adolescents aged 10–19 years (CSO and UNFPA). For administrative purposes, Swaziland is divided into four regions namely Hhohho in the northern part of the country, Lubombo in the east, Manzini in the central region and Shiselweni in the south. The Hhohho and Manzini regions are well developed compared to Lubombo and Shiselweni regions.
Manzini region is the industrial and economic hub; hence people tend to migrate from the other regions in search of work in the industries there. This mobility, it is argued, has indirectly contributed to high HIV incidence in Manzini specifically and the country generally (Crush, Raimundo, Simelane, Cau, & Dorey, 2010).

Swaziland has the highest HIV prevalence in the world. According to the first and only demographic survey conducted, in 2006–2007 (CSO & Macro International, 2008), the population prevalence was 19%; that is, one in five people aged two years and more was infected; the adult prevalence (15–49 years) was 26%, and for those considered to be in the sexually and economically active population age group (18–49 years) it was 31% (CSO & Macro International, 2008). This was still the case in 2013 (Bicego et al., 2013). Although data on adolescents are limited due to age-band reporting (0–14 and 15–49), estimates indicate that in 2014 almost 12,000 Swazi adolescents were living with HIV Joint United Nations Programme on HIV and AIDS (2015). Furthermore, of the 13,000 people who were newly infected in 2013, 42% were adolescents aged 18–19 years, and this percentage increased to almost 60% when those up to 24 years were counted (Bicego et al., 2013; Ministry of Health [MoH], 2014). The National HTC annual report 2012 further noted that very few adolescents present for testing in the health facilities, despite the successful scale up of HIV testing and counselling (HTC) through decentralisation of services to primary health care facilities and outreach clinics (MoH, 2013). Although there is little insight into the local social processes underlying these alarming data, participants in the study we report here mentioned fear as a core reason for low or late uptake testing by adolescents. This included fear of a possible HIV-positive diagnosis and their parents’ and friends’ reactions to it, of gossip, being bullied and stigma, of having to take antiretrovirals (ARVs) for life, fear of death and fear about the future. Participants also mentioned parental resistance in testing their children because an HIV-positive diagnosis might indicate that they (parents) were also infected. The requirement for parental consent prior to testing, unfriendly and judgemental attitudes of health service providers, lack of privacy and inconvenient operational hours in health facilities, as well as the perception that the clinic or health facility is a space for sick people, were also mentioned by adolescents as reasons for not seeking HIV testing services.

The research on which we draw here focused on adolescents’ motivations for testing and their response to an HIV-positive diagnosis. We also investigated how they navigated their social environment and the health services in their daily life with HIV, particularly in relation to stigma, disclosure and adherence. Here, we consider the data related to kinship, and the meanings of the family in Swazi adolescents’ daily lives.

Over the course of the fieldwork, the phrase “we are family” often came up. How it was used was surprisingly fluid, referring to very different social levels and groupings, including the nuclear family, the Swazi Nation and HIV support groups. The national HIV policy and guidelines identify families as integral partners in the HIV response. When adolescents present to a health facility for an HIV service, they are asked to bring their parents or guardians for the purpose of consent and ongoing psychological and social-economic support. The Swaziland National Multisectoral Strategic Framework (NSF) 2009–2014 alludes to the need to promote family members as carers for people living with HIV (PLHIV) at home (National Emergency Response Council on HIV and AIDS, 2009, p. 58). The extended-NSF (eNSF) 2014–2018 espouses the need for strategies to strengthen families, including to contribute to the home-based care of orphaned and vulnerable children and PLHIV (National Emergency Response Council on HIV and AIDS, 2014, pp. 40–42). The National HIV Prevention Policy (MoH, 2012) also called for the empowerment of families so that they can serve as an information resource for adolescents, and contribute to HIV prevention in this population group. How the family is represented in HIV policies and guidelines follows conventional descriptions of its structure. Usually different forms of households are listed, such as female-headed, child-headed or elderly-headed households. But this is remote from the meanings emerging from conversations with adolescents, raising questions about how a family is constituted in the context of HIV care.

