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Caregiving and Experiences of Health, Illness and Coping in the Context of Paediatric and Adolescent HIV and Poverty

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Abstract

The contextual challenges in the context of HIV negatively impact the social ecology of the families. The consequences of this are that it adversely impacts the psychosocial functioning of caregivers and health and well-being of the children. The findings showed that caregiving is performed, not only in the context of maternal HIV infection, but also in the context of inadequate material and financial resources and single-head households where women assume the primary caregiving role. Caregiving is also complicated by the issue of maternal death and abandonment, where relatives (i.e. mainly grandparents) assume the role of the primary caregivers of children infected with HIV. On the other hand, emerging studies that started to focus on enhancing resilience in children whose caregiver is HIV positive holds promise to the fact that adequate interventions can have long-lasting benefits on the developmental and psychological trajectory of HIV-positive children and their HIV-positive caregivers. Consequently, the link between poverty and HIV/AIDS has been established, and its impact on perinatal, infancy and early-childhood development outcomes is clearly documented.

Keywords: HIV, paediatric HIV, maternal HIV, poverty, caregiving

1. Introduction

The role of caregiving for a child in many cultures is the primary responsibility of the mother. Young children, especially, are more dependent on their caregivers and, as a result, are vulnerable to declines in the quality of caregiving [39]. Given the multigenerational nature of HIV infection, it is worthwhile, from a research perspective, to explore what impact the disease is having on this role, more so given the fact that 98% of children infected with HIV

results from mother-to-child transmission [59]. Furthermore, with more and more perinatally infected infants progressing into childhood and adolescence, the need for empirical data to demonstrate and help understand the impact this pandemic is having on the surviving children and their family structures is underscored. This is especially so given that some surviving children are raised by mothers infected with HIV as well as many being orphans living in abject poverty [15, 43]. For example, it has been shown that South Africa has more than 60% of double orphans being raised by grandmothers or relatives other than the biological parent [53] and are living in poverty, which poses additional challenges in caregiving. It has been argued that poverty exposes perinatally HIV-positive children to various psychosocial risk factors, which often co-occur and impact negatively on the child's neurodevelopment, thereby contributing to poor health, lack of readiness for school, poor academic performance and psycho-emotional problems in childhood and adolescence [29]. This chapter presents a systematic and critical review of the literature on caregiving in the context of HIV/AIDS and poverty associated with perinatally HIV (PHIV) infection in children.

2. Body

2.1. Methodology

Literature searches were carried out using PubMed, PsycINFO and Google Scholar. A combination of words with the subject terms was used to identify relevant articles. The search terms included 'HIV', 'HIV infection', 'Child and Adolescent HIV', 'Paediatric HIV', 'Maternal HIV', 'Biological and Non-Biological Caregivers and HIV', 'HIV and Poverty', 'Stress and HIV Illness', 'Nutrition and HIV', 'Caregiving and HIV', 'HIV Orphans', 'Attachment and HIV' and 'Extended Relatives and HIV'. Appropriate journal articles were identified, while in addition to this, the author also used the references cited in the identified articles to find other publications. The search and appropriateness of the articles were guided by the following broad objective to be addressed in the chapter which was

- To understand the challenges associated with caregiving in the context of child and adolescent HIV.

In order to meet the objective, the following questions were guiding the literature search:

- What are the experiences of being HIV positive (caregiver health status) and a caregiver of an HIV-positive child (child health status)?
- How does HIV influence the caregiving capacity of the primary caregiver of an HIV-positive child?
- How does poverty impact the experience of an HIV-positive caregiver to care for an HIV-positive child?
- Does having to live in an impoverished context have any impact on the overall physical, psychological and social health of the caregiver and the child living with HIV?

- What network of support system is in place for assistance in caregiving of the HIV-positive child, and how does this impact on coping with having to care for an HIV-positive child?

Procedure for the inclusion of relevant articles:

All online abstracts of the selected studies were reviewed, and eligible studies were obtained and reviewed by the author. Studies were included in the review if they met following criteria:

- focus was on HIV/AIDS,
- children younger than 16 years (account for paediatric and adolescence) and were perinatally infected by their mothers,
- HIV, poverty, child and caregiver's physical and/or psychological health outcomes were focus of the study,
- raised by either biological mother or extended relative, and
- both qualitative and quantitative studies were included.

