

Blessing's (Life) Story: An Adolescent in Residential Care Living with HIV

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Abstract

The lifespan of perinatally HIV-infected children in South Africa has increased owing to the availability of antiretroviral treatment, allowing growth into adolescence and beyond. There is limited knowledge of the lived realities of adolescents with HIV. This paper, using life story methodology and based on Blessing's narrative, provides an intersectional, complex view of the experience of one such teenager who is perinatally HIV-positive, was abandoned by his family and is living in a residential care facility. His story powerfully illuminates the specific construction of adolescence in this context, focusing on identity formation and the need for connection. The narrative also points to service providers' practice when engaged with such youths.

Keywords: perinatal infection; adolescence; HIV and AIDS; identity; social connectedness; residential care facility

Introduction

I want to have a chance with who I am. (Blessing)

This article employs life story methodology to illuminate the lived reality of a teenager impacted by residential care and his HIV and AIDS status, and to identify how these factors construct his adolescence. It is centred on a narrative related by Blessing (pseudonym) in 2016, when he was 13 and living in a residential setting. As an infant, Blessing's mother left him behind in hospital. He has no knowledge of his parents' identities or story, though research shows that young, poor mothers, stigmatised by their own HIV and AIDS status, may intentionally abandon their children, believing they are offering their children a better future (Thabane and Kasiram 2015). The hospital nurses gave him a name that suggests strength and fortitude. He was then placed in a



Johannesburg facility (which had been established in 2001 to care for orphaned babies who were perinatally HIV-infected).

Blessing offered his story to us when we were researching the intersection of HIV and AIDS, adolescence and residential care among youths who were perinatally infected. We had conducted focus groups with the youths in the facility and invited them into interviews. Only Blessing participated. He did so, hoping his published story would reach his parents and persuade them to reconnect with him. While we clarified that this was an unlikely outcome, Blessing was passionate about this story. Because his choice posed an ethical dilemma, his consent was again sought. Additionally, we provided him with an opportunity to review the transcript. Emotional support was offered by his counsellor.

We understand this story through the conceptual lens of intersectionality. Intersectionality critically illuminates the ways in which dimensions of social location interact regarding privilege and/or marginalisation (Dumbrill and Yee 2019). This poignant telling of a young person's struggle with his health status, life in a residential setting and adolescence allows us to witness the interplay of these dimensions in identity formation. Blessing's story potentially provides practitioners a window into the lived realities of other young people dealing with similar challenges.

Literature Review

To conceptualise the confluence of these social dimensions in Blessing's experience, we focus on literature that speaks to adolescence, HIV and AIDS status, residential care and abandonment.

Adolescence (along with the terms "adolescent", "teen/teenager" and "youth") refers in Western developmental psychology to the transition from childhood to adulthood. This phase includes specific physical, sexual, cognitive, moral and social developmental changes (Van Dyk 2008; WHO 2013). However, the assumed developmental norms do not necessarily reflect global adolescent experiences (De Leonibus et al. 2014; Jordan, Patel, and Hochfeld 2014). As such, in South Africa, factors such as early parenthood, mass poverty, race, and geographical location shape a particular experience of adolescence (Patel et al. 2017).

Importantly, the interaction with HIV and AIDS constructs adolescence in unique ways, especially for young people living in communities where there is a high prevalence of the illness. For example, they may have to deal with the emotional and practical implications of caring for and losing loved ones and/or being cared for by relatives (NACCW 2014; Van Dyk 2008). Of the three million children identified as single or double orphans in 2012 (Matthews et al. 2014), most come from poor communities where their circumstances increase their vulnerability to further impoverishment

(Beegle, De Weerd, and Dercon 2009). When encountering many practical and psychological challenges, such teenagers tend to have lower self-esteem and self-control than their non-orphaned peers (Isaranurug and Chompikul 2009). For youths who are HIV-positive, such pressures are amplified through prejudice, stigma, exclusion, isolation and economic hardships, potentially resulting in mental health challenges (Boyes and Cluver 2015; Kruger 2006; Zhao et al. 2014). Associated poorer educational outcomes (Orkin et al. 2014) may limit access to further education and employment (Heckman 2008). A range of health, education and social welfare supports is thus required, though such responses continue to be inadequate in South Africa (Cluver et al. 2013; Orkin et al. 2014; WHO 2013). Despite the lack of appropriate formal supports, the resilience of already under-resourced communities in taking care of those affected by HIV and AIDS needs to be recognised (Betancourt et al. 2013; Kruger 2006; Mistry et al. 2012).