In this article, we explore the meanings of the family as referred to by Swazi adolescents, and how these meanings are embedded in the context in which they find themselves at specific moments in time and space. While acknowledging the importance of the family as a primary unit of care for adolescents living with HIV, ensuring not only material and physical support but also psychological care (Reis, 2009), we will argue against a universalised and protocolised notion of the family, and argue for a HIV service that is sensitive not only to the different socio-familial contexts of adolescents, but also to adolescents’ own perspectives and meanings. By illustrating the dynamics that shape the meanings of the family in everyday life, we argue for a re-thinking and re-interpretation of the family in relation to HIV care of adolescents.

**Methodological approach**

The study was carried out in two purposively selected areas (one rural and one urban) in the Manzini Region,
the economic hub of Swaziland. The region was chosen because it is the most densely populated of the four (31%), and has the highest proportion of adolescent population, highest proportion of PLHIV and a high number of health facilities providing HIV services compared to other administrative regions of the country.

Data were collected from July 2012 to December 2013 using key informant interviews, focus group discussions, repeat in-depth interviews and participant observation. All interviews and focus group discussions were conducted in the local language siSwati by the first author, were audio recorded, transcribed verbatim and translated into English by a bilingual transcriber. The transcribed scripts were checked for consistency with audiotapes by the first author. Analysis was inductive and thematic. Emerging themes were analysed through constant comparison both during and after fieldwork, and were further explored until data saturation was reached. Ethical clearance was granted by the Swaziland national health research review board, and approved by community leadership.

Interviews with adolescents form the core of the data. One hundred and five adolescents living with HIV and on antiretroviral therapy (ART) participated in the study, of which 61 participated in single-sex, age-categorised focus group discussions, and 44 took part in in-depth interviews. Adolescents were recruited through their facility health care workers or support groups. The recruitment from health facilities was conducted in two stages: the first author approached health facilities for assistance with identification and recruitment of potential participants. Health care staff were asked to approach potential participants when they came for their monthly refill of ARVs, informed them about the study, and gave them an information sheet and consent forms to present to their parents or guardians. This was followed up a week later with a phone call to further explain the study, clarify questions and to gain parental consent. If agreeable, staff would refer participants to the first author, who would explain the study again. If they agreed to participate, the adolescents then signed an assent form.

Of the individually interviewed adolescents, 16 were recruited for multiple interviews, but 3 were only interviewed once because 1 died and the other 2 relocated from the study area. This article draws largely from the 13 in-depth case studies of adolescents (aged 12–19). Multiple in-depth interviews (from three to nine) were held with each of the adolescents over a period of 18 months.

**Characteristics of participants**

Of the 13 adolescents, there were 8 males and 5 females, aged from 12 to 19 years (median 13.6 years). Eleven of the adolescents had been infected perinatally, and most of their childhood was characterised by poor health due to recurrent sicknesses. One was infected through unprotected sexual intercourse; the other was not sure how he got HIV but thought it was through assisting an injured friend. All of the adolescents knew that they were living with HIV, and all were on ART. Their HIV status had also been disclosed to selected members of the family or school. Six adolescents were born of unwed parents; three were double orphans and seven were single orphans. All but four were living with either a parent or a relative who was also HIV-positive and on ART. Five of the adolescents were living in skipped generation families, two in a stepfamily setting, another two with single parents (mothers) and three were living with extended family members. Only one was living with both parents.

**Conceptualising the family in Swaziland**

The family has been a subject of study for social scientists for a long time, but there is no consensus on its definition, as it varies in structure and functions across different cultures and at different times within the same culture (e.g. Georgas, 2003; Gough, 1971; Levin, 1999; Murdock, 1949; Tilly & Cohen, 1982). Georgas (2003) proposes that conceptualisations of the family embrace the multi-layered and complex web of determinants and practices that historically and culturally shape these structures and functions. Here we follow Levin (1999, p. 96), who maintained that “the everyday use of ‘family’ relates to a social group that [could be] biologically, legally [or] emotionally connected … [and whose] meaning can be derived from the context in which it is used and the tone of voice of the user”. This broad definition responds to the need for a non-normative conceptualisation of the family as an analytical tool to explore the relationship that embed the adolescents’ portrayal of the family in relation to their everyday experiences of and with HIV.

