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Qualitative exploration of HIV-related stigma and the psychosocial well-being of children orphaned by AIDS

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Abstract
Children orphaned by AIDS continue to display lower levels of psychosocial well-being. While HIV-related stigma has been identified as a risk factor for healthy psychosocial development, there remains an inadequate understanding of orphaned children's experiences and perceptions of HIV-related stigma and its impact on their psychosocial well-being. This study explored children orphaned by AIDS perceptions and experiences of HIV-related stigma and how it has affected their psychosocial well-being. This study used a qualitative exploratory descriptive design. Thirteen participants between 8 and 17 years of age were purposively selected. Data was collected using individual open-ended face-to-face interviews, observations and field notes. Data was transcribed and analysed using a thematic analysis. Three key themes emerged, (1) children's experiences of stigma and discrimination; (2) children's perceptions of HIV-related stigma; (3) and the psychosocial well-being of children orphaned by AIDS. Children were highly perceptive and experienced HIV-related stigma as a result of their association with parental HIV/AIDS, regardless of their own HIV status. Experiences and perceptions of HIV-related stigma were identified to negatively impact the psychological and emotional well-being, social well-being, perceived social support, self-concept and self-esteem, and future orientation of orphaned children. This qualitative study contributes towards an understanding of orphaned children's experiences and perceptions of HIV-related stigma and how it may affect their psychosocial well-being, which is useful for informing future research and policies and programmes guided towards ensuring the well-being of children orphaned or made vulnerable by AIDS.

Keywords HIV/AIDS · Orphans · HIV-related stigma · Psychosocial well-being · Exploratory design

Introduction

The outcome of the HIV/AIDS epidemic is the emergence of one of the largest orphan populations in the world, as 17.3 million children were parentally bereaved by AIDS-related causes by the year 2011 (Caserta et al. 2016; Chi et al. 2014). Sub-Saharan Africa has been the most severely affected, as 15 million orphaned children are located in Sub-Saharan African, with 2.5 million orphaned children residing in South Africa (UNICEF 2013). Children orphaned by AIDS (COA) is defined as a child/ren under the age of 18 years, who have/has lost one (single orphan) or both (double orphan) their parent/s to HIV/AIDS (Tran and Mwanri 2013; Sharp et al. 2015; UNICEF 2004). COA are likely to experience adversities and stressors associated with orphanhood that may affect them in various ways. These include poverty, food insecurity, inadequate housing, difficult living situations, educational disruption, maltreatment, exploitation, and violence (Harms et al. 2010; Skovdal et al. 2016; Li et al. 2015). Studies (Skovdal et al. 2016; Doku et al. 2015) suggest that COA experience poorer psychosocial well-being than other orphaned and non-orphaned children. Psychosocial well-being refers to the amalgamation of mental and social well-being which widely reflects an individual's thoughts, feelings, behaviours, and reactions to their social environment (Fujishima-Hachiya and Inoue 2012). Psychosocial well-being thus addresses the holistic well-being of COA (Snider and Dawes 2006), which is essential for the healthy growth and development of a child, and plays a pivotal role in their ability to reach their full potential. Numerous risk factors have been identified in contributing to COA poorer levels of psychosocial well-being and

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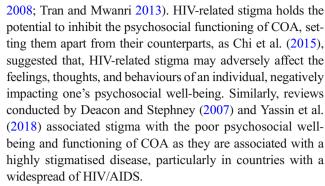
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these include parental loss and bereavement, financial deprivation, the lack of educational opportunities, social isolation, abuse, and exploitation (Ishikawa et al. 2010; Snider and Dawes 2006; Stein 2003). Studies (Caserta et al. 2016; Chi et al. 2015) focusing on the psychosocial well-being of COA have also identified HIV-related stigma as a silent stressor.

HIV-related stigma, the "prejudice, discounting, and discrediting directed at people living with HIV/AIDS (PLWHA) and groups and communities with which they are associated" (Lin et al. 2010. p. 544), transcends beyond individuals infected by HIV/AIDS, and is directed at their families and uninfected children. Children in HIV/AIDS-affected families are likely to suffer from stigmatisation at home, at school, and within their leisure environments (Xu et al. 2009). Therefore, the possibility exists that the cause of paternal bereavement leads to the stigmatisation of COA regardless of their own HIV status (Chi et al. 2014; Gamarel et al. 2017; Thurman et al. 2006).

Goffman's (1963) conceptualisation of tribal stigma represents the devaluation, rejection, and victimisation of COA based on their relationship with a stigmatised individual/s, being their HIV-positive parent/s. Four primary measures of HIV-related stigma, enacted stigma, vicarious stigma, and perceived and internalised stigma have been identified as experienced by COA. Enacted stigma captures the interpersonal aspect of stigma which embodies the prejudicial attitudes and discriminatory behaviours of others directed towards the stigmatised individual which may be manifested as rejection, avoidance, violence, verbal insults, exploitation, and abuse (Bogart et al. 2008; Scambler 1989). Witnessing or hearing about acts of enacted stigma of others is referred to as, vicarious stigma, which is likely to result in the increase of perceived/felt stigma (Steward et al. 2008). Contrastingly, perceived and internalised stigma captures the intrapersonal aspect of stigma. Perceived stigma refers to an individual's perception and subjective awareness about the prevalence or normativity of HIV-related stigma within society. Internalised stigma is the process of an individual accepting the negative evaluation of society as they regard their discredited status as truthful and valid and incorporate these negative evaluations into their personal values and sense of self (Chi et al. 2014; Steward et al. 2008).

