Chapter 4

Three Decades of HIV/AIDS Pandemic: Challenges Faced by Orphans in Tembisa, South Africa

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Additional information is available at the end of the chapter

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Abstract

This paper was extracted from a broader study conducted on the effectiveness of social support mechanisms provided to human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) orphans in Tembisa, Gauteng Province. Using a qualitative research design, an interview guide was designed for in-depth interviews, which were conducted with 12 HIV- and AIDS-affected and -infected orphans. In addition, a focus group discussion was run with 13 children's caregivers and two social workers were interviewed as key informants. Nevertheless, this paper discusses the challenges faced by orphans of HIV and AIDS. Maslow's hierarchy of needs was used as the theoretical framework of the study. The findings indicate that the death of a parent signifies the disruption of the basic pattern of a child's life living in the urban area where the role of extended families does not exist as compared to rural areas where a child belongs to the whole village. There are challenges that are impacting on the daily lives of the HIV/AIDS-affected and -infected orphans. Notably, the participants' narratives suggested that there were challenges in terms of health, shelter, education and food. It is concluded therefore that the war against the impacts of HIV and AIDS is still far from being achieved.

Keywords: HIV and AIDS, social support, challenges, orphans, caregivers, social workers

1. Introduction

Human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) is one of the major public health challenges and it is a pandemic worldwide [1]. Statistics released by Statistics South Africa showed that the population of the country was estimated at 54.96 million by mid-2015 with approximately 48% being male and 52% female [2]. Furthermore,

Statistics SA showed that the estimated overall HIV prevalence rate is approximately 11.2% of the total South African population. The total number of people living with HIV is estimated at approximately 6.19 million in 2015. For adults aged 15–49 years, an estimated 16.6% of the population is HIV positive [2].

Further, HIV/AIDS has increased the number of orphans enormously to the extent that the United Nations in 2000 defines an orphan as a child who has lost one parent. This is because, when the first parent is killed by the disease, the next one follows within a short period of time. The death of both parents leads the child to be called a double orphan [3]. However, in most African nations, the fact of the matter is that the burden of parental death from AIDS is the greatest with 12.3 million children under the age of 15 having lost one or both parents to AIDS [4]. There is an estimation that 12 million children aged 17 and younger in the sub-Saharan Africa have lost one or both parents mainly due to HIV/AIDS [5]. This sordid truth is not far-fetched even in the Southern African region. Then, it was concluded that these children are often left in the care of caregivers who have limited resources and abilities to care and provide for their psychosocial needs [6].

The General Household Survey in 2007 identified approximately 3.7 million orphans (children without both parents) living in South Africa. This survey also indicated that the number of children who had lost both parents had increased over the previous 5 years (2002–2006) and of further interest was that during 2006, 77% of all orphans were of school-going age—7 years and above.

Substantially, there are international articles that place primary responsibility of the welfare of children on parents or guardians and extended families. These are the Convention of the Rights of the Child (CRC) (Article 5) and the African Charter on the Rights and Welfare of the Child (AC) (Articles 9 (3) and 18). However, the African norms and values just like the aforementioned articles also articulate such child-welfare values. Even Kawewe [6] argues that in many African traditions the extended family is part and parcel of child rearing with the villagers and community members playing a role as the child is viewed as belonging to everyone. He further concludes that the AIDS pandemic defies the concept of the analogy 'it takes a village to raise a child' as many communities can no longer cope with those in need of care. As a result, children are left without caregivers. Some are left in alternative care such as adoption, non-relative care or institutionalization.

South Africa is a signatory to the Declaration of Commitment of the United Nations General Assembly Special Session on Children held in 2002 (UNGASS). One of the articles of the Declaration states that

> By 2003 develop, and by 2005 implement national policies and strategies to:
>
> Build and strengthen governmental family and community capacities to provide supportive environments for orphans and boys and girls infected and affected by HIV and tAIDS including by providing appropriate counselling and psycho-social support, ensuring their enrolment in school and access to shelter, good nutrition, health and social services on an equal basis with other children, to protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance. (Article 65)

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In the past few years of the post-apartheid regime, profound political and social changes have been seen in South Africa, with the government taking the lead in introducing significant social welfare policy changes [7]. Major objectives of social welfare policies in South Africa are alleviating poverty and enabling the previously disadvantaged communities to have access to basic social services [8]. The social security system (mainly social grants) is the government's chief initiative in tackling poverty and inequality through which, according to [9], it has over 16 million beneficiaries accessing the social grants provided for by the government. Among these grants is a grant for children known as the Foster Care Grant.

