

Supports Mechanisms and Needs of Foster Parents of Children Living with HIV in South Africa

Jenni-Kate Warwick, Johannes John-Langba*

Department of Social Development, University of Cape Town, South Africa

*Corresponding author: Johannes John-Langba, Department of Social Development, University of Cape Town, South Africa.

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Abstract

The burdensome role of providing care to a HIV positive child in the South African foster care system cannot be underestimated. Foster carers of HIV positive children have been shown to need financial, practical, emotional, psychological, social, professional development, problem solving, respite and community support. Utilizing the theory of social support, this study explored the support mechanism and needs of women providing care for children in the foster care system in South Africa. In-depth interviews were conducted with 18 foster parents accessing services from two institutions in Cape Town, South Africa. Findings indicate that foster mothers of HIV positive children do not feel adequately supported in their caregiving role. Family support, organizational support, and religious beliefs were reported as the main support mechanisms for foster mothers of HIV positive children. Financial support, emotional support and training were reported as areas in which the foster mothers felt the need for additional support. Recommendations for child welfare policy and practice are proposed.

Keywords

Foster care; Foster mother; add Foster parents; South Africa

Introduction

The support mechanisms usually needed by foster carers in general, are financial, practical, emotional, psychological, social, professional development, problem solving, respite and community support [1]. According to Duran [2], when these needs are met, they are better equipped to meet the needs of the child in their care. Support for foster carers can come through the foster mother's own family, the foster child's biological family, professionals, other foster carers and foster carer associations [2].

Of these support systems, family members were the most used form of support, followed by support from social workers [2,3]. There was a general lack of support from community and community resources and other foster carers, but that when there was community support, it generally came through the church, medical professionals and occasionally through the local schools [2]. In South Africa, various studies documenting the challenges of caring for HIV positive orphans have also made mention of support mechanisms that are being used or that would be recommended for those providing care specifically to HIV positive orphans. For the most part however, these studies seem to show that current support structures are being overwhelmed by the circumstances facing foster carers [4]. According to Simpson [5], belonging to a church community was a significant form of support for caregivers (not specific to foster carers) in South Africa [4]. However, they found that foster carers in their study felt that many at the church did not understand their circumstances. In this particular study, support groups provided by a local NGO for foster carers to discuss their concerns and challenges were reported to be the most effective form of support for the carers [4,6]. Studies have shown that foster carers of HIV positive orphans would benefit from more support with regards to their emotional, financial and physical wellbeing [7,4,8]. According to Kiggundu and Oldewage-Theron [4], the nature of this support should be in the form of support groups, income generation programmes, easier access to government resources, orphan education, parenting workshops, and an overview of the grant application process to make it more accessible in South Africa [4]. In the South African context, adults and children were becoming ill quickly and many HIV positive mothers could not manage or afford to look after their sick children prior to the introduction of antiretrovirals in the country. Grandparents were overwhelmed by the burden of taking care of both their sick children and sick grandchildren [4].

This, along with the increasing death rate of adults with AIDS, led to the establishment of many residential facilities for such children, where appropriate care could be provided.

Since the introduction of anti-retrovirals (ARV) in South Africa, many children who had previously been very sick, now have the opportunity to live longer, healthier lives. This change meant that the move to residential care needed to be re-evaluated as children were no longer in need of just day to day care, but more importantly, they needed to be raised with the future in mind. While in residential care, the children were guaranteed good nutrition and strict adherence to their drug regimes, but they were missing out on life in a family in a broader community. It is for this reason that the Department of Social Development shifted their position to increasingly advocate for care within homes in communities, rather than in institutions and it is for this reason that this study focused on foster care being provided in the context of a family home rather than an institution. By the end of 2012, more than 58 children had been successfully reunified with members of their extended family, or were placed in foster care.

Although various research studies on the challenges of providing foster care for AIDS orphans have been carried out in the rural areas of KwaZulu-Natal and in Gauteng [4,8,7] there is a dearth in research on the support needs and challenges of providing foster care to HIV positive in urban and peri-urban settings in South Africa, and in the Western Cape province in particular.