While few empirical studies have been conducted on HIV-related stigma and COA, it has gained much interest as stigma resulting from parental HIV/AIDS remains a key challenge for COA (Adejuwon and Oki 2011; Kheswa and Duncan 2011; Sharp et al. 2015; Zhao et al. 2012). COA may experience multiple measures of HIV-related stigma which may be extended to them in a variety of ways namely, overt discrimination, bullying victimisation, denied access to a formal education, social isolation, and being denied support services as a result of the negative attitudes embodied by healthcare and support providers (Kheswa and Duncan 2011; Lichtenstein

2008; Tran and Mwanri 2013). HIV-related stigma holds the potential to inhibit the psychosocial functioning of COA, setting them apart from their counterparts, as Chi et al. (2015), suggested that, HIV-related stigma may adversely affect the feelings, thoughts, and behaviours of an individual, negatively impacting one's psychosocial well-being. Similarly, reviews conducted by Deacon and Stephney (2007) and Yassin et al. (2018) associated stigma with the poor psychosocial well-being and functioning of COA as they are associated with a highly stigmatised disease, particularly in countries with a widespread of HIV/AIDS.

Despite substantial efforts to combat HIV-related stigma, it remains prevalent in contemporary day and poses a public health challenge and may negatively hinder healthy psychosocial development in COA (Li et al. 2015; Sharp et al. 2015). Little has been done to understand the manner in which HIV-related stigma affects the psychosocial well-being of COA (Chi and Li 2013; Deacon 2006; Sharp et al. 2015). Firstly, to date, there has been a rise in evidence examining the impact of different measures of HIV-related on the psychological health of COA while overlooking the psychosocial and holistic well-being of COA. Secondly, as current knowledge is dominated by statistical studies, few studies have set out to explore and understand COA experiences of HIV-related stigma with regard to their psychosocial well-being, thus limiting our understanding of COA experiences and perceptions of HIV-related stigma and its associated impact on their well-being. Lastly, the few studies focusing on the experiences of COA gathered these experiences from relatives, caregivers, and other adults associated with the child. This study, therefore, aimed to explore children orphaned by AIDS perceptions and experiences of HIV-related stigma and the manner in which it has affected their psychosocial well-being.

Methodology

Study design

A qualitative approach with an exploratory descriptive study design was adopted for the study. This study design allows for the in-depth, rich, and holistic understanding of HIV-related stigma and the manner in which it affects the psychosocial well-being of COA (Polit and Beck 2004). The study was guided by the research question: "How do children who have been orphaned by AIDS perceive and experience HIV-related stigma and the manner in which has affected their psychosocial well-being".

Study setting

The study was conducted in a suburb and an informal township in Cape Town, which is situated in the Western Cape,

South Africa. South Africa has the highest population of individuals living with HIV/AIDS, with a large population of orphaned youth, estimated at 2.3 million youth (UNICEF 2015). The high prevalence of HIV/AIDS in South Africa is accompanied by high levels of HIV-related stigma manifesting in various ways from peer rejection and violence to murder (Gamarel et al. 2017). Thirty percent of the Western Cape Province's population consisted of children, of whom 6.7% of children were orphaned either paternally, maternally, or both. The study areas had a population of 237,414 individuals, with children under the age of 18 years amounting to more than 27% of the population (Statistics South Africa 2011). The study was conducted at two sites, (1) a child and youth care centre founded in 1919. The centre is a registered non-profit organisation offering community-based provision for residential care and support for vulnerable children affected by poverty, violence, and orphanhood; and (2) a township area severely affected by poverty, violence, and HIV/AIDS.

Study population

Purposive, criterion non-probability sampling technique was used to recruit participants. This sampling technique allowed for the inclusion of participants meeting a predetermined criterion of importance aligned with the aim of the current study (Patton 1990, 2001). Additionally, this technique allowed for the collection of in-depth information from participants. Children were eligible to participate in the current study if they, (1) were between 7 and 17 years of age; (2) have lost one or both parents to AIDS-related causes; (3) are HIV-negative; and (4) have been orphaned for more than 6 months. Children were required to be HIV-negative to ascertain whether experiences of HIV-related stigma resulted from parental HIV/AIDS rather than the participants' own HIV status. To prevent reactions of acute bereavement and distress, children orphaned in the last 6 months were excluded from the study (Boyes and Cluver 2013). Thirteen participants were purposefully recruited for their participation in this study (Polit et al. 2001), and interviews were conducted between November 2017 and February 2018. The sampling process ended once data reached saturation and no new themes emerged.