The Foster Care Grant is also used to provide support for children orphaned by HIV and AIDS; it is orphans who have lost both parents who are the most likely to be receiving the grant, providing that children remain in the care of foster parents [10]. Partially reflecting the effects of a deepening HIV and AIDS pandemic, since 10 years ago, when HIV-related orphaning rates started rising rapidly, the use of the Foster Care Grant changed. The number of Foster Care Grant beneficiaries rose from 43,000 in 1997 to 300,000 in 2006 [11]. As of 30 April 2016, approximately 545,000 children were receiving the Foster Care Grant [9].

The Sowetan reported that the Social Development Minister Bathabile Dlamini, in Gugulethu, had highlighted that caregivers were reported to be misusing social grants [12]. According to the government, these social assistance grants are to assist caregivers to give orphans (in this case, HIV and AIDS orphans) a better life, a chance to be respectable members of the community and reduce poverty. However, a number of studies carried out so far have indicated that child poverty is still exceedingly high [13, 14]. According to UNICEF's report on the level of child poverty, it was clearly indicated that poverty was deepening in various parts of South Africa [4]. It was further argued that poverty and unemployment are key concerns that impact on a family's capacity to care for their children [7]. They also noted that previous inequalities in education, health care and basic infrastructure have also contributed to the backlog in present services [7]. The vulnerability of children, especially those living in poor areas, is compounded by HIV and AIDS.

A number of researchers [15, 16] have indicated that the HIV and AIDS pandemic is one of the greatest threats to the realization of child rights in South Africa and sub-Saharan Africa. Research by the Children's Institute demonstrates some of the multiple vulnerabilities faced by children before the death of caregivers [17]. Children often take on the responsibility of caring for sick adults and are unable to attend school or study because of the difficulties at home. In short, children's experiences of orphanhood and its compounded vulnerabilities begin long before the death of a significant adult. It is not surprising that many of the subsequent experiences of children who have been orphaned are poverty-related—such as an inability to afford school fees and school uniforms, prolonged experiences of hunger, inadequate housing and poor access to water [17]. On the other hand, Meintjes and Hall [18] reported that although the government and civil society have expressed concern about the growing number of children living in child-headed households, there is little evidence to support this fear.

The Department of Social Development provides care and support to orphans and vulnerable children and their caregivers and these include child-care forums, community-based drop-ins, home-based care centres, early childhood development programmes, among others. For the purpose of this study, support mechanisms refer to all social support given to HIV and AIDS

orphans in Tembisa Child and Family Welfare Society Organization. This assistance might be from social workers, care workers or givers and other members of society, offering support to orphans affected and infected with HIV and AIDS. The need for continuing social welfare policy reform processes and providing support mechanisms for responding to orphans and vulnerable children in South Africa is critical for policymakers. This research therefore evaluated the social support provided to HIV and AIDS orphans in Tembisa, Gauteng. A huge emphasis is placed on the challenges faced. The study focused more on the challenges faced by female caregivers as they form the bulk of Tembisa Child and Family Welfare Society's caseloads and the HIV and AIDS orphans in their care.

2. The research problem

The AIDS epidemic has affected many children in South Africa leaving them either affected or infected [19]. These children are left behind with the greatest challenge of all which is figuring out how to survive, they are left with responsibilities way beyond their capacities, and they lack financial, emotional, physical, mental and material support to care for themselves. In addition, they are left under the care of people who are financially, emotionally, physically or mentally incapable to care for them [20]. The government has put forward means to assist these children to cope with the difficulties of life, but regardless of these there is still a need to determine how effective the measures put forward are assisting.