In historical studies, “the” African family is typically described as a kin group of three or four generations occupying several houses in a shared bounded space (the homestead), and sharing in the social and economic functions of the group. This kin group would actively take part in the nurturance and socialisation of children who would grow up under the watchful eye of grandparents, uncles and aunts, fathers and mothers, and elder sisters and brothers (Nyambedha, 2004); and it would provide strong social and economic security – particularly in times of great need such as during illness or death – as well as a sense of safety and belonging (Foster, 2000; Foster, Makufa, Drew, Kambeu, & Saurombe,
In Swaziland such extended families were built along the patrilineal kinship structure, with members of three or four generations of a patrilineage staying together in the same homestead (Khumalo, 2006; Van Schalkwyk, 2006). Children assumed their father’s surname at birth, but for a child born out of wedlock the father’s family had to pay inhlawulo (damages) and timvimba (an additional fine) in the form of cattle to the child’s maternal family as acknowledgement of having impregnated the girl before marriage. Should the two decide to marry, these cattle would be counted as part of lobola (bride price). The child belonged to the maternal patrilineage until either inhlawulo or lobola had been paid (cf. Russell, 1993a). Payment could be postponed, sometimes until the child matured; especially for girls the prospective benefit of receiving lobola at their marriage could balance the immediate cost of inhlawulo. Children were nurtured and socialised by their natal parents and other paternal and maternal kinfolk. Consequently, a child had many categorical fathers, mothers, aunts, uncles, brothers and sisters. Central to children’s socialisation was the emphasis on respect and obedience, particularly to elders. Individuals and communities were expected to support and care for each other according to well-defined hierarchal relationships (Verhoef, 2005). Children who lost their natal parents were cared for by the extended family and the community. According to Kuper (1950), there was no such thing as an orphan since every adult in the family, kin group and community was a parent to the child. This is the family to which the headman is referring in the epigraph.

However, this image of the extended family derives from earlier anthropological and historical studies, which typically neglected the voices of women and children, and partly reflects concerns with the loss of connectedness and the rise of individualisation that characterises modern life. Particularly in cities, where roughly a fifth of the population resides, the nuclear family has increasingly become the preferred living arrangement over the last half of the twentieth century (Ferraro, 1991; Russell, 1993a, 1993b).

Although urban families keep ties with their extended families in rural areas, these are not as cohesive as before (Chirwa, 2002, p. 107; Zamberia & Mabundza, 2014). Since colonial times, the legal system in Swaziland has been dualistic, resulting in two legal types of marriage: “Christian marriage” under Roman Dutch Law, and customary marriage under traditional law. But increasingly people chose to delay marriage or not to marry at all, to separate or divorce, and many children are raised by single parents in extended, often multigenerational households. The last national household census (CSO, 2008) established that 46% and 10% of households were headed, respectively, by adult women or girls, indicating that most children are growing up in female-headed households.

The HIV/AIDS crisis has exacerbated the pressure on traditional safety nets for children in Swaziland and weakened both the extended family structure and the nuclear family. Swaziland experienced high HIV mortality during the first decade of the millennium; free ART became available only in 2004. A key informant noted that between 2003 and 2005, he and his colleagues were burying on average three employees of his company a day, until management made HIV testing and disclosure mandatory for its personnel and established an ART clinic on site (KII, August, 2013). Those dying were mostly young husbands and fathers, breadwinners for their families. At the end of 2013, approximately 78,000 children had been orphaned by the epidemic (UNICEF, 2013). As elsewhere in Africa, there is little social security in Swaziland, and members of the extended family often took over caring for family members living with HIV/AIDS and orphans (cf. Abebe & Aase, 2007; Chirwa, 2002; Mathambo & Gibbs, 2009; Richter et al., 2009). Due to the high mortality rates, even relatively wealthy families saw their resources depleted, due to usually prolonged illness with AIDS (Chirwa, 2002; Kaleeba & Sunanda, 2004; Mathambo & Gibbs, 2009). Often children came to stay with grandparents who were already struggling to meet their basic needs. How do these dynamics materialise in the daily lives of adolescents? What does this mean for their experience of and perspective on the family? In the following section, we present five case studies representing common variations of family that exist for HIV-positive adolescents.