Adolescents who have been perinatally infected have further needs. Despite the availability of antiretroviral therapy, some may face chronic diseases in the form of opportunistic infections, advanced stages of the virus, stunted growth, delayed onset of puberty and cognitive challenges (Abadia-Barrero and Castro 2006; Cambridge 2001; Coleman and Toledo 2002; Earls, Raviola, and Carlson 2008; Merchant and Lala 2012; Zhao et al. 2014). In addition to physical consequences, there are emotional stresses. Some youths only become aware of their status during adolescence owing to delayed symptomology or the lack of previous disclosure (Marfatia and Smriti 2010; The Lancet 2006). In addition, these adolescents have daily reminders of their disease through their medical regime. Even though non-adherence can cause drug resistance and prompt the virus to escalate, some teenagers avoid their medications because of peer pressure, poverty, stigma and their life stage (Lowenthal et al. 2014). Further, self-disclosure can be emotionally loaded. Youths avoid sharing their status (also regarding intimate relationships) because of the fear of stigma and discrimination, though non-disclosure typically results in feelings of shame and inferiority (Bauermeister et al. 2009; Mpopu and Jacobs 2017). Overall, adolescents confronted by HIV and AIDS face many emotional, social and physical barriers, particularly if they have been infected through mother-to-child transmission.

Given that Blessing is considered an abandoned youth living in a residential setting, it is important to briefly explore issues pertaining to this context. Abandoned children living in formal substitute care are provided with the important security of food, shelter and education. Nevertheless, challenges arise from long-term care, such as stigmatisation for not living in a “normal” family (Roy, Rutter, and Pickles 2000) and difficulties related to self-esteem, confidence, peer relations, academic performance and behaviour (Morantz and Heymann 2010). When children are removed from their family and communities, they tend to be distanced from the social systems that potentially provide them a sense of personal and cultural identity, belonging and social and community connectedness (Morantz and Heymann 2010). Adolescents raised in

residential care need to explore new ways of gaining a sense of identity and belonging to avoid alienation and isolation (Brendtro, Brokenleg, and Van Bockern 2005).

While there is information regarding the impact of children being raised in residential care, less is known regarding the experiences of adolescents with HIV and living in care. At the time of the study, only two investigations had highlighted the experiences of this specific group. In a Trinidad and Tobago care facility for youth with HIV, the issue of permanency planning arose unexpectedly when it became evident that these children were surviving owing to antiretroviral therapy, and moreover, had families in the community with whom they could reunite (Cambridge 2001). Another study regarding Nkosi's Haven in South Africa, found that these children were appreciative of their basic needs being met. However, they grappled with the stigmatisation of living in a care facility, specifically for persons with HIV and AIDS; the strict medication regimes; and lack of gender appropriate role models. The teenagers felt dehumanised, shamed as well as disempowered regarding age-appropriate decision-making (Dube and Ross 2012). Our investigation confirmed these trends, noting that for these adolescents the intersection of their HIV and AIDS status, their developmental phase, and their residential care rendered them powerless and stigmatised in many areas of their lives (Schmid and Chiba 2017). While valuing the love and care demonstrated by staff and the importance of their basic needs being met, the teenagers deeply desired greater agency regarding their daily lives. It was further evident that these youths had been divorced from their communities and languages of origin and were attempting to construct meaningful identities but lacked appropriate models to build on as black, abandoned, HIV-infected youths in residential care.

Blessing, in sharing his life story, offers further depth into the challenges faced by this group of teenagers. His story particularly illustrates the complexity of identity formation and social connectedness and the yearning for a sense of belonging.