2.2. Findings

2.2.1. Poverty, psychosocial risk factors and caregiving

Despite the shift in South Africa's political dispensation from apartheid to democracy, it should be noted that a large number of South African citizens still live in abject poverty [52] as is the case in many Sub-Saharan countries. It is estimated that the South African child population accounts for approximately 18.7 million, with 2.3 million of them still being forced to live in shacks or some form of informal dwelling [27]. Moreover, from this population, approximately 30% under the age of five live in over-crowded conditions. In a study conducted in 2007 by the Housing Development Agency, it was found that approximately 6000 households are still headed by children under the age of 18 [41].

Living conditions for a large number of people are still characterised by a lack of access to quality basic services, including adequate housing, electricity, safe and clean running water, toilet facilities and refuse removal services [51]. A study conducted by Iversen et al. found that nearly 7 million children in the country still do not have access to clean, safe, drinking water in their households [27]. According to StatsSA, about 25.2% of households in the Eastern Cape had no access to flush toilets as compared to the Western Cape which had more than 50% accessibility [51]. In terms of access to piped water, the Eastern Cape is considered the worst, remaining below the national average. While it can be argued that some improvement did occur since the new political dispensation assumed power, a large number of children are still exposed to harsh socioeconomic living conditions [27, 41, 51]. These conditions create an environment that fuels vulnerability to mental and physical illness and easily spreads diseases.

The capacity to care for children usually suffers as the impaired mental state of a parent living with a primary chronic life-threatening illness like HIV does not only disrupt parenting ability but also adversely influence the attachment between parent and child [30]. The disruption is further exacerbated by the fact that HIV often co-exists with poverty, which means the

infected mother and child will probably live in socioeconomically disadvantaged contexts that pose additional challenges [13, 18, 23]. Research has established a link between the negative effects of poverty on parental roles and child development [16, 35–38]. Poverty has also been associated with negative parental health, which independently and jointly impacts the child's cognitive and social-emotional well-being in an adverse manner [15, 32]. Furthermore, economic deprivation creates a catalyst for psychological stress and vulnerability among caregivers, which further predisposes them to depression [28]. Hence, a caregiver confronting impoverishment on a daily basis is more likely to be stressed, which in turn may impede the quality and quantity of her parenting [9, 31]. The implication of this dynamic has an overwhelmingly negative effect on the child's developmental outcome. Low socioeconomic status (SES) has also proven to be associated with a variety of obstacles hindering effective rearing, such as inadequate nutritional provision, lack of time for cognitively stimulating activities in the parent-child dyad and poor parent-child relationships owing to associated stress [23]. The association between SES and home environment therefore suggests that children infected with HIV and who are living in poverty also live in less stimulating and less supportive home environments. This is certainly plausible given the reciprocal nature of the child-parent dyad and their environment. Additionally, maternal infection may affect the quality of caregiving which, when combined with poverty, may further frustrate the attachment relationship, resulting in poor child-development outcomes that is even observable in late adolescence [15, 30]. Studies focusing on healthy, pre-term, disabled and chronically ill children also support the premise that poverty serves as a risk factor for poor cognitive and socio-emotional functioning outcomes [32]. Some researchers argue that poverty is the single factor most associated with HIV/AIDS vulnerability, physical and mental ill health, impaired parent-child dyads and child development outcomes [15, 20–22, 28, 29].

2.2.2. Parental health and relationship to caregiving

Until recently, most research focused exclusively on parenting interactions with healthy children and those children confronting chronic illness and disabilities [55, 57]. While there is a growing number of studies on the plight of caregivers infected and affected by HIV/AIDS in developed countries, there are still very few from developing countries [39]. Not only do HIV-positive mothers have to battle their own illness and witness the deaths of others in the same predicament, they also have to deal with the knowledge that their children are infected with the disease and still raise them [22, 24]. As a result, they are often burdened with the inability to confront their own mortality as well as that of their children. It is documented that childhood chronic illness brings about significant strain on the family system, including high rates of maternal depression and anxiety, marital distress and adjustment problems [5, 6, 55, 56]. Likewise, parental illness has been shown to impact caregiving capacity and to increase the risk of psychological problems in affected children [19, 42].

The caregiving behaviour of a parent and the quality of the early parent-child relationship are two factors that have been identified as influencing and promoting development outcomes in children [3, 45, 46]. As stated by Sameroff et al. '...development, particularly in the earlier years, is a function of ongoing cycles of child-caregiver transaction that weave together the fabric of psychological functions, including the mental health of the young child' [49].