Recruitment procedure and data collection

Participants were recruited through the help of the directors of non-profit organisations, social workers, counsellors, and community workers. The recruitment process began with the researcher contacting several non-profit organisations, social workers, and community members—assisting orphaned or AIDS-affected children—to explain the purpose and significance of the study. An information sheet was provided to all respective parties in order to be distributed to potential participants and their guardians to solicit their voluntary

participation in the study. Directors, health-service providers, and community workers approached eligible families to ascertain if their children would like to participate in the study. Once approval was attained from guardians or parents, potential participants met with the interviewer to start the process of informed consent. Participants were provided with informed consent which included information about the aim and purpose of the study, confidentiality, voluntary participation, perceived risks and benefits of the research being undertaken, and contact details of the primary researcher for further queries. Additionally, the aim and purpose of the research study were explained to participants in a language that they understood, and all questions regarding the study or process were addressed. No deception was used and the correct information was given to participants, legal guardians, and non-profit organisations. The verbal consent of participants was attained and audio-recorded, while consent and assent forms were signed and collected from legal guardian/s before the interviews were conducted.

Data was collected through individual open-ended face-to-face interviews. The interviews were conducted in a private setting and time to the choosing of participants by a trained investigator. The interviews ranged between 20 and 50 min, being no longer than an hour as suggested by Marshall (1996) and were conducted in English and Afrikaans. With the permission of participants, the interviews were audio-recorded. The purpose of the study, perceived benefits, limitations to confidentiality, and the possibility of any risk or harm were reiterated before the interview, affording participants an opportunity to withdraw their participation (National Health Research Ethics Council 2015; Tsheko 2007). Pseudonym names were assigned to participants, while, no personal descriptors were used throughout the course of the interview.

Considering the high rates of non-disclosure of parental HIV/AIDS, specific questions pertaining to HIV/AIDS or HIV-related stigma were not asked unless mentioned by participants themselves. Engagement techniques were used to establish rapport with younger participants prior to the interview to reduce anxiety and increase their comfortability (Irwin and Johnson 2005). The researcher acknowledged that participants were regarded as vulnerable children implying an unequal relationship between the researcher and participant. Therefore, trust was maintained by (1) communicating any changes or amendments to the research project; (2) promoting the best interest of participant and protecting their well-being; (3) continually reiterating the conditions of participation; (4) refraining from any action that constitutes improper pressure on the participant to participate; (5) creating a space for the participant to freely discuss their concerns (Human-Vogel 2007). Safety monitoring, through observation, was used to identify any sign of distress displayed by participants. Field notes and observational cues were recorded by the researcher at the end of each interview, documenting the context of the

interview and highlighting key emerging themes and any adverse events.

Data collection tools

An interview guide consisting of a series of open-ended questions and prompts was adapted along the (1) guidelines proposed by Shaw et al. (2011) and (2) the findings of a study conducted by Yassin et al. (2018). The interview guide served to guide the interviews, promoting the descriptive exploration of COA perceptions and experiences of HIV-related stigma and its impact on their psychosocial well-being (Barbour and Schostak 2005). The interview guide was suggestive and flexible rather than rigid and instructional to "improvise fruitful questions and peruse unanticipated lines of inquiry" (Millward 1995, p. 429). To avoid distress and remain sensitive to the nature of the study, questions did not specifically refer to parental bereavement or HIV/AIDS but remained sensitive to detect experiences of HIV-related stigma and poor psychosocial well-being. As the interview guide was the primary data collection instrument, a pilot study was conducted to (1) test the quality of the instrument; (2) reduce bias; (3) identify ambiguities; (4) clarify the wording of question; and (5) identify difficult and unnecessary questions as suggested by Noor (2008) and Chenail (2011).

Data analysis

Atlas. ti (version 8) was used to facilitate the process of data analysis which followed the steps outlined by Braun and Clarke (2006). Given the exploratory nature of the current study, thematic analysis was conducted allowing for a rich and detailed account of the experiences and perceptions of COA to emerge (Braun and Clarke 2006). The interviews were transcribed verbatim and the quality of each transcription was double-checked by the primary researcher. The transcripts were actively read and notes were made to establish familiarisation with the data. After repeated reading, 328 initial codes were created and grouped into meaningful clusters resulting in 20 refined codes. The 20 meaningful codes and their extracts taken from transcriptions were collated giving rise to three primary themes and five sub-themes representing the data. Themes and sub-themes were further refined by re-examining the codes of each theme or sub-theme and their extracts to determine whether codes and as a theme as a whole reflected the true nature and meaning of COA perceptions and experiences of HIV-related stigma and the manner in which it has impacted their psychosocial well-being. The refinement of themes resulted in the amalgamation or further breaking down of possible themes. Upon the finalisation, each theme was defined by identifying their essence and named accordingly. The findings of the study are reported below.