Life Story Method

We utilise a qualitative approach to this research project, wishing to reflect ambiguity, texture and nuance (Bless, Higson-Smith, and Sithole 2013). Blessing's sharing motivated us to employ a life story approach to disseminate his account because this honours the narrator's voice. In particular, we adopt an anti-oppressive, feminist lens to the life story, which reveals the dynamics of social structures and location in untold stories and silences, allows the invisible to be seen, and highlights strength in the face of oppression (Mafile'o and Api 2009). Through the life story method an individual will, through an interview using open questions (Rubin and Babbie 2005), present a window into the participants' reality and to what they consider salient. The narrators write themselves into their own story (Roets and Goedgeluck 2007), attaching meaning to what is being related (Brannen 2013), identifying new perspectives (Roets and Goedgeluck 2007) and possibly reinterpreting the story (Meneghel 2007). The narration

may not only alter the person's conceptions of self but can shift how the narrator is perceived (Mitchell 2005). The postmodernist understanding of the life story method is that every person's story is unique, and yet within this particular story there may be relevant commonalities for others in similar circumstances. Blessing's story may thus echo the story of the collective of youths in care dealing with HIV and abandonment. Further, Brannen (2013) suggests that there is value in this method even where the initial intent by the narrator was not specifically to share a life story. In Blessing's case, for example, the interview format provided a framework for him to share his experience as his story.

Life story as method has been criticised because the narrative is typically related to an interviewer. The researchers may impose their own structure, biases and interpretation on the story. Because narratives must be contextualised, the interviewer has the power to shift the meaning of the story in placing the story within a broader frame (Brannen 2013). We have chosen to present an uncut version of Blessing's story to avoid any appropriation or amendment of this youngster's narrative, though we recognise that we too have offered to place this account within a particular framework by offering core themes and interpreting these. We have lifted out these themes utilising content analysis. Both initial themes and categories were confirmed by the two researchers, adding trustworthiness to the process (Bless, Higson-Smith, and Sithole 2013). This paper is further constrained by utilising one short narrative and relying only on Blessing's voice to provide potential insights into the experiences of adolescents with HIV and AIDS growing up in care, though his story is set against the background of the parallel research. The fact that we did not have a relationship with Blessing beyond the research raises ethical issues around using this information, though we attempted to deal with such issues by ensuring he was connected to a counsellor, offering him explicit consent, and ensuring him that he could review the transcript.

However, despite such limitations there is value in hearing this brief life story articulated by a teenager directly affected by the issues under discussion. Because a life story legitimates offering an unaltered, authentic spoken account, allowing these words to (largely) speak for themselves, what follows is Blessing's uncut story: a story of what it means to be a teenager who has grown up in care, and carried both an awareness of his HIV-positive status and knowledge of his early abandonment.

Blessing's Story

[“Mama” refers to the staff at the residence. Although this facility assumed all the children taken in were abandoned orphans without family, this was proven incorrect when relatives made contact with the agency in about nine cases. Further, it is the practice for caregivers at this residence to offer a formal diagnosis to the child only at puberty, despite all children having been on a daily medication regime.]

Mama L told me my story about one year ago. She said I came to LS [residential facility] at three months from the hospital. She asked me first if I wanted to speak about my parents. I had questions before. I did not understand why parents were fetching others and not me.

They found me in the hospital. My parents left me there. Mama L told me I was very skinny. They could not find my parents. Mama L told me to achieve what I want to be.

I talked to other kids. It became a big thing. I told guys at school that I am an orphan. I want people to know who I really am. Because I said, "It is me, I am one of 28 at LS." Mama L told me that I should not talk to anyone. This is hard advice to follow – why keep it a secret? If someone comes up to you, you want to say to them what the situation is. You don't want to say the wrong thing and after that they find out. You want to be honest.

I was found at N Hospital. I know I am Zulu because the mamas knew my surname.

I only speak English now. I say I don't understand [when others speak to me in Zulu]. Learning another language now would be too hard. English feels like my language.

I do want to find my parents. Mama L says my parents are away – you can't find them. Also, the social workers know nothing. If you publish this in the whole world and in South Africa, maybe my parents will read this and find me.

Some of the kids here feel like family to me. I think I will continue with them through my life.

I want to become a lawyer. That is a good job for me because I like to talk. I think it takes four years or so.