The majority of orphans and vulnerable children in South Africa are left in the care of old and weak women or sickly caregivers. The government has made recommendable success in combating abject poverty and hunger through social assistance programme [21]. Even after such measures, issues such as fraud still hover around and most caregivers and orphans are still battling with meeting challenges of day-to-day living. However, [21] continues to argue that the high prevalence of HIV and AIDS among caregivers has worsened the challenges of child poverty. The government in 2005 enacted the Children's Act 38 of 2005 which provided under Section 155 and 156 for the orphans of whatever nature to be associated with Foster Care Grants. The grant was to assist foster parents put the orphaned children through school, clothe them and shelter them. Due to the backlogs in many organizations assisting with the application of these grants and the misuse of such grants by some foster parents, the survival of HIV and AIDS orphans is still a struggle far from being won. The previous inequalities in education, health care and basic infrastructure have highly contributed in caregivers being unable to care for orphans and orphaned children [21].

3. Theoretical framework

This study is anchored on Maslow's theory of human needs [22]. Maslow's theory of human needs depicts the hierarchy in a manner where needs in the lower level should be met before an individual can progress and satisfy the needs in the next level. This theory has five levels of needs, the lowest being the most basic need that a body cannot survive without and the top of the pyramid the least basic human need [23]. The lowest level of the pyramid is physiological

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needs, safety and security needs, love and belonging needs; at the top of the pyramid are esteem needs and self-actualization. Once a need is satisfied an individual will be able to go to the next need [24].

This theory is relevant in this study as HIV/AIDS orphans have needs that should be met in order to fulfil their responsibilities. Orphans are driven by several factors to strive to satisfy the bottom need, and then move on up the hierarchy. Therefore, through understanding their challenges as AIDS orphans, ways of motivating them to fulfil their lives can be developed and implemented.

4. Research area and methodology

Data presented in this paper were collected from Tembisa and the participants included HIV/AIDS orphans and their caregivers and social workers. The purpose was to get views from both the orphans themselves and the people who cared for these orphans. It is believed that once the researcher has developed an understanding of the rationale behind the choice of engaging in any form of research (either qualitative or quantitative), he designs the study [25]. Therefore, a qualitative research design was selected for this study. The goal of this method was to learn about the phenomenon and get in-depth information and feelings of the participants.

The study was conducted in Tembisa Township in the East Rand of the Gauteng province in South Africa. The township is just a few kilometres outside the Kempton Park and the second largest township in Gauteng after Soweto. Its population is estimated to be a little over 500,000. The township came about during the apartheid era as a beacon of hope to the black families who were evicted from their homes. Many people live in poverty and in shacks or the recently built houses from the government (Reconstruction and Development Programme). Tembisa Child and Family Welfare Society provides social services to the township, especially for HIV/AIDS orphans and their caregivers.

This study was only limited to HIV and AIDS orphans being serviced by Tembisa Child and Family Welfare Society and also residing there. The study also targeted the caregivers of the orphans and the social workers who were servicing them. Therefore, this research made use of 13 caregivers, two social workers and 12 orphans. For the purpose of this study, the non-probability procedure in the form of purposive sampling was utilized to select the sample. The orphans were selected purposefully from the database of HIV and AIDS orphans receiving services from Tembisa Child and Family Welfare Society. The samples were drawn from the caseloads of social workers.

The study used semi-structured interviews with the aid of interview guides. The interview guide consisted of non-directive unstructured questions which were written in English, but the interviews were conducted in both English and Zulu. The questions on the research guide were meant to guide the researcher to keep to the objectives of the study. The interviews conducted were recorded with an audio recorder to make it easy to capture all the data and also to avoid misquoting the participants.

Focus groups were also used as a method of collecting data and they targeted care givers. Focus groups are a means of understanding how people feel or think about an issue [26] and can help understand how people feel about the issue being studied. Participants in the focus groups were allowed to share their perceptions, points of views, experiences and wishes without any pressure. An environment that is tolerant and non-threatening to all participants was created. Once the research reached a point of saturation [27], the data collection process was concluded.