Ethical considerations

The study was approved by the University of the Western Cape's Human and Social Sciences Research Ethics Committee under ethics reference number HS17/1/17.

Trustworthiness

The trustworthiness of the study was ensured by credibility, transferability, dependability, and conformability as suggested by Shenton (2004). Credibility was ensured by (1) adopting well-established research methods previously used in qualitative data; (2) a pilot study to gain familiarity with the culture of participants and organisations prior to the study to establish an understanding of the phenomenon and trust; (3) triangulation of data by using in-depth face-to-face interviews, field notes, and observations; and (4) qualified and experience investigators. The in-depth account of the study's background and description of the phenomenon allows for transferability. Dependability was ensured through explicitly accounting for the study site, criteria for participant inclusion, sample size, data collection methods, data collection procedure, and the time period in which the study has been conducted so that the study may be replicated. Lastly, conformability was ensured by the reduction of researcher bias through the use of bracketing, provision of in-depth methodological procedures, and the acknowledgement of limitations of the study.

Findings

Sample characteristics

The demographic characteristics of participants are presented in Table 1. Thirteen South African children consisting of nine males and four females participated in the study. The age of participants ranged from eight to 17 with a mean age of 11.85 years. All children included in the sample were HIV-negative, according to their caregivers. Of these orphaned children, seven were maternally orphaned, two were paternally orphaned, and four of them were double orphans. The length of time being orphaned ranged from 13 months to 14 years. At the time of the interview, all of the participants attended school and were receiving a formal education. Majority of the participants received care from a residential care facility run by house mothers and fathers while the remaining participants resided with extended family.

Three primary themes emerged from the data namely, (1) children's experiences of stigma and discrimination; (2) children's perceptions of HIV-related stigma; and (3) the psychosocial well-being of orphaned children. Each theme has been divided into sub-themes to highlight pertinent aspects of the data.

Table 1 Sample demographics

	Male	Female	Total	%
Children	(n = 9)	(n = 4)	13	
Age				
8–10 years old	8	0	8	61.53
11–17 years old	1	4	5	38.46
Orphan status				
Maternal orphan	4	3	7	53.8
Paternal orphan	2	–	2	15.4
Double orphan	3	1	4	30.8
School attendance				
Yes	10	3	13	100
No	–	–	–	
Living arrangements				
With extended family	1	4	5	38.5
Residential care facility	8	–	8	61.5
Other	–	–	–	
Caregivers				
Relatives	1	4	5	38.5
Residential care	8	–	8	61.5
Relationship with child				
Surviving parent	1	–	1	7.7
Grandparent	–	1	1	7.7
Other relatives	–	3	3	23.1
Residential care mothers/fathers	8	–	8	61.5

Children's experiences of stigma and discrimination

Participants reported that their new living conditions were marked with overt discrimination as they were rejected, excluded, and received differential treatment compared to other children within their residential homes. Participants further expressed that they were not welcomed, isolated from others, and excluded from events and activities that included other children within the home. As explained by one participant below:

> So when I came here to my grandfather's sister, … I saw that I was shown that I was not from there. Like they would isolate me from the things that they were doing. So sometimes they would go to the mall, all four of them and then I would be left behind I would feel that I'm being picked out and I didn't get much things. They would buy them tekkies and clothes for December and I wouldn't get one. (Female, 16)

Younger children in residential care reported that they have been abandoned by their extended family, as they left the orphaned child in the care of a residential facility and discontinued all visitation as indicated below:

They send me here, they don't fetch me. They don't visit me … They can, but they don't (Male, 9)

Children living with extended family reported more severe accounts of stigmatisation and overt discrimination including physical, verbal, and sexual abuse, in the homestead compared to children living in residential care. Children were beaten, criticised, and sexually assaulted by others. As explained by participants below:

> So after my mother died in 2003, my grandmother raised me until 2011. So I went to stay with my grandfather's sister here at LA44 because my grandmother was abusing me … because sometimes she would beat me for things that, she would take out her stresses and things and beat me. (Female, 17)

> I feel like they are going to, because the kind of situation we live there it's very different. I would say they would criticise me, because even for the good things that happen to me (Female 16)

> And when I was small, I was almost molested by my grandmother's sister's son. Ja, so he molested me in a way that he made me do oral sex to him, and ja. (Female, 14)

While children residing in residential care lacked experiences of abuse received from their extended family, they continually reported bullying victimisation received from their peers. Orphaned children were called names, beaten, thrown with stones, sworn at, and insulted by their peers. As explained by participants below:

> That my friends swear me out … They are thrown stones at me and stuff. (Male, 7)

> They fight with me, they swear my mother out and they kick me" (Male, 10)

> sometimes the other children want to hit me. My friends want to hit me when I do nothing to them … And they swear me out (Male, 12)

Experiences of enacted stigma contributed to experiences of internalised stigma, known as self-stigma as COA accepted negative views of themselves as truthful and valid. Participants internalised the negative views of

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others resulting in them developing feelings of shame, embarrassment, self-hatred, dirtiness, and being unworthy and unlovable. As expressed by a participant below:

> Grade 9 ja, Grade 9 after my mom passing, I was meeting this boy, but then like whenever he wants to touch me, I wouldn't allow him. I wouldn't allow him because I was like no, I feel dirty or I feel no, I'm not good enough (Female, 17)

> Yes, I think it's part of the reason why because I don't want to feel like I'm dirty, you know? It is, because I feel like it creates that error in other people, because maybe some people would look at themselves and feel disgusted, or maybe I also have this disease, because they never disclosed this to me, maybe I also have this. This disease, my mom had this thing, or my dad has this thing. (Female, 17)

Enacted stigma and vicarious stigma alike contributed towards participant's perceptions of HIV-related stigma associated with parental illness and death. Vicarious stigma acted to convey the existence of HIV-related stigma to orphaned children increasing their perceptions about the risk and likelihood of experiencing overt discrimination. Vicarious stigma was described as, talking about the deceased parents, the ill-treatment of infected individuals and acts of stigmatisation directed at children affected by familial HIV/AIDS. Experiencing, witnessing, and hearing about overt discrimination contributed towards the COA perceptions of HIV-related stigma. As two participants explained:

> it's because of the people I grew up around, I'm sure the girls, most of them I grew up with them, because I used to live with them, and I saw how they grew up and how the family members treated them. And not just them, you know, just around me I'm hearing stories from people. I think that's why I strongly believe that there is stigma around HIV (Female, 17)

> Well I don't know, because I only heard last year that she was positive, so it was not something that I really had in mind, but yes, some children say like your mother passed away from that disease, whose going to do this for you if you come with us and all that stuff. (Female, 14)

Perceptions of HIV-related stigma

The results indicated that COA were perceptive of HIV-related stigma and spoke extensively about the nature and prevalence of overt discrimination associated with HIV/AIDS within their communities. These perceptions were associated with the fear of falling victim to acts of overt discrimination from their family, friends, and the community. As one female participant disclosed:

> Because I think in society, you know when you have HIV, people look at you differently. I don't know, maybe they look at you like as if you're dirty or you don't belong, or they judge you. I don't know. But based on like TV now and hearing things, I think the normal people when they know you have HIV, they kind of like oh uh-uh don't approach this person. They treat you differently. (Female, 17)

Non-disclosure of parental infection and death

Perceived stigma was also expressed through COA accounts of non-disclosure of familial HIV/AIDS. COA expressed negative feelings about the disclosure of parental HIV/AIDS to others and appeared to be concerned about the negative consequences disclosure may yield. These fears were based on their perceptions regarding the nature and prevalence of HIV-related stigma. To avoid experiences of overt discrimination, COA avoided disclosing their association to HIV/AIDS in order to be positively perceived by others as explained below:

> But I don't feel like telling my story. I do tell my story, but to people that I know that it's going to be kept a secret, or it's going to be confidential. (Female, 14)

> I never speak about the HIV part, so if anyone will ask me what happened to your mom, or if it happens, maybe I'm doing an oral in class and I want to share my story, and then I always mention the cancer part. But never that she had HIV, because I'm scared what will they think of me. So I will always mention the cancer and not the HIV part (Female, 16)

Many expressed that the cause of parental death was concealed from them by extended family out of fear that they may be ill-treated and rejected by others. Often concealment of parental cause of death caused COA to embody feelings of sadness and anger, while contributing to their perceptions of HIV-related stigma as one female participant stated:

I was very angry and it took a while for me to actually forgive my grandmother, because I feel like even if my mom, why didn't she tell me that she had HIV I knew everything about her, why would she keep this one from me? Maybe she thought I was very young and I wouldn't be able to handle it, or maybe I'd look at her in a different way, I don't know. (Female 16)

Despite the presence of HIV-related stigma, three participants reported a culture of non-discrimination from extended family and educators. Children noticed no differences in their relationships with others despite their association to parental HIV/AIDS. Contrastingly, children reported an increase in acceptance, support, and love received from family member and educators. However, such support and acceptance was received in the presence of non-disclosure. These experiences are conveyed by the reports of participants below:

my granny, she was the person who was always supporting me, and my family members, they're all supporting me. My dad was very supportive … He showed me love, that's where he was really close to me (Female, 17)

They are all nice to me … They share with me, they always talk to me, they help me … They listen to me when I have a question. Help me on the school work (Male, 9)

The psychosocial well-being of children orphaned by AIDS

The findings of this study suggested that poor psychosocial functioning may be attributed to experiences and perceptions of HIV-related stigma associated with parental HIV/AIDS. Several domains of psychosocial well-being and functioning affected by experiences and perceptions of HIV-related stigma were outlined in the findings of this study and includes (1) psychological and emotional well-being; (2) social well-being and perceived social support; (3) self-concept and self-esteem; and (4) future orientation.