At school my English is good, my Afrikaans is average, and my Maths is not so good. Tomorrow I start at high school in Grade 8 at Q School. I would have liked to have gone to J School, but it is said I must go to Q because my marks were not good enough for J. It feels unfair, because my friends G and N are going to J. If I get my marks up, then maybe I can go to J – they said if I work hard and improve my marks I can go. They're strict and all at J, but they have sport I would like to do. I want to do athletics and drama. Maybe I can do that also at Q.

The first day at the new school will be exciting. But it will also be boring because G and N won't be there. I will have to make new friends, which will be hard. It will be like starting in Grade 1 again but with older kids.

It is embarrassing to tell who I am. If I write a book it would be a problem for us (because I would speak about LS and the others would not like that). For me it is really important to say who I am. I want to do this without affecting the others. I thought of saying this in front of the whole school and just get it over with.

Where will this be published? What if my parents read this?

I want to get it over with, meaning, I want to have a chance with who I am. Uncle T (he works in the office) is an orphan also. It has not affected his life so much. I feel I should stop asking – it gets boring. But I don't know what to expect.

I dream of being a lawyer, journalist, actor or fashion designer. One day I would like to have a partner. Maybe only once I am at university. I don't like to gossip, but a sister here is in a relationship and she thinks her boyfriend is going to break up with her. I think that is good because she is too young to be in a relationship.

I could talk about my things with N and G. They also live here at LS. But now it is boring.

Living at LS is okay but I feel [Mama L's adopted son] gets all the things, this is not fair. I asked Mama L why he could have a phone and she said she could trust him. 'If I give it to you guys, how will you manage it?' He is non-HIV.

For me to live here is okay. It is great and fun. We wanted homes and to have families like this. I do feel loved here. When I was in Grade 2 I fought with the housemother – I just did, but then I stopped. She said, 'I still love, I am here for you'. She said, 'I came from Malawi to be here with you, to feed and clothe you'. I will still know her when I am older. If she had to die, even though she is not my mother, I would mourn her.

Those with non-HIV have freedom and have places to go. They don't have lots of tablets to take. No, I don't know others with HIV who are not living in a home. At least I am here, that's a good thing.

I don't remember when I was told I was HIV-positive. It feels like I have always known. Sometimes I feel different to those who are HIV-negative, but sometimes I feel the same. They can go out with their parents.

Once we went to a squatter camp to give them gifts. This did not feel good. I felt disgusted by their environment, by what they eat. I don't feel good around those people.

I have not gone to my mama's home because she is from Malawi.

I share a room with S. He is one of the worst to share a room with. He leaves a mess everywhere. I can't clean. I like to do schedules, be organised and have a clean environment. But now it is just fine with him. We only have mini fights. I just put his clothes on the bed. He doesn't understand me at all. He's been bullied at school and then comes home and bullies us. He is older than me. But I feel sorry for him. I saw this movie about a lawyer who was a sinner and who did not represent this offender properly who did the thing out of love of God. Later, she was in an accident and trapped in a car, and he let her out. She did not understand why. He said he must love his enemies more than himself. That's me. I don't know the Lord, but I feel we must love our enemies.

I want everyone to know I am an orphan. I live in a home. I am HIV-positive. There was a girl in school whom I told everything, and she knew everything about me. Maybe people won't want to touch me when they know, but I don't care.

I think that is everything that I want to say about my life.

Discussion

Blessing's rich story speaks to the dilemmas he faces with regard to his identity formation. He also talks about his desire for connection and belonging. These two themes are explored below.

Identity: Being Honest

Developmental theory suggests that identity formation, including developing individuation and autonomy, is a key task for teenagers. It involves the adolescent evaluating attitudes, values and beliefs to which they have been exposed and are discovering. Identity formation and the associated challenges are a major issue for Blessing. He reflects his identity as multidimensional. This incorporates his HIV status; residing in "a home"; having been abandoned as an infant; being a member of a quasi-family; having certain values; being both a Zulu and an English speaker; being a learner and a friend; and having aspirations. Blessing seems to draw strength from those aspects of his social location which he experiences as positive. For example, he is proud of his assumed Zulu heritage and values his eloquence in English. Blessing implies that he is not just a person living with HIV, or only an orphan, or simply a child in residential care, but that he is a complex being. His wish to disclose all aspects of his identity suggests that he has a strong idea of who he is. Within this, though, there seems to also be vulnerability as Blessing infers essential differences from his schoolmates.