Qualitative data analysis was used. Data analysis was explained as the process of bringing order, structure and meaning to a mass of data collected [26]. Qualitative data analysis according to Ref. [26] is a search for general statements about relationships in different categories of data. The researchers went through the transcripts of the collected data with the use of a translator. Data analysis was done through the process of thematic analysis. Through reading the transcripts, the researcher came up with the underlying meanings of the information gathered. This process was repeated until a list of topics was acquired. Topics were then clustered together into baskets and were labelled as 'major topics', 'unique topics' and 'leftovers'. Data were then categorized into themes after finding the most descriptive wording for the topics [26].

In line with the ethical requirements of research, the researchers consulted with relevant authorities to gain access to research components. In order to gain access to the participants, the researchers firstly gained permission from the university in the form of an ethical clearance certificate. Other ethical procedures, including informed consent, anonymity and confidentiality, as well as participant debriefing were put into place during and after data collection. Potential respondents were verbally informed at the start of the study that their participation was completely voluntary and verbal consent of their participation was obtained. Caregivers provided verbal consent for themselves and their children. The children themselves gave consent for their participation and child-friendly language was used.

5. Results

This section provides the findings of the study, according to the themes that emerged. Firstly, the biographical information of the participants is laid out. Thereafter, the challenges faced by orphans, caregivers and social workers are presented.

5.1. Biographical characteristics of participants

Interviews were held with 12 orphans within the age range of 10–18 (both affected and/infected with HIV and AIDS). In terms of gender, these children were proportionately selected, that is, they consisted of six males and six females. A total number of eight children interviewed were both affected and infected with HIV and AIDS and four indicated that they were affected only. Seven of the orphans were maternal orphans with unknown fathers, two were paternal orphans with unknown mothers and three of them were double orphans.

The population of orphaned children in Tembisa is very high with Tembisa Child and Family Welfare Society recording a number of more than 3000 families every year. The average

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dependency ratio in most of these families is 1:3. In all cases reported to the organization, of every 10 children, eight are orphans affected or infected by HIV and AIDS. Furthermore, amongst 13 participants who were in the focus group discussions, there were three child-care workers and 10 caregivers. All of the participants were female black Africans. The participants' ages ranged from the age of 21–65 years. Two social workers were also interviewed as key informants.

5.2. Challenges faced by HIV and AIDS orphans

The study aimed at investigating the challenges that were being faced in the provision of psychosocial support to HIV and AIDS orphans and the results of these are highlighted in this section.

5.2.1. Theme one: poor health

HIV and AIDS has in the past presented a continuum of complex health issues that ranged from protecting personal health to ensuring that societies have adequate supplies of health care. In Tembisa, the main hospital (Tembisa Hospital) has a facility specifically for children infected with HIV and AIDS. All the children participating in the study who were on anti-retro viral medication or immune boosters claimed to attend *check-ups* at the hospital (Masakhane clinic). Child F stated:

> I started taking Anti Retro Viral treatment at the age of 5 (now 15 years old). It has been a routine for me and they are now like a part of me. My aunt usually takes me to the clinic for my check-up, but when she is not available to do so I go on my own…

Caregivers reported to understand the need to keep the children under constant monitoring to ensure that they did not default on their medication. It was, however, an agreement with most of the participants in the focus group that keeping track of what the children ate and did during school hours was difficult. They reported that because these are children and they like to experiment, they eat most of the things that they are told not to eat at the hospital. They eat these things behind the caregivers' backs. Such defaults only come to light when the children's viral loads spiral after hospital check-up.