Pending belonging: Lindani

Lindani was at the clinic in August 2013, where he got his monthly medication refill. Both his parents had died from HIV-related illnesses when he was six years old. When he was diagnosed with HIV and TB four years later, he was put on medication. Aged 13, he could be mistaken for a 10 year old: short for his age, sickly and frail, with hearing problems as a complication from one of the TB medicines.

Lindani had lived with his parents in the compound of the company where his father had worked. When his father died, Lindani and his mother had to vacate the company house. His parents were not legally married, and his paternal family had not paid the required lobola for his mother or inhlawulo for him; therefore they had to relocate to his maternal home. His mother died eight
months later, leaving him to be cared for by her own mother. Lindani’s grandmother had had six children including Lindani’s mother: all died from AIDS.

The family’s homestead was a picture of abject poverty – two badly kept structures made of sticks, mud and thatched roofing. Rainfall would force the occupants (Lindani, his grandmother and an 18-year-old cousin, also on ART) to seek accommodation with neighbours. Apart from a small vegetable garden and five goats, their only source of income was the three-monthly government elderly social grant of E600¹ (US$60). This amount was barely enough for their basic needs, let alone paying for transport to the local hospital, or for an operation to restore Lindani’s hearing. However, Lindani also received support from his paternal family, and they paid for his school fees, uniform and other occasional needs. Once in a while they also visited one another.

In many conversations, Lindani voiced his concern over his living conditions. He felt that he would be better off at his paternal home, because some of his aunts and uncles were in salaried employment. But his wish to stay with his paternal relatives was also driven by emotions, as he felt that the home of his grandmother was “not his home”. “Life is not good here, I am not accepted”, he observed:

“They [grandmother and cousin] sometimes remind me that where I live is not my home. They often say I do not bring anything to the table as food when I come from my family [father’s family]. My grandmother here often asks why I do not want to live with them [grandmother and cousin] now that she has taken care of me following the death of my parents. She always says that my family never paid lobola for my mother so I cannot go to stay with my family. (Interview, October 2013)”

When interviewed separately, his grandmother reiterated that Lindani’s maternal home was not his “real home”, by which she meant his home by virtue of his patrilineage. Yet she defined his belonging in relation to his paternal home: because no inhlawulo or lobola were paid by the paternal family Lindani ngeSwati sakitsi walapha ekhaya (“in our Swazi culture Lindani belongs at this home”). This contradiction caused Lindani’s sense of impermanence in staying with his maternal grandmother.

In line with dominant norms requiring children to be non-confrontational and obedient towards their elders, and afraid of rebuke, Lindani had not told his grandmother his preference to live with his paternal kin: this allowed, in his own words, “peace to prevail” between him and his grandmother. But he had no doubt where he felt he belonged. He spoke of my family when referring to his paternal homestead and uncles and aunts, and of my grandmother’s home when referring to his maternal home where he lived.

In current-day Swaziland, traditional institutions regulating rights over children are eroding, if only because Christian marriage offers an alternative and noncompliance does not lead to sanctions. However, the cultural practices of lobola and inhlawulo are still central in determining where children belong and how they are cared for. In her study of care arrangements of children infected and affected by HIV and AIDS in Lesotho, Block (2014, p. 718) notes that although even for traditionally married couples the payment of a bride price was no longer common, its absence “was the cultural lynchpin on which maternal caregivers [often grandmothers] based their claims on children”. Lindani’s maternal grandmother did not so much use the lack of payment to claim her grandchild for her own lineage, as to use the ambivalence where the boy belonged as a lever to claim the outstanding payment. This left the boy a pawn in financial feuds between families, his belonging pending on conditions he himself had no say in or power over. This affected his emotional health while simultaneously reinforcing his wish to relocate to his father’s family.