Blessing thus wants to be seen in his fullness and believes that complete transparency would be cathartic – creating space for him to express openly the complexity of his feelings and identity as well as furthering closer relationships with his peers. The literature suggests self-disclosure may indeed be positive, improving connection and resulting in reduced mental health issues (Mpofu and Jacobs 2017; Tshabalala 2014; WHO 2014). However, Blessing also suggests that discussion of these (very personal) issues can become "boring". This may imply that resolution is difficult. It may also point to the tabooed nature of the residents' health status as in the late disclosure of the diagnoses and the sanctioning by his caregivers as well as his co-residents of his self-disclosure. It may therefore be that Blessing is engaging in self-censorship. Notably, even in such ambivalence, Blessing conveys that he would rather self-disclose – and do this on his own terms – than be exposed later. In this regard, Blessing demonstrates the desire for agency that is typical of teenagers (Glendø 2017).

Further, the class and racial context in which Blessing finds himself is likely to contribute to his identity formation. Blessing is being raised in a residence that portrays middle class dominance (reflected in the division between professional and support staff, and in the intersection of management and whiteness). He lives in a predominantly middle class, white neighbourhood and attends a school where black students form a minority. It appears that he identifies as middle class: Blessing has middle class professional aspirations; and engages in othering of those who are poorer as exemplified in his “disgust” with persons living in informal settlements. He may be seen to be performing whiteness in his comfort with being a monolingual English speaker. Blessing is living outside the ethnic community with which he chooses to identify. He has not articulated tensions in this identification, but it can be anticipated that dissonance may still emerge. If Blessing finds difficulty in negotiating his identity in terms of race and class, he may be exposed to further social marginalisation (Abadia-Barrero and Castro 2006). While Blessing conveys confidence in who he is, he simultaneously presents as fragile and insecure. This yearning for connection is picked up as the next theme.

Social Connectedness – Sense of Belonging

Blessing seeks social connectedness and belonging. Synergos (2014) explains that social connectedness is the quantity and quality of valuable relationships people have with each other. Normative psychology privileges peer relationships. However, adolescents need also to deepen social connections and find belonging within family relations (Neufeld and Maté 2004). The substitute care literature demonstrates that youth ageing out of the system tend to turn back to biological families; where this is not a possibility, security as an adult is compromised (Holland 2009). Moreover, functional and geographical communities are important to adolescents in acquiring intergenerational social and cultural capital, networks and values (Synergos 2015). The absence of familial, peer and community belonging may result in feelings of loneliness, mistrust and isolation, and youth-seeking connectedness through risky behaviours and associations (Brooks et al. 2012; Synergos 2014).

Blessing’s social connectedness can be understood on a number of levels. First, Blessing locates his sense of belonging within the residential care context. He regards as family his two best friends and the children with whom he shares his home, as well as his house mother and other staff at the facility. Indeed, he expects to have lifelong connections with these people. Blessing experiences a degree of trust, empathy and belonging in this setting (Brendtro, Brokenleg, and Van Bockern 2013). However, while Blessing is hopeful that this residential community will be a lifelong one for him, he has no assurance that it will be so. It is not clear from his narrative if he is aware of this. Our parallel study demonstrated that this organisation, while maintaining that the residents are its long-term responsibility, does not have a commensurate long-term care plan (Schmid and Chiba 2016).

Second, Blessing does not appear to have solid peer connections at school. The other black learners (with whom he is seeking relationships) are multilingual and as he puts it “non-HIV”, which in his perception limit possibilities for commonality and connection. Like others at the residence, he would like life without HIV and residential care, and desires good friendships with peers outside of the residential setting – an understandable adolescent yearning (Tomé et al. 2012).