Psychological and emotional well-being

As interviews progressed, it became evident that the psychological and emotional well-being of COA was indeed affected by experiences and perception of HIV-related stigma associated with parental HIV/AIDS. Most participants expressed feeling distressed, depressed, and

sad because of overt discrimination received from others and often cried to console themselves as explained by participants below:

I'm sad, or I'm looking back in my life and everything, I will just lock myself in the room and cry … I close the door, I start crying and crying and crying and then I come and I say everything is going to be fine, and that the Lord knows why all these things had to happen to me. (Female, 16)

I would say depressed, but there are times when I feel happy, but most of the time I feel depressed. (Female, 16)

Participants reported that they avoided speaking to others about their concerns and problems, as they remained fearful of being stigmatised. To address these fears, children employed emotion-focused coping strategies which include silence, self-isolation, and withdrawal. As two participants reported:

I sometimes don't talk about everything because now I'm scared of how people are going to look at me. So I wouldn't share some of the things that's happening to me, so it makes me, I don't know, it makes me a person who is quiet sometimes (Female, 14)

I'm never seen outside, so I don't know what people think; they've never said anything to me. I don't usually get any, I don't have friends in my community, so I'm always at home. I don't even know my neighbours, like that's how I stay at home. (Female, 16)

The withdrawal and self-isolation contributed to the psychological distress experienced by COA and negatively impacted their emotional well-being, as it restricted their ability to healthily express their feelings and concerns to others (emotional regulation). Poor emotional regulation was met with feelings of sadness, anxiety, depression, and helplessness (poor emotional status). As one participant describes:

I'm not able to communicate to other people easily. I don't communicate with people with my problems. I'm always a smiling person, always keeping what I'm feeling inside. I'm not showing it to other people (Female, 16)

Social well-being and perceived social support

Children reported that their social well-being was affected by non-disclosure surrounding parental infection and death. One female participant explicitly acknowledged the role of non-disclosure in limiting the social support she received from others as she stated:

> In fact it affects you because you find that there are people who would love to help you, but now because you are silent and you're not talking about it, and then sometimes you won't receive the help that you can receive, and then you end up making decisions on your own, and sometimes decisions are decisions to end up literally repeating even the history, you know. Or making decisions that at a stage you're going to regret (Female, 17)

Children struggled to form healthy interpersonal relationships. Their inability to express their feelings or discuss traumatic life events limited the intimacy and connection they felt towards others. Most participants reported that they were unable to form good relationships with their extended family and caregivers, from whom they received limited support. As a female participant reported:

> My family, there's no one that I could say I would sit down and talk like this … they are not like 100 percent there, because most of the time I do my things myself, I apply for school for myself, like I'm the one who is always … And they're not even asking what's happening? I should always be the one who tells them now this is happening (Female, 16)

However, another female participant stated that she had good relationships with members of her extended family, who provided her with continuous financial and emotional support as she explained:

> my granny, ja, passed away so she was the person who was always supporting me, and my family members, they're all supporting me (Female, 17)

Older participants reported healthier fraternal relationships as most had a trusted friend with whom they have formed a connection. These close friends provided COA with the needed social support for them to healthily discuss important life events and stressor they are unable to convey with their extended families. While younger children relied on their educators for social support. Educators assumed the role for helping COA. These ideas are presented in the excerpts provided by a female and male participant below:

> I'll just be speaking to a friend and the next thing I find myself talking to her about everything that happened, and then after I would feel lighter about the situation. (Female, 16)

> They are all nice to me … They share with me, they always talk to me, they help me … They listen to me when I have a question. Help me on the school work. (Male, 9)

Self-concept and self-esteem

Upon initial perceptions, participants gave the impression that they were confident about themselves and had high levels of self-esteem. As interviews progressed participants, accounts of internalised stigma reflected their lack of self-esteem and the negative view they held of themselves. Participants appeared to believe that they were a burden, unloved, unworthy, and dirty and displayed a lack of uncertainty regarding their decisions, constantly comparing themselves to others. As explained by two participants below:

> I would feel as if they don't love me. I think it's because of the situation I grew up in. I'm very sensitive when it comes to the people I care for and what they think, and sometimes maybe it's nature (Female, 14)

> I feel like I don't love myself, not in terms of, like for me I compare myself with other people and I saw them, the mistakes that I have with the other person that they don't have, and I would say to my mind I thought they are the ones that are brainwashing me and think about things that are inappropriate (Female, 16)

Future orientation

Surprisingly, all participants displayed a positive future orientation as they appeared to be hopeful and optimistic about their futures in which they were able to pursue their aspirations and goals as explained by one female participant:

> I see a strong person, I see someone who is going to be successful in life, regardless of what she went through. But now what it has done is that like I told myself that whatever I do in life, I don't also see myself with boys. (Female, 17)

While younger participants were unable to articulate what they would like to do in the future, they appeared optimistic

and reported that they would like to study when they grow up. One male participant explained that he would like:

> To be a actor, then I study at collage drama and everything (Male, 9)

While older participants appeared ambitious about their future, they lacked consistency and clarity regarding the pursuit of their future aspirations and goals. Instead, participants expressed their desire to pursue several career paths simultaneously, remaining indecisive about their future plans. These ideas are expressed by one female participant:

> I wanted to be part of the casting agency and then I had to save up money when I go to my first year, so I know that I have already money in there and then I wanted to study to become an interior designer, and then to be there. And then at a later stage to study more about the human skin, to become a dermatologist and have my own spa and all that (Female, 16)

Participants lacked perceived control over their future and often questioned why they have experienced misfortune as expressed by one female participant below:

> I would think my friend maybe got treated in chance and then she went to that school, what about me? What happened? What did I do to deserve this? But at the end of the day I only say God has a reason for everything. So I just think that (Female, 16)

Discussion

This study explored COA perceptions and experiences of HIV-related stigma and how it has affected their psychosocial well-being. The findings of this study highlight the presence of HIV-related stigma in the lives of COA as a result of being parentally bereaved by AIDS-related causes rather than their own HIV status. COA were rather perceptive of the presence of HIV-related stigma and experienced various measures of HIV-related stigma from their families, friends, and surrounding communities. These perceptions and experiences affected various domains of their psychosocial well-being including their psychological health, emotional well-being, social well-being and perceived social support, self-concept and self-esteem, and future orientation.

The current study identified enacted stigma, also known as overt discrimination, as the most reported measure of HIV-related stigma experienced by COA. Threatening, discriminatory, and isolating behaviours received from others are consistent with those discussed in previous studies (Chi et al. 2014;

Caserta et al. 2016; Harms et al. 2010), as children spoke openly about being rejected, excluded, bullied, victimised, abandoned, abused, and being treated unfairly by their extended family, friends, and community members. However, there were key differences in reports of enacted stigma across COA. Younger children living in residential care reported being abandoned, bullied, and victimised while, older children living with extended family reported being treated unfairly and abused within their new homesteads. Despite the variation in experiences of enacted stigma, COA consistently associated feelings of distress, depression, anxiety, and sadness with their accounts of overt discrimination, indicating psychological distress and a negative emotional status. Enacted stigma has been previously identified as a key contributor to the psychological distress experienced by COA, as social exclusion and overt discrimination places COA at increased risk for developing internalising, emotional, and behavioural issues in comparison to other groups of orphaned youth (Asanbe et al. 2016; Cluver and Gardner 2007; Cluver et al. 2012; Chi et al. 2014; Zhao et al. 2012).

Fearful of experiencing enacted stigma, COA isolated and withdrew themselves from others. Major and O'brien (2005) identified self-isolation and withdrawal as emotion-focused coping strategies to protect one's self from traumatic events, like stigmatisation. These emotion-focused coping strategies were similarly associated with COA experiences of vicarious stigma. Vicarious stigma, previously identified by Cluver and Gardner (2007) and Steward et al. (2008), leaves COA fearful of experiencing stigmatisation and discrimination as vicarious stigma contributes to COA perception of the prevalence of enacted stigma within their communities. Emotion-focused strategies restricted COA capacity for healthy emotional regulation, as they were unable to appropriately expresses their feelings and emotions regarding stressful and challenging life events with others further contributing to their development of a negative emotional status and psychological distress (Cheney 2015; Bogart et al. 2008; de Klerk 2012; Zhao et al. 2009). As a result of both enacted and vicarious stigma, COA were rather perceptive of the stigmatisation associated with HIV/AIDS within their communities.
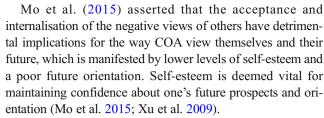
Experiences of perceived stigma were conveyed through COA accounts of non-disclosure and silence as they actively concealed the cause of parental illness and death from others to avoid stigmatisation and discrimination from others. COA experienced a profound sense of anxiety and fear when faced with the disclosure of parental HIV/AIDS, encouraging the acts of non-disclosure and silence among COA. These findings are consistent with Goffman's (1963) suggestion that individuals conceal negative information about themselves through strategies of passing and covering, to protect oneself from stigmatisation and discrimination. Similarly, related studies (Mo et al. 2015; Thupayagale-Tshweneagae and Benedict 2011) have indicated that COA often fear disclosing

their association with familial HIV/AIDS because of the associated stigma and strive to minimise their experience of enacted stigma. Similarly, accounts of non-disclosure were adapted by extended family as the cause of parental illness and death was concealed from COA to protect them from HIV-related stigma. However, these attempts were met with the development of feelings of anger and resentment in COA. Strategies of silence and non-disclosure actively hinder COA ability to form a sense of intimacy and healthy trusting interpersonal relationships with others. In the absence of healthy interpersonal relationships, COA question the perceived social support received from others, which refers to COA subjective perception of the extent to which others are able to provide the support, resources, and assistance necessary to cope with stressors and adversities including parental bereavement and discrimination (Cohen and McKay 1984; Galvan et al. 2008; Prati and Pietrantoni 2009; Wei et al. 2016; Xanthopolous and Daniel 2013). The availability or perception of social support has been identified as a protective factor and an effective critical resource able to reduce psychological distress and enhance the coping-skills of COA (Doku et al. 2015). Doku et al. (2015) propose that children who receive inadequate support from their families are depressed, sad, lonely, and withdrawn, while those who receive adequate support display healthier psychosocial development. Therefore, silence and non-disclosure places COA beyond the reach of attaining the social and psychological support needed for healthy psychosocial well-being (Xu et al. 2009).