Based on this premise, the caregiver's health and overall well-being is thus of critical importance in relation to exploring the child's health and well-being. Mothers infected with HIV commonly live as single parents, in economically disadvantaged environments with not much social support and their children may therefore be at risk of ill health [9]. When a caregiver confronts a chronic illness, the children usually suffer as the caregiver's capacity to care for them becomes interrupted [45]. The consequences of such a disruption can have multiple adverse effects on the psychological functioning, neurodevelopment, physical health and well-being of the affected children [46, 47]. In addition to this, poor child-health adds even greater demands to a caregiver's already strained load [45]. Consequently, in situations where a caregiver is infected with HIV, she is now confronted with the dual challenge of being a patient and a caregiver [22].

The multiple stressors associated with being HIV positive and caring for HIV-positive children are most likely to place these women at an increased risk of mental health problems, which in turn will exacerbate the stress associated with parenting. This may result in a vicious cycle impacting the caregiver-child dyad negatively. Positive caregivers may be unable to cope with the stressful reality of their HIV illness and may also be overburdened by carrying the sole responsibility of caring for their infected children [9]. Being HIV positive is also associated with the increased risk of having mental disorders (see [8] for review). For example, one of the most commonly associated mental illnesses is depression, which is rooted in life circumstance, illness, poor support networking structures and daily life stress [8]. The emotional toll of parenting can be high, partly because parents are relatively socially isolated and do not always get support from the community and their extended family [9]. Many HIV-positive mothers must deal with their illness in isolation owing to the stigma associated with the disease, as well as prevalence of HIV-related discrimination remaining rife in communities, and their fear of rejection and abandonment by relatives and close associates [25, 26]. These experiences further compound the stress experienced by mothers as caregivers, thus complicating the problems inherent in parenting. Literature on research investigating the impact of maternal stress and depression is in consensus, in that it has been associated with adverse outcomes on both parenting and childhood neurocognitive and socio-emotional development (see [20–22, 28, 30]). With regard to the impact of parental depression on the parenting role, research suggests that there is a breakdown in attachment between the caregiver and child, and as a result, the caregiver-child relationship suffers. Furthermore, due to the debilitating nature of parental depression, parents are less likely to carry out their functioning role as parents and as a result are less likely to engage in behaviour repertoires consistent with enhancing a child's neurocognitive, social and emotional development and well-being [20–22, 30].

Caring for a child is a time-consuming and emotionally taxing activity that becomes exponentially more burdensome if the caregiver is ill and has a child suffering from a chronic illness; hence, their increased vulnerability to developing depression, especially in the absence of poor social and financial support structures [54]. The caregiver may be overwhelmed with constant concerns over the child's health and worries about the future and as a result may be flooded with feelings of inadequacy. These concerns may create heightened levels of distress and in turn these caregivers may experience a lack of confidence in their ability to parent as they are unable to meet their children's needs. In a study conducted by McLearn and colleagues, the

parenting practices of depressed mothers were investigated, and the researchers concluded that depressed mothers engaged in parenting practices were most likely to impact negatively on the children's overall development [34]. Parenting practices showed no clear structure and routine, and parents were less likely to engage in play behaviour with the child, breastfeed, talk to, read books to, or respond to the child's non-verbal cues [34]. The consequent effect on the child's developmental outcome can be devastating and may even have long-lasting implications. As indicated by Knitzer et al. [30], depressed caregivers are more likely to expose their children to health risks and less likely to adhere to health advice for themselves and their children. Depressed caregivers will also find it more difficult to respond to and manage chronic illness in their children [30]. As a result, children parented by depressed caregivers are known to display a spectrum of cognitive and socio-emotional problems [20–22], including strong associated behavioural problems such as attention-deficit/hyperactivity disorder, conduct problems, anger and violent behaviour, depression and anxiety [29, 30]. Moreover, cognitive deficits observed in children who are exposed to depressed caregivers have shown to negatively affect school readiness and the success of these children [30], and they have even exhibited deficits in social competencies [28]. Consequently, these children who have a greater tendency to engage in negative social behaviours are at greater risk of peer pressure and have a low social concept. Finally, children parented by depressed caregivers have a high risk for developing antisocial behaviour [20–22]. As indicated by Forsyth [19], children born to mothers infected with HIV have shown to present more psycho-developmental problems, which is likely to be a consequence of the disruption in the parenting and caring capacity of the mother as a result of the HIV infection and the associated stress that is accompanied by the illness.