**Wandering home: Mpendulo**

HIV/AIDS redefines social relations, including those of the family (Block, 2012), and when resources are scarce, mechanisms of exclusion may uproot a child’s life. Mpendulo was 14 years old in 2012, and like Lindani he had lost both his parents (presumably to HIV) at a very young age: his mother when he was two years old, his father two years later. At his death, his father left behind an estate consisting of a modern four-roomed house at the paternal homestead, and savings and pension money to be distributed among his four children born of three women: Mpendulo, his older half-brother and half-sister from his father’s first girlfriend, and a younger half-sister from another woman. The older siblings were employed: the brother in a hardware shop in a town about 200 kilometres away; the sister was a teacher in a nearby primary school.

Like Lindani, Mpendulo lived at his father’s work place during his early childhood and they were very close; it was his father who took him for HIV testing when he fell sick after his mother’s death. After his father’s death, his uncle (father’s younger brother) was assigned as executor of the estate, but Mpendulo’s elder half-brother accused him of squandering the estate money, took over the administration and had his wife and children occupy their father’s house. The half-brother had not been forthcoming with money, resulting in a severe drift among the siblings. Mpendulo felt “robbed of our share of our father’s earnings by my
brother and his wife”. Mpendulo moved between several maternal and paternal extended family members, but he experienced a lot of stigma, and eventually settled at his paternal homestead in his father’s house. However, his life there was difficult because, in the words of his uncle:

He did not see eye to eye with his sister-in-law who did not like the fact that Mpendulo was HIV positive … in one incidence the sister-in-law found him eating food from a plate that was not designated for him. She scolded the boy for using the plate; stating that … he will infect her children with HIV. That angered Mpendulo a lot. He said he felt unwelcomed and not wanted. His brother tried to intervene but it did not work out so he decided to leave and came to stay with us … We think he is happy here. The only thing he talks about is that if he had money he would go and stay at his father’s house. (Interview, October, 2012)

In 2012 Mpendulo was living with his uncle in a dilapidated four-roomed house occupied by 11 people, including the uncle’s wife and their three children, another uncle and his wife and child and Mpendulo’s younger sister and her child. They relied on subsistence farming and piece-jobs for a living, as none were fully employed. In numerous interactions, Mpendulo shared how he felt “unwanted”. He felt comfortable with his younger uncle and his wife who were also living with HIV and on ART, as “they accepted me and we discussed our sickness without a problem”. But he would feel hurt when his uncle complained that Mpendulo did not contribute to the household. He felt his inability to contribute was caused by his brother’s refusal to process his share of their father’s estate, and he himself carried the brunt of this as lack of money often forced him to take his medication on an empty stomach.

In 2013, Mpendulo decided to join a support group at a hospital, gained assistance from the Social Welfare Office and in May that year finally got his share of his father’s estate. He was just 15 years old when he came back to claim his place in his father’s house, upon which his sister-in-law left with her children to stay with her husband. The support group had become very important for Mpendulo. Besides

learning more about the disease, the pills and other things, they also provide me with money that I use to buy food … I feel welcomed. Like I have a family when I am with them. I always look forward to the meetings. Fieldnotes, 2013

**Connecting with peers: Simangele and Sizwe**

When illness leads to the involvement of care-related institutions, people may also be offered new channels for belonging. It is tempting to present support groups as a panacea for the lack of support and connectedness experienced by adolescents with HIV, as a family substitute. Bailey (1988) refers to this type of family as “psychological kinship”. Such people do not have legal or blood connections but are brought together by socio-emotional and psychological experiences and needs, and a sense of reciprocity. However, a support group may be valuable even when there is a functioning family.

The first author met Simangele in 2013 when she was 14 and had been on ART for five years. After she fell sick in 2008, her mother, already living with HIV, encouraged her to test, and Simangele started taking medication the same year because her CD4 count was low. Simangele lives with her mother in a modern house in a suburb and enjoys good social economic status. Her parents never married and Simangele has no relationship with her father, who married another woman. This did not bother her, as both her maternal family and the support group for adolescents provided her with strong support:

In teen [support] clubs we share everything with each other about HIV like growing up, dating, medications, food and other things. I learn a lot from the other club members and from the doctors and nurses … It’s like we are one big family. (Interview, September, 2013)