There is also an apparent gap in research that focuses on the foster care of HIV positive children in South Africa. Existing studies had focused on the challenges and support needs of all children affected by HIV/AIDS, regardless of their HIV status. There is also a gap in evidence related to the care of children who are HIV infected but have been abandoned as opposed to being orphaned, notwithstanding the wide spread occurrence of this phenomenon in South Africa. This study therefore focused on HIV positive children, in order to try to ascertain the experiences of care givers specific to their care. Utilizing family stress and general systems theories, this study explores the support needs and mechanisms available to foster mothers of HIV positive children in South Africa. It examines existing support available to foster carers of HIV positive children as well as their support needs. Family Stress Theory [9] is a developmental theory that explores why some family systems adapt and even grow and thrive when faced with situational stressors or transitional events, while other family units deteriorate and disintegrate under similar circumstances. The stress linked to foster care is played out and experienced in the family in which the foster child is placed [9,10]. General systems theory emphasizes interdependence and interaction between the components of a system and has an interest in what makes social systems, in this instance, families, maladaptive or adaptive, making it useful for understanding family dynamics. General systems theory also plays a key role in understanding the impact of stress on the foster family, as it views the family as an interconnected system [11].

Method

This study utilized a qualitative research design to explore the support mechanisms and needs of foster carers of HIV positive children in South Africa. In-depth interviews were conducted with 18 foster parents that access services from two non-governmental organizations in Cape Town. Due to the broad client base of one of the organizations from where respondents were recruited, a fairly diverse population was found in terms of geographical location, population group and socio economic status.

Of the 18 respondents that were interviewed, 16 were female, and two were male. Four of the respondents were White, two were Indian, four were Coloured and eight were Black. Their socioeconomic status ranged from a formally employed professional to unemployed grandmothers, living off their state pensions and the foster care grant. A purposive sampling technique was used to select foster carers to participate in the study based on the criterion of fostering a HIV positive child. In order to participate in the study, respondents should have been providing care to the same HIV positive child for a period of at least two years so as to differentiate between general 'teething' challenges and long-term challenges that foster mother's experience. The interviews were conducted in the preferred languages of the participants recorded with the permission of the respondent. A total of 18 in-depth interviews were conducted using a semi-structured interview schedule. The interviews were recorded, transcribed and analyzed using an adaptation of Creswell's approach to qualitative data analysis was employed [12].

The qualitative data collected was verified for trustworthiness using the Lincoln and Guba [13] approach to qualitative data verification by assessing the credibility, transferability, dependability and conformability of the data. The study obtained ethical approval from the Ethics in Research Committee of University of Cape Town as well as from the two organizations was the recruitment of the foster carers was undertaken.

Findings

This study found that the support mechanisms of carers of HIV positive children were ecological and systemic mainly at the macro level. The main support mechanisms utilized by caregiver's include community, religion/spirituality, service providers and the family unit. The support needs of carers of HIV positive children in South Africa were mainly with the financial, emotional and training domains.

The family as a support mechanism

It was very clear almost across the board that support outside of the immediate family is hard to come by for foster carers of HIV positive children. Some of the foster carers reported that their family members were initially hesitant when they took on their foster child, but all reported 100% support from their immediate family after the fostering had taken place. Levels of support from extended family networks varied across the families represented.

An interesting observation is that out of the 18 interviews that were conducted, 16 were with women, of whom 10 were single parents. Those who were married reported their spouse as being their biggest supporter, as evidenced through the following quote:

We do everything half half. We don't give half each; we give 100% each, which helps. – 44-year-old foster father

Those who were single parents reported needing to rely more on extended family networks:

Interviewer: And you say your family has been supportive?

Respondent: Very supportive...from the beginning, right from the beginning. For me, it's just me, my sisters and my brothers, that are all. So we are, we are a very close family. – 58-year-old foster mother

Support from older biological children was also very key:

My kids are fully with him and they tell everyone that he's their little brother and my son will tell Lolo, his little daughter, that he is her uncle Mark...All the support is in this house. – 48-year-old foster mother

In many of the families, it seemed that family members would each take on different aspects of the child's care. One would be the primary care giver at home, one would see to it that the child gets to their appointments, one will see to it that the child gets to school. This arrangement of mutual involvement seems to work well in these families.