Furthermore, the caregivers mentioned that they could not afford nutritious food to give the children. The two social workers who were interviewed also highlighted that the health of orphans deteriorated at times because of lack of nutritious food to eat which is required by those who were living with the virus. One of the social workers said:

> When we send the children for assessments to our doctor or the nurses here, we usually find out that the child's health would have deteriorated in terms of their CD4 count. This is usually caused by the children not eating the right food they are supposed to eat for example vegetables and fruits. (Social Worker 1)

5.2.2. Theme two: inadequate shelter

Of all the children in the study, five reported to be residing in either '*shacks*' or as tenants in outside rooms. Four children reported to be staying in their parental homes and three reported that they lived in the homes of extended family members and that their parents never owned houses of their own. One child stated that:

> I live with my three siblings in my grandmother's house. My mother used to live with us before she fell sick and passed away. Lucky for us, we are the only family my grandmother has now. (Child D)

For most of these children, though the case is quite different and another child highlighted that:

> My aunt has four children of her own and they are girls. She and my mother stayed together in our shack from the time I was born. The shack is two roomed and had one bedroom which my aunt and cousins sleep in. Two of my cousins now have children… there is hardly any space… (Child H).

5.2.3. Theme three: poor school performance

The loss of a parent due to any disease is not easy for a child. Losing a parent to HIV and AIDS is not easy for most children as they suffer from psychosocial effects and often lose concentration at school. Seven of the children interviewed were aware that their parents died of HIV and AIDS and two of these witnessed the illness and death of their parents. Child B reported:

> I was twelve and the eldest. I would help to wash and dress my mother. She was very sick but did not want to go to the hospital until it was too late… She passed away at home in my presence (sobs)…

The child reported that during the time her mother was sick, she went to school occasionally so as to help look after her. Her performance at school dropped a lot that she had to repeat some grades. Four years later, she still remembered the death of her mother like it was yesterday.

In all the interviews, the children indicated that when their parents had the HIV- and AIDS-related sicknesses, their performances in school were affected. Four of the participants suffered through absenteeism from school and hence missed out on some lessons and important tests. Others (six) had to drop out of school after the death of their parents and re-start at a later stage in a new school with present caregivers. Some (two) because of family circumstances were forced to enter into the system and be institutionalized, hence resulting in stigmatization by other learners in those schools. These and other factors have resulted in lower performance by most HIV and AIDS orphans as well as the overburden placed on caregivers to address their needs.

The caregivers also highlighted that the children's performance at school were poor. One caregiver mentioned that:

> At one point I was called by the principal of the school because of the poor performance of my sister's child I am staying with. The principal mentioned that the child was so brilliant but after the death of her mother her grades were getting lower and lower (Caregiver AA)

5.2.4. Theme four: food insecurity

Health and nutrition statuses tend to decline as less money is often available to properly feed the household. One caregiver reported that the greatest challenge they had with caring

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for the orphans was that it was not easy having an extra mouth to feed with the present day economy. She stated that:

> I have five children of my own and when my brother died, his three children came to stay with me as his wife died too and I am the only family left. Two of his children are attending school and the youngest is at crèche… my salary was not enough to feed and clothe my children (Caregiver BB)

Through the organization's Family Preservation programme, many community children find a source of food security from the food parcels handed out every month. Normally, family preservation is meant to work with a family for at least 6 months and discharge afterwards. One social worker stated this:

> Some of our clients are placed on family preservation as a temporary measure whilst we work on processing their foster care applications which normally take longer than a year (Social Worker 2).

Tembisa is not an agrarian region; hence farming for food is not an option for many caregivers. None of the community members in the focus groups reported to have a backyard garden in their homes as they claimed that space was taken up by outside rooms which they used as a source of income.

Child B reported that she and her siblings stayed with their parents in the rural areas of Limpopo where life was simple and much cheaper. After the death of their mother, they had to move to Tembisa to stay with their maternal aunt as she was the only surviving family they knew. She described life in Gauteng (Tembisa to be precise) as very expensive as their aunt had to put food on the table every day, clothe them, pay bills and school fees. When asked how they survived, one care giver said that, 'We wait a long time to have foster care grants paid out and most of us are unemployed and survive on part time jobs that give us less than R500.00 a month…'

Another caregiver also highlighted that, '… if it were not for the outside rooms I built from a loan I got from the bank last year, life would be very hard for us… Rental money from tenants helps us…'. For most orphans, the loss of parents meant no more income in the house.