Third, Blessing feels deeply abandoned. He is troubled by having insufficient information regarding his biological family and not having been “claimed” by them. His Zulu name is all that offers him a potential link to his familial and cultural origins. Knowing at which hospital he was born is the only tenuous indicator of his community of origin. Finally, as a black youth, living in a predominantly middle-class white neighbourhood and raised to speak only English, Blessing is divorced not only from his family but also from any relevant community. The facility aims to develop community connections to church but in this narrative Blessing does not indicate any meaningful relationships with this faith community. Overall, this sense of abandonment and lack of history seem to impact his identity formation, creating uncertainty (Spano 2004). His social location may lead to feelings of isolation and compromise his mental health (Synergos 2015).

A strength which may mitigate a lack of rootedness and ultimately a transition out of care is Blessing’s aspirations for the future (Refaeli 2017). Blessing’s dreams and hopes include becoming a professional and having an intimate relationship. Despite his current social circumstances, he sees a future that is no different from any other (middle class) youth. It seems that the encouragement from his caregivers support this belief in himself. He backgrounds his health concerns and prioritises his thoughts about his future and what he might achieve. These expectations suggest that Blessing views himself as capable and resilient (Glendø 2017). At the same time, noting his current educational performance and limited formal supports, such hopes may be unrealistic. Currently, however, these expectations are part of how Blessing sees himself.

In sum, Blessing is a boy who seeks autonomy, individuation and independence, and carries significant resilience. He has a complex sense of who he is, even if, for example, he does not speak to his own subjectivity of race and class, his gender identification and his gender orientation. Blessing is compromised in that he does not have the permission and safety to transparently share his story and full identity and must manage the taboos surrounding his health status. While he is connected to the individuals within the residential facility, he is not offered the certainty of a long-term quasi-familial network. He longs for parental connection and claiming, and desires greater social intimacy with his non-HIV peers. Blessing identifies as middle class but may need to further integrate the apparently contradictory elements of his racial and class location. Becoming meaningfully embedded in a community with which he chooses to identify may be of value to him.

Blessing's experiences are echoed in the research in which he and his peers participated collectively. Those outcomes focused on the desire particularly for agency and autonomy, and for contextualised responses (Schmid and Chiba 2016; 2017). However, Blessing's voice further emphasises the need for relevant and appropriate connection on multiple levels, as well as for unfettering identity development by removing taboos.

Practitioner Support

An intersectional lens highlights that Blessing's identity has been shaped by his abandonment, HIV status and residential care location. His agency to act on identity formation, social connections and future aspirations is constrained – more than for adolescents not faced with abandonment, residential care and HIV status. To respond in a transformative manner, social work practitioners and caregivers engaging with youth in Blessing's situation must appreciate this particular construction of adolescence. Enabling such youths to embrace their full identity while mitigating negative consequences is essential. Service providers need to break the silence around taboo subjects and create safe spaces (perhaps through counselling) to solve these challenges (Mpofu and Jacobs 2017; WHO 2014). Such teenagers require active support and space to develop relationships with “non-HIV” peers. Although not specifically identified as a need by Blessing, meeting others facing similar challenges may also be beneficial.

The importance of a broad, meaningful social and cultural network must be supported. Accordingly, residential care facilities must actively facilitate adolescents' deep connection with community, including communities of origin. This might occur through supporting youths' engagement with faith communities, sport and cultural participation or volunteering. Another important intervention in advancing community connection in South Africa is facilitating the learning of language beyond English. Finally, residential care organisations originally established to care for ill babies need to develop clear plans for the future so that the teenagers in their care are prepared for early adulthood. Service providers must therefore adopt a multilevel care strategy that firstly recognises the complexity of (among other social markers) being a teen, living in care and having an HIV and AIDS health designation, and secondly takes into consideration not only the personal, but also structural impacts.

Conclusion

Blessing's story is a powerful one. His account speaks to the complexity of living a life of multiple intersections. Blessing's testimony suggests that responsive caregiving supports youth by facilitating full expression of self, appreciating multidimensional social location, encouraging connections with communities of origin, and committing to their future. Offering such a nuanced response remains a challenge for caregiving of this group of youths in South Africa. Although not explicit in the data presented in this paper, how best to support perinatally infected, apparently abandoned children raises

numerous questions regarding substitute care and its relevance. Noting that there are a large enough number of adolescents perinatally infected, abandoned and growing up in care, it is hoped that greater attention be paid to these very vulnerable teens' particular experience of adolescence.

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