2.2.3. Impact of HIV on parental interaction

The strain of caring for a sick child while managing one's own illness and bearing responsibility for children is a tremendous burden on many mothers infected with HIV [6]. As is the case of rearing children with other chronic illnesses, maternally HIV-infected children tend to make unique and often greater demands on their caregivers. Therefore, it is plausible to assume parenting for caregivers of children infected with HIV is marked by increased worry, emotional pain and other concerns when compared to caregivers of children without illness [11]. Coscia et al. [15], in their study exploring the relationship between home environment and HIV-infected children's cognitive functioning, found an association between parental interaction and disease severity. As the child's disease progressed, the caregiver's interaction became less stimulating and supportive, thus creating a higher vulnerability for poor cognitive development and socio-emotional functioning. These researchers suggest that as the HIV-positive child becomes more ill, perhaps the caregivers' relationship with the child weakens. One hypothesis is that the HIV-positive caregiver does not expect the HIV-infected child to survive beyond early childhood and this influences the caregiver's capacity to bond with the child. Another hypothesis is that the sheer burden of caring for a chronically ill child, particularly under harsh conditions, may cause resentment. Equally, HIV can be argued to cause a breakdown in the quality and quantity of the critical early relationship between the caregiver and child. Poor bonding, for example, may in turn impact on developmental outcomes.

As shown in studies of pre-term babies, environmental factors such as effective parenting characterised by warmth, sensitivity, consistency and connectedness have a positive relationship with cognitive and social-emotional competence [50, 55].

Effective parenting has been shown to facilitate healthy caregiver-child dyads and is associated with greater optimal development outcomes in children [48]. This premise is located within the theoretical perspective of secure attachment coined by John Bowlby [10]. Bowlby was the first of many theorists who described the importance of caregiver-child relationship and its effect on children's development outcomes [10, 45]. According to Bowlby, securely attached children have an internal representation of the caregiver as stable, responsive and caring that serve to provide the child with a secure basis from which they can explore their environment, grow and develop [10]. Subsequent research related to parenting has successfully demonstrated the relevance of attachment models. Treyvaud and colleagues, in a study of pre-term infants, found a positive relationship between cognitive development and sensitive caregiving [55]. Therefore, children whose caregivers interacted with them in a warm and positive manner showed particularly positive outcomes in cognitive development [55]. Similar results were echoed in a study conducted by Richter and Grieve [46], where the relationships between home environment and cognitive functioning were explored among a sample of South Africans. Consensus from these studies was that facilitative, warm, positive and sensitive caregiving contributed to positive cognitive development and healthy psychological functioning in these ill-health children. Thus, the results illustrate that the quality of a caregiver's interactions and his/her ability to create an environment conducive of learning and development is positively associated with cognitive development in children and operates as a protective factor against the adverse effects of poverty. Richter [48] recommended that such effective parenting is important and should be encouraged as it can mediate the effects of poverty and promote development in children. Consequently, the findings of these particular studies are encouraging as they demonstrate the importance of enhancing caregiver-child interaction, which in turn can promote optimal outcomes in children.

2.2.4. Role of extended relatives

On the other hand, the increasing HIV pandemic in South Africa poses a substantial threat with a detrimental impact on the provision of care for children. As biological parents become ill or even die and are unable to care for their children, the responsibility of caring for these children is often transferred to grandmothers, aunts, other children and relatives [1, 7, 12, 13, 43, 44]. As a consequence of the impact of HIV, the family structure may change. Due to the incapacitating nature of HIV/AIDS or even deaths of parents, the need to provide some form of guardianship for the affected and infected children must be prioritised [14]. As indicated by Richter [48], it is not uncommon in the African context for relatives to assume a caretaking role of HIV orphans. However, the assumption of caretaking responsibility often occurs in the context of other factors such as having to raise other grandchildren and cousins. These relatives are often still in the process of grieving for multiple family members who died of HIV and are even confronted with continued stigmatisation from the community [1, 2, 43]. This often places additional stress on relatives caring for HIV-infected children.