Despite the lack of familial support and emotion-focused coping strategies, COA were able to form healthy fraternal relationships as most children reported having at least one close friend. One possible explanation would be that of non-disclosure as Qiao et al. (2012) suggest that non-disclosure is met with increased perceived support and a reduction in stigmatising behaviours received from others. This ideology may also address the culture of non-stigmatisation reported by participants.

Maintaining healthy trusting relationships largely impacts the psychosocial dimensions of self-esteem and self-concept (Du et al. 2015). Through social support, COA may receive positive appraisal reasserting a positive evaluation of themselves (Du et al. 2015). In its absence, COA displayed lower levels of self-esteem and a poor self-concept, expressing that they are unloved, unworthy, dirty, and a burden to others. These accounts may be identified as experiences of internalised stigma (Mo et al. 2015). With a lack of social support, COA lack the positive appraisal of others and are unable to manage negative actions and feedback received from others (Du et al. 2015). Additionally, the lack of social support may hinder COA participation in positive social activities negatively affecting their self-esteem and optimism about the future (Adejuwon and Oki 2011; Ishikawa et al. 2010).

Mo et al. (2015) asserted that the acceptance and internalisation of the negative views of others have detrimental implications for the way COA view themselves and their future, which is manifested by lower levels of self-esteem and a poor future orientation. Self-esteem is deemed vital for maintaining confidence about one's future prospects and orientation (Mo et al. 2015; Xu et al. 2009).

Participants although, optimistic about the future, continued to expressed uncertainty and a lack of confidence regarding their future prospects, expressed their desire to pursue multiple career paths simultaneously. Surprisingly, all children were enrolled in school and were receiving a formal education. This finding is inconsistent with previous studies that suggested HIV-related stigma limited the educational opportunities available to COA and the adoption of emotion-focused coping strategies resulted in increased school non-attendance which hindered the attainment of scholastic knowledge, consequentially negatively influencing the future orientation of COA (Xu et al. 2009).

This study may have several potential limitations. Non-disclosure and sensitivity surrounding the discussion of parental illness and death restricted the number of participants who were willing to participate in the current study. However, the number of participants remained sufficient to gather rich and full accounts from COA. The study was conducted with participants situated in South Africa; therefore, the results may not be generalizable to other regions, but may allude to issues of HIV-related stigma and its associated challenges, in ensuring the well-being of orphaned and vulnerable children in regions severely affected by HIV/AIDS. Lastly, younger participants may be unable to fully express and convey their experiences due to continuing cognitive and emotional development occurring during the phase of pre-adolescence. Despite the highlighted limitations, the study contributes to our understanding of the lived experiences and perception of COA regarding HIV-related stigma and the challenges these experiences pose to their psychosocial development and well-being.

Implications for future research and practice

The findings of this study have several implications for future research and practice. Future studies should focus exclusively on HIV-related stigma and its outcomes on the psychosocial well-being of COA. There is a need for longitudinal studies to measure long term effects of HIV-related stigma on the psychosocial well-being and development of vulnerable and orphaned children. Future research should include a larger sample population, to provide more generalizable results and a greater understanding of the lived experiences and perceptions of COA. As stigma affects the well-being of COA, it is essential for practitioners and clinicians to remain cognisant of overt discrimination, silence, and non-disclosure when working

with COA. Considering the association between social support and psychosocial well-being, it is important to strengthen the support system available to children affected by HIV/AIDS to bring about a reduction in psychological distress and improved psychosocial well-being. Resources such as individual counselling and cognitive behavioural therapy may prove beneficial in reducing internalised stigma and correcting irrational beliefs about ones-self. These interventions offer COA skills such as stress management, improved coping strategies, and an improved self-esteem and self-concept. Family interventions and therapy should be considered as an intervention to reduce stigma, strengthen familial support, and improve the psychosocial well-being of COA. Social welfare services may be able to monitor the living environment and conditions in which a child is placed, ensuring their well-being. The availability of these services serves as a contact point for children to express or report any ill-treatment and abuse or poor living conditions. The findings of this study highlight the continuing need for stigma awareness campaigns and reduction efforts within communities affected by HIV/AIDS. Lastly, there is a need for the development of tailored programmes for children negatively affected by HIV-related stigma to firstly, bring about a reduction of stigma and to promote, improve, and support healthy psychosocial well-being of COA.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of the Western Cape and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the University of the Western Cape's Human and Social Sciences Research Ethics Committee under ethics reference number HS17/1/17.

Informed consent Informed consent was obtained from all individual participants included in this study.

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