Sizwe in contrast was disappointed by what the support group had to offer him. His mother passed away when he was seven, and five years later, in 2009, he was diagnosed with HIV and has been on ART since then. He tested in the company of his paternal grandmother after repeated episodes of sickness. In 2013 he lived in an extended family with his grandmother, his sister who was three years older, five half siblings from five different women and three cousins. His father, also HIV-positive and on ART, lived in another homestead a few kilometres away. Sizwe attended in a support group twice but stopped because:

It was not helping me in any way … no one was able to address my problems … I felt I was just wasting my time … It is difficult to know that I will be taking the pills for the rest of my life, or to think that one day I will die of this thing. (Interview, October 2013)

Sizwe voiced a lot of anger, first, at his grandmother, who “went about telling anyone who cared to listen that I was HIV positive. I hate her” (Interview, September 2013). Because of her “irresponsible disclosure”, Sizwe experienced discrimination from friends, neighbours and his school to such extent that he had to change schools. But he was mostly angry with his father, who at their last meeting had informed Sizwe that he (father) was also HIV-positive. Sizwe said: “I have nothing to talk to him about; as far as I am concerned I don’t have a
father ... he gave my mother HIV because he was a womaniser.”

A hole in the chest: Sabelo and Dudu

Even with full support from family members, being without one’s natal parents can cause feelings of loneliness and a sense of not being at home. In 2013, when we met him for the first time, Sabelo was 15 years old and like Lindani, he was born out of wedlock. His mother married his stepfather when Sabelo was four years old, and he still lived with them and his two younger half-sisters. He tested positive to HIV in 2010 when he was 12, and started taking ART in 2011. His mother and maternal grandmother were also HIV-positive and on ART; his stepfather and half-sisters were HIV-negative. Sabelo described his stepfather as very supportive and their relationship as very good. His “family” – his mother, stepfather and sisters – met all his basic needs. Sabelo explained that he did not consider his biological father as family, although he referred to him as his “real” father, and wished to have a relationship with him because “there are things I feel I cannot talk about with him [stepfather] and I need my real father; I just wish I had a relationship with my father”. Describing it as a deeper feeling, while pointing at the left side of his chest, he reflected:

I sometimes feel like it is empty here [pointing on the left side of his chest], like there is this big hole ... like if I had a relationship with my real father, singavaleka lesikhala lengisivako la [this hole I feel in here would be closed].

Dudu expressed a similar longing. She was 12 years old and lived with her maternal grandmother, who had lost five of seven children to AIDS and barely survived by selling fruit and handicrafts. Dudu was also born out of wedlock and neither inhlawulo nor lobola had been paid. Her mother had died when she was two years old. Dudu’s own health had started to deteriorate. Her father refused to consent to her being tested for HIV, but with consent of her grandmother, Dudu was tested, found HIV-positive and put on treatment. Her father rejected and disowned her, refusing to pay her school fees and so seriously threatening her prospects; because she had an employed father, she did not fulfil the criteria to access support for vulnerable orphaned children. This was of great concern to Dudu and her grandmother, but her father’s rejection hurt Dudu at a deeper level. In between sobs she shared:

He [father] doesn’t talk to me nor care about me, it is like I do not exist. Even when we meet he turns the other way. If I greet him he doesn’t respond. I think he doesn’t like me because I am HIV positive ... It hurts a lot ... I pray every day that he finds it in his heart to accept me. (Interview, September 2012)

Discussion

We chose these cases to represent some of the common family structures that shape the experiences of Swazi adolescents living with HIV: two double orphans, one living with his maternal grandmother and the other with paternal kin; two maternal orphans, one living with her maternal grandmother, the other with his paternal grandmother; and two adolescents with both parents alive, one living with her mother, the other with his mother and stepfather.