So I'm the one now who took her for the medication, because if I leave the cards at the house, my sister sometimes don't want to accompany her. So then I took the cards to stay with me so I can always look the dates so I can bring her. – 52-year-old foster aunt

The role of extended family members in providing additional parental role models for the children was also important, as evidenced in the following quote:

We talk about him (the child's biological father) and he said 'he's not my daddy.' My one daughter's husband, she takes him as her daddy, because she was very small when she came to live with us. – 68-year-old grandmother

Family support was clearly the most readily available form of support available to the participants in the study.

Community support mechanisms

The majority of the foster carers reported feeling quite isolated from the rest of their community and did not feel that the community was supportive, as evidenced through the following quote:

It's too hard...because you know, the other Gogos, they don't know about this. Other Gogos don't know about this. Now that's why it is too hard for us to manage. – 56-year-old grandmother

In many instances, the family had not disclosed the child's status for fear of stigma or gossip from the community, as evidenced by the following quote:

If I've got a bad day, I'm staying with my bad day in my house... because you tell the neighbor that you've got a bad day, you thought maybe he can help you to sort your problem, but at the end of the day, you going to hear from the community gossiping about your things. – 39-year-old foster mother

A 52-year-old foster mother felt that the community was un-supportive due to fear and ignorance:

I think they are afraid. They think it's a germ, like a thing like a magnet, it won't get off you. And they see it every day there by us. There are also classes (in the community)... you can come and learn about this and that, but they are not supportive.

In one instance where the foster carer did disclose to a neighbor, she ended up being very hurt:

... So I took one of my neighbors into my confidence about Tom's status and then she went and told everybody at that time Tom was around nine or 10. She told everybody. I said, I always thought that some of the people around here were very much educated, but they, it's almost like they didn't want to let Tom play with their children anymore. And they kept their children away from Tom and that made him like he just stayed inside, he didn't go out and play with the children. –58-year-old foster mother

The discussion around community support served to highlight the isolating effect that stigma and fear can, and often does, have on foster carers. While not explicitly stated, it seemed that many of the foster carers felt a strong need for community support but felt that desiring this kind of support was futile, due to the challenges that disclosure presented to them.

Organizations as sources of support

Of the 18 foster carers interviewed, ten had foster children who initially came from a children's home. The majority of these foster carers mentioned feeling that the organization where their child had been prior to being placed in their care had been helpful and a good support to them, at least initially. ... That organization is a very big support. They don't lose touch with us. Whereas it will take months for you to come again, but we feel that if we've got something that we're struggling with, we know where to come...– 26-year-old extended family member

The majority of the foster carers mentioned that they would like additional organizational support, and many said that they know there are organizations out there that can help, but most hadn't taken the time to look into accessing the support that the relevant organizations might offer.

I think that I felt that I could cope on my own... I'm very much a loner and happy to be just on my own, um, I thought that I could cope without all of that. And yes, there is support out there; there are groups out there. There are support groups and offerings...but I thought that I could cope on my own, and it just showed that I couldn't. So that's why I ended up sick in hospital and that sort of thing. But yes, there is help out there if you need it. If you ask, there is. I just didn't ask. – 57-year-old foster mother

It would appear that many of the foster carers would benefit from a database of information about the support services available to them, as many were aware of resources available to them, but weren't sure how or where to access them.

Religion and spirituality

Ten of the 18 respondents reported belonging to a religious group and the majority of them felt that they had been well supported by their religious leader or the staff, but not necessarily by the rest of their religious community.

The people, no! Because I don't think they feel the pain that we have to go through. All the things that we have to go through – 43-year-old foster mother

Many of the foster carers alluded to relying on God/a higher power to get them through the difficult days. Many reported a sense of calling to being a foster parent and spoke about drawing strength from God for the task at hand. One respondent became very overwhelmed during the course of the interview and stopped to spend time in prayer, which seemed to strengthen her to continue with her story.