6. Discussion

The aim of the paper was to explore the challenges faced by HIV and AIDS orphans in Tembisa. The data obtained in the study is aligned with the literature which portrays orphan-related challenges which are impacting on the daily lives of the HIV/AIDS-affected and -infected orphans. Notably, the participants' narratives suggested that there were challenges in terms of health, shelter, education and food. According to [27], the death of a parent signifies the disruption of the basic pattern of a child's life. With death comes the challenge of meeting the child's basic needs.

The study highlights that the HIV/AIDS pandemic leaves a trajectory of orphans under the care of overloaded elderly women to assume an inexplicably major role in societal provisions,

while undermining their engagement in civil society. This relates to what was outlined that many orphans are being cared for by the already structurally marginalized women, particularly elderly grandmothers often living in destitution [1].

The extended family network that has traditionally existed in Africa and South Africa is finding itself increasingly under strain because of HIV/AIDS [28]. The Department of Social Development in 2012 outlined that the HIV and AIDS pandemic has disrupted family, community and social structures, and has led to a marked increase in the number of orphans and other vulnerable children. The findings of the study strongly support the available literature that argues that children orphaned by HIV and AIDS depend mainly on their extended families to meet their basic needs.

In the case of infected children, their health is determined by the nutrition they get and getting access to their treatments at the right times. Lack of proper finances was found to be a big challenge as most caregivers were either unemployed or at the age of pension. The findings further suggest that although the government has placed certain supports such as social assistance grants, their inaccessibility makes it hard for caregivers to support HIV and AIDS orphans. Increasing poverty can cause a degradation of the immediate family environment and increases health risks whilst reducing its ability to obtain health services [29].

The results of the study also showed that the education of the orphans is disrupted. As [30] put it across, the loss of a productive family member is likely to be a financial burden and might push a family into poverty, increasing the likelihood that a child orphaned by AIDS will miss out on school. More literature confirms this, that, educationally, as poverty and HIV/AIDS reinforce each other, many orphans are denied the right to an education [31, 32]. UNICEF [33] showed that children orphaned by AIDS may miss out on school enrolment, have their schooling interrupted or perform poorly in school as a result of their situation. However, the figures released in 2013 by UNICEF revealed that in most countries in sub-Saharan Africa, the gap between school attendance of orphans and non-orphans has significantly narrowed, although progress varies across the region.

The study indicates that the physiological needs of the orphans are not being met. As Maslow's hierarchy of needs outline, if the physiological needs are not met, the human body cannot function properly and will ultimately fail. These needs are thought to be the most important; they should be met first. Therefore, the plight of orphans could be addressed in the same manner where their basic needs are met for them to get fulfilled.

Since the year 2002, there have been a diverse set of problems associated with the use of the foster care system to provide financial assistance to the country's increasing number of orphans [34]. There has been evidence that the social worker and court-based foster care system are not coping with the demand for foster care orders. In May 2011, the North Gauteng High Court ordered the Department of Social Development to design a comprehensive legal solution to the foster care crisis by 2014 [35]. This was due to the fact that a large number of Foster Care Grants had lapsed by 2009 leaving vulnerable children without assistance while social workers were unable to provide quality services to abused children due to higher foster care caseloads. At the same time, caregivers and children had to wait an unreasonably long time

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for their grants to be processed. Nevertheless, there has been criticism on the Department of Social Development for a slow and limited response to the crisis in the foster care system [36].

The current Foster Care Grant system demands that the applicant produces both parent's death certificates and affidavit stating who they are in relation to the child and why they are applying for the grant. It is with no reasonable doubt that some orphans are left in the care of extended relatives and grandmothers who have no clue who the fathers or sometimes mothers of the children are. Most of the orphaned children are left without birth registrations and caregivers face problems when trying to register the births of the children. While the access to the Child Support Grants has increased substantially over the years, the Foster Care Grant remains a favourable option for those who can access it because it is more than three times the amount of Child Support Grants [37].