Furthermore, the above-mentioned caregivers may experience heightened levels of psychological distress as a result of the increased stress associated with their situation and may require social and health support too [4, 44]. Literature, on grandparents as caregivers of HIV-infected orphans, shows for example, that caregivers' personal ill health may prevent them from adequately responding to the needs of the child [40]. In the context of limited capacity, foster caregivers, particularly grandparents, may prioritise the physical well-being of children over the learning, intellectual and emotional needs of said children. Correspondingly, the coexistence of HIV with poverty further limits caring capacity as caregivers frequently have difficulty accessing health services, they have to deal with complex medical treatment and struggle to acquire financial assistance to meet the health and nutritional needs of the children [13, 35–38].

2.2.5. Enhancing resilience as a protective coping mechanism

Research has shown that parental illness impacts negatively on positive parenting as it increases parental stress and disrupts the parent-child relationship. This has stimulated interventions that can enhance positive parenting in HIV-positive caregivers in low-and middle-income countries. While evidence suggests that maternal illness is considered a risk for poor outcome in their children, where HIV-positive mothers were given the opportunity to enhance their capacity to deal with their illness and to strengthen parent-child relationship, the outcomes proved to benefit both the mental health of the caregiver and the child [33, 39]. A few studies that emerged have started looking at the resilience in young children whose mothers are living with HIV in an attempt to improve developmental and psychosocial outcomes for both the HIV-infected mother and the child [17, 33, 39, 47, 58]. In the study with HIV-positive mothers from South Africa, there were also HIV-positive mothers who were able to express their own desires to live positively, for themselves and their children; they were also able to recognise how their own behaviour was affecting their children, and this had a positive impact on their ability to parent and communicate effectively with their children [58]. This suggests that there are caregivers who show resilience and work very hard to care for their children. Interventions directed at the mother-child relationship were able to further enhance HIV-positive mothers' capacity to cope better with their own illness and, as a result, be able to build psychological resilience in their children [58]. It is well demonstrated that resilience has the capacity to affect the long-term trajectory of a child's emotional, cognitive and adaptive functioning. In another large study conducted in Tswane, South Africa, among 390 mother-child pairs, an intervention that focused on mother-child dyads was not only able to enhance the parent-child relationship, but it also resulted in significant reduction in children's externalising behaviours, while improving the children's adaptive functioning [17], for at least a year following the intervention. Evidently, also in the study was a significant reduction in depression among children. Importantly, benefits were not only noticeable for the children but also for the HIV-positive caregivers who engaged in less-frequent avoidant coping behaviour [17]. A similar finding was found in Murphey and Marelich, who established that HIV-positive mothers in their study were able to better cope, and this translated into better adaptive potential in their children [39]. The benefit of interventions focusing on caregiver-child dyads has the potential to have a long-lasting resilient effect on both children and their HIV-positive caregivers. Recently, the first large study that examined the relationship between HIV/AIDS and positive parenting, using

a sample of 2477 caregiver-child dyads, was conducted in KwaZulu-Natal [31]. Findings from the study indicated that HIV-positive caregivers and those caring for AIDS-orphaned children engaged in less positive parenting in comparison to non-affected families. However, non-HIV sick caregivers or those caring for orphans with other chronic illnesses were not associated with any positive parenting. The findings were mediated by psychosocial risk factors such as poverty, caregiver's depression, etc. However, the study does suggest that a parenting programme that is aimed at improving caregiver psychological health and encouraging positive parenting has the potential to safeguard against risks of poor child psychological and physical health outcomes in HIV-affected families living in poverty. This finding is promising that HIV-exposed caregivers have the ability to engage positively with their children, albeit, as the finding suggests, the effect size was small [31]. This nevertheless suggests, if adequately tailored interventions are implemented to look at strengthening the child-caregiver relationship, that it can ameliorate the children's response to the exposed adversities. This, in turn, has the potential to have a lasting impact on children's developmental and psychological outcome. The findings from these studies are promising as it indicates that while many children are at risk for various negative psychosocial outcomes, mothers living with HIV and those caring for AIDS orphans can be resilient and are able to take adequate care of their children, despite the challenges.

2.3. Conclusion

In conclusion, the findings from this systematic review show that HIV-positive caregivers and those caring for HIV-orphaned children also often live in poverty-stricken contextual realities which pose additional challenges to the caregiving context. The consequences of this are that it has adverse effects on psychosocial, health, and well-being of both the children and the caregivers. However, on the other hand, some intervention studies with HIV caregivers and/or HIV-positive children, albeit limited, do hold the promise to ameliorate the adverse impact of both HIV and poverty on caregiving.

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