From the adolescents’ descriptions of what they considered to be their family, the caregiving they received formed a necessary element. This entailed providing for basic needs (such as shelter, food, etc.), educational needs (fees, uniforms) and health-related care (such as being taken to the clinic for HIV testing, consenting for treatment, reminding one of medication and clinic appointments, being provided with money for transport and managing disclosure wisely). Many families caring for adolescents living with HIV find themselves in fragile economic circumstances that directly impact on treatment trajectories, when fares for transport to the clinic or the food that must be taken with some medicines are not available. Some family structures are more vulnerable than others, amongst them skipped generation families, where unemployed grandparents care for their orphaned grandchildren. Lindani’s wish to stay with his more affluent paternal kin instead of with his impoverished grandmother was partly driven by a rational weighing of where his basic needs would be best provided. Mpendulo, younger stepbrother to the oldest son in a complex paternal homestead, did not rest until he got the rightful share of his father’s estate. Both situations reflect Swaziland’s complex dual legal structure and lack of social security. Lindani’s wish to live with his paternal kin was curbed by his maternal grandmother’s tenacious appeal on her right to financial compensation under the traditional institutions of lobola and inhlawuho. These could not be legally enforced, but were tied in with his grandmother’s hope for a good life as an elder, bereaved as she was by the death of all six children in whom she had invested these hopes. Whereas Mpendulo’s father willed to divide his estate equally amongst his four children, Mpendulo’s older half-brother acted according to a deeply felt principle of inheritance where an estate is inherited from older son to older son, and Mpendulo had to take shelter with his uncle, himself a younger and therefore relatively disempowered son.
However, the adolescents in our study considered being cared for at a deeper level: of being accepted, being connected and welcomed. To Lindani, it was about living in a social space where he was accepted unconditionally, not provisionally “as long as inhlawulo has not been paid”. The stigmatisation experienced by Mpendulo as a result of his HIV status caused him to move between his extended maternal and paternal kin until he finally came to live alone in his father’s house. Sabelo, while being cared for in many ways by his mother and stepfather, still felt a hole, an embodied emptiness related to missing his real father in his life. While rejected by her father at early age, Dudu still nurtured hope that he would accept her in his life. All stories speak of the need to belong.

Belonging, like identity, results from complex socio-psychological processes. From our findings, belonging emerges as a sense of being safe in the right place with people one feels connected with, and as a process of becoming: “an ongoing project entailing a sense of hope for the future [and] a part of everyday practices” (Yuval-Davis, 2011, p. 4). Ortner’s (2006) perspective on how subjects pursue goals and enact projects according to their culturally and socially shaped dispositions and desires is helpful here. Constantly changing emic perceptions of the self, others and the world gives rise to hopes and desires on which adolescents act intentionally and pursue their projects, even with limited space for manoeuvre (Ortner, 2006). Sizwe’s perception of himself as the victim of his father’s womanising and his paternal grandmother’s irresponsible disclosure of his HIV status steered him into anger and breaking off the relationship with his father. Similarly Mpendulo’s perception of himself as being wronged by his half-brother and his wife made him pursue his rightful share of the estate.

But perceptions, hopes, desires, intentions and projects are themselves shaped by and negotiated in the environments in which they are embedded, and by the values internalised through socialisation and ongoing interactions with important others. For Swazi adolescents living with HIV, the importance of belonging is felt most acutely in its absence. Their focus is on fathers living with HIV, the importance of belonging is simultaneously hierarchical and reciprocal dependencies that characterise the parent–child relationships adolescents living with HIV have lost, and long for and negotiate.