Research by the Children's Institute demonstrates that the extension of the Child Support Grants to all children can play a critical role in supporting children through the AIDS pandemic in South Africa [38]. It argued that the current financial assistance offered by government to orphans (namely the Foster Care Grant) is inappropriate and inadequate in the face of HIV and AIDS because the number of foster care cases in many parts of South Africa already exceeds the capacity of social workers and courts. As a result, many orphans are unable to access Foster Care Grants. This is the case as Tembisa Child and Family Welfare Society where families have to wait a year or two before their applications are processed. At the time of processing, some children are already deceased or the prospective foster parents themselves. In other cases, the children end up moving to other areas as the prospective foster parents cannot afford to provide for them.

Even after the government has allowed for extension orders for foster care to be extended until the child turns 18 and not every 2 years, there is still many social workers and courts are facing in the bid to make foster care applications much faster for clients [39]. The continued use of the administratively complex foster care system for the provision of basic financial support for orphans brings the child protection system to its knees rendering it even less able to provide protection to children who really need it.

The Children's Institute further noted that the poverty of children is neither synonymous with nor exclusive to orphanhood [34]. According to them, a social security system, which provides grants to orphans under the age of 18 without providing adequate support to many other impoverished children whose parents are alive, is simply discriminatory. In other words, it fails to make provisions for the multitude of other children growing up in vulnerability due to HIV and AIDS. There are many South African children growing in the care of HIV- and AIDS-infected mothers or fathers and receive no social support from the state [40]. Their vulnerability is therefore not taken into consideration because one of the parents is still alive.

7. Conclusions and recommendations

Almost three decades into the HIV/AIDS pandemic, most people have an understanding of how AIDS-related deaths impact families [41]. From the discussion of the findings, it can be

safely concluded that HIV and AIDS orphans in Tembisa face many challenges in terms of health, education, food and shelter. This means that the physiological needs of these orphans are not met. The fight for the impact of HIV and AIDS is far from being won even though the world has three decades of living in the era of this pandemic. There is therefore a need to provide for ongoing support systems for HIV and AIDS orphans.

While the broader literature confirms that extended families play an important role in care, other data highlight a high level of strain felt by carers. The findings show that caregivers themselves are struggling with dealing with the HIV and AIDS pandemic as they themselves are carriers who also have to deal with the loss of their children or parents, and are left with the burden of caring for orphans. The burden becomes unbearable because most of the caregivers are unemployed and those that are employed make a low income and have other dependents to care for. Accessing state assistance is sometimes a major problem as some orphans are left without birth registrations. Those that do get the assistance are either finding it not enough or as argued by researchers are misusing it. Therefore, the following recommendations are suggested:

- There is an urgent need for kinship caregivers to be given greater support, both financially and emotionally.
- Keeping the orphans and vulnerable children in education should remain a key role of the child care advocates.
- Health education to improve the orphans' knowledge of the dangers they put themselves in when they do not leave a healthy lifestyle. If HIV- and AIDS-infected children are taught how to live healthy lifestyles the re-occurrence of orphanhood due to HIV and AIDS could be stopped. Furthermore, a healthy lifestyle means a long, fruitful life, hence caregivers do not have to go through the pain of losing the children like they did the parents of the children.
- There should be interventions designed to address structural factors such as administration of the Foster Care Grant which may improve outcomes for both caregivers and children.
- Finally, interventions directed at families should take into account the abilities, needs and challenges faced by different types of caregiver, rather than generalizing such that food and shelter needs can be met.

8. Limitations of the study

Due to the purpose of the research, participants might have overemphasized their situation in a hope that the researcher might bring quality services in due course. On the other hand, the participants might have given socially acceptable answers in order to hide their situation and thereby distorting the data that were being collected. Also the fact that one of the researchers was part of the Tembisa Child and Family Welfare Society's social workers might have influenced some responses to be biased. However, the researchers had an informed consent with the participants whereby the aim and objectives of the study were clearly laid

out. The participants were informed that the research was for academic purposes, hence the biasness was limited. This also developed trustworthiness among the participants as they were assured of privacy and confidentiality. The time frame of the research was also a limitation. Regarding the small sample that was used for the study, the findings are not conclusive and cannot be used to make generalizations about the population of interest. However, they develop an initial understanding and sound base for further decision-making.

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