Family is a slippery concept when HIV/AIDS support groups are concerned, such as the teen clubs that some of the adolescents in our study attended. Sizwe hoped to find solutions there for his stagnated situation – and we may infer, his stagnated rage – but he was disappointed. Mpendulo and Simangele, however, described how their group felt “like a family”. This referred to both the practical support they received and the feeling of connectedness and acceptance, as it enabled them to safely share their feelings and thoughts pertaining to their life and HIV. This insight into the role of support groups is not new, of course. In his study of men on ART in Bushbuckridge, South Africa, Mfecane shares how his interlocutors “felt at home when in the support group” (2010, p. 12). Zambian adolescents describe support groups as a “community, a source of psychosocial support … where they feel valued and offer each other a sense of identity” (Mburu et al., 2014, p. 13). Similarly, Moyer and Igonya (2014) noted the lack of family support for PLHIV in Nairobi, Kenya, and how support groups take on the role of non-biomedical support. Miller makes the same point for China in this issue. Adolescents in our study shared a bio-therapeutic identity, having HIV and being on lifelong treatment with ARVs. If we follow Levine’s observation (1999, p. 96) that the meaning of “family” can be derived from the context in which it is used and the tone of voice of the user, on first sight support groups do qualify as family in some adolescents’ lives. But their role should not be constructed as per definition in opposition of, or substituting, a failing family. In Simangele’s case the support group functioned parallel and in addition to rather than in substitution of what Swazi adolescents expect from their biological kin. In the context of Swaziland adolescents’ ongoing projects to belong (cf. Yuval-Davis, 2011, p. 4) connecting with peers in support groups may be interpreted as horizontal – crosscutting sometimes tight and safe family ties, not unlike the age-sets so fundamental to Swazi culture (cf. Reis, 2008). Our data also suggest that support groups do not replace the simultaneously hierarchical and reciprocal dependencies that characterise the parent–child relationships adolescents living with HIV have lost, and long for and negotiate.

**Limitations**

The study was conducted in two areas in one region of the country. The four regions are similar in many ways, but the study region is more densely populated, and has the highest proportions of adolescents, of PLHIV and of health facilities providing HIV service. Therefore the experiences and views expressed may not be representative of those of adolescents in Swaziland in general.
Furthermore, our project faced several challenges that may have limited the depth of the data. First, because HIV is regarded as a sexually transmitted infection and discussing sexuality between adults and children is generally considered inappropriate, some participants may not have fully shared their views with the first author, an adult native Swazi woman. However, the length of the fieldwork, the presence of the first author, allowed for the development of rapport with most participants, and our use of interactive data collection techniques, such as diaries, drawings and informal conversations, and engaging adolescents in the data collection, helped create safe spaces for discussing sensitive issues. Second, participants may have limited the information they offered as they perceived the first author as a knowing insider. However, the iterative data-gathering process was steered by regular reflection meetings with the co-authors, allowing for in-depth probing into pertinent issues. Finally, according to our ethical guidelines, informed consent was needed from both the adolescent and his/her parent or guardian. Due to their parents not granting consent, some adolescents could not be included even though they wish to be, whereas others may have agreed to participate out of obedience to their parents or guardians or out of respect for the researcher. The utmost care was taken to inform in an age-appropriate way adolescents of their rights with regard to participation in the study including the right to refuse to take part, to withdraw at any time or to refuse to respond to questions that they were not comfortable responding to, and this was monitored as an ongoing process.

Conclusion

The family, as framed by the headman at the beginning of this article, referred to the responsibility of the community and by extension, the Swazi nation, for those affected by HIV/AIDS. This meaning was not reflected in the actual experiences of the adolescents in our study. Traditional institutions used to support and structured relations between maternal and paternal kin and regulated belonging – such as inheritance through the eldest son, lobola and inhlawulo. While still shaping adolescents’ dispositions, hopes and desires, sanctions are easily escaped. Some adults skilfully navigate these institutions not always in the best interest of the child, thereby creating obstacles for adolescents rather than supporting them in their quest for care. In the final instance adolescents living with HIV depend on their biological families for material and medical support but also for psychological care (Richter et al., 2009). However, what is conceptualised as an adolescent’s family in policies, programmes, standards and guidelines should be based not only on the factual care arrangements that adolescents find themselves in, nor on legal definitions of rights and responsibilities, but also on adolescents’ perceptions, hopes and desire to belong.

Note

1. At the time of the study the exchange rate between the USD ($) and the local currency-Emalangeni (E), was 1$1:E10.

Acknowledgements

The authors are grateful to all the adolescents, and their parents or guardians, who shared their personal stories of growing up and living with HIV, as well as the professionals, community health workers, partners in the MaxART consortium and everyone who contributed to the study directly or indirectly. The study was part of the explorative and preparatory phase of the collaborative project Maximizing ART for Better Health and Zero New HIV infections (MaxART), led by the Swazi Ministry of Health.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

Funding information: The authors are grateful for the generous support of the Netherlands Postcode Lottery and the Amsterdam Institute for Social Science Research, StopAIDS NOW!

References