This reliance on God is expressed in the following two quotes: ...Because I know it is hard to look after our small babies, because we are grandmamma. It is hard because we don't know what...but we must get strong, we must get power from God in this time. This time is not nice, it is so bad. You must trust God also to help you. –56 year old grandmother

He gives me big, big strength, more than anybody who can talk to me. – 39 year old foster mother

When asked what kept them going through the tough times, one of the respondents responded as follows:

Ja, just a conviction that you know, this was something that God wanted us to do and a commitment to um love her and do what was best for her. – 55-year-old foster mother

The belief in a greater power that would sustain them through their difficult times and the conviction that God had chosen them for the task at hand were clearly very important protective factors for many of the foster carers.

Support needs of carers of children living with HIV

When asked about the kind of support they would like to receive, or receive more of, the responses mainly related to financial, emotional and training support needs.

Financial support needs

The majority of the respondents reported that while the grant is helpful, they feel that it should be more than it is, due to the many needs that they encounter in caring for their foster children.

Yes, it's not enough. Because I must buy something for school, and the winter things, and then the hospital also call me and tell me I must pay the money... – 56-year-old grandmother

Another foster mother in her fifties lamented:

They can give a little bit more than they giving now... If I buy everyday 3 breads and that money is gone! And where's the things you must put on the bread? Where is the plate of food? Where is the juice? – 52-year-old foster mother

One of the foster carers expressed disappointment that the foster care grant doesn't take into consideration those children that want to continue studying after school as it ends when the child turns 18.

The only thing that I was very disappointed... cos I got the foster care grants, and then when Laura went to college, I asked if there is no way that, because I'm alone, is there no way that they can maybe extend it. So they said no. They don't give the foster care grants to tertiary education. – 58-year-old foster mother

A number of the respondents also mentioned that they would like it if social services or the hospital were able to help them materially with clothes and food for the children.

I wish if you can, the social workers here, can give us some of the groceries you saw. Because you see my mother is working there at home, and all the people there belong to her, she is the grandmother. You see, so I wish they could give her something to eat, you see. – 52-year-old foster aunt

So I can't buy everything – the clothes, the food, in order for them to be able to eat healthy, I wish it can help to have maybe sometimes when it's cold, some more clothes. Stuff like that, and with their education as well. – 39-year-old foster mother

Emotional support needs

A number of the respondents reported a need for more emotional support than they currently have, with many suggesting that a support group that could offer on-going support would be a good vehicle for the emotional support that they desire, as evidenced in the three quotes below:

Umm.if we can get a counselor in our area, I won't mind... We have to stand together, we have to work together. If your child is sick, maybe I can help you. You don't know that work, maybe I do. Just to stand with each other. – 43-year-old foster mother

It's the on-going support, more than a course. Because once you've done a course, it's very seldom that what you've been taught is going to fit with that child. – 57-year-old foster mother

I can like to have a support group. As I said before, as the kids grow up, I don't know what things are coming for the future, so if everything comes, I must be stronger for them. – 39-year-old foster mother

Many of the respondents reported struggling to understand their foster child at one time or another and felt that they would benefit from being able to talk to someone who could possibly help them to understand and having someone that their child could talk to.

It's so difficult. My granddaughter will tell me 'oh mammy, you don't like me'. I think (I need) somebody to help me to know about her. – 56-year-old grandmother

Tanya had a very traumatic early childhood...they think she had been abused and neglected in her first 3 years of life. Besides then living in a group home for children for 9 years, um a lot of emotional needs, um counseling. But I think not the normal kind of sit and talk counseling, I think like the play therapy setting would have been better, but start that very early and just get them used to the idea of you know, what HIV is. – 55-year-old foster mother

Some of the respondents alluded to the fact that just being able to talk about their circumstances through the interview process had helped to lighten their load.

I feel so light after talking about it. It was nice to talk to you. – 43-year-old foster carer

Caregiving training needs

All of the respondents reported that they would have felt better equipped to care for their foster children if there had been some sort of training course or material offered to them when they took on their children. Only the Xhosa speaking foster carers who had received their children from one organisation reported having received any form of training and those interviewed felt that it was very helpful. The rest of the foster carers had not received any information on living with HIV or on the adjustment that they and the child would go through when the child joined the family.

One foster mother sourced her own training when issues emerged with her foster child and felt that she would have been more prepared if she had received the information in advance: After Tanya came to us I took a counseling course...you know, after pulling our hair out we talked to her (the counselor) and she would give us some things to read. And I thought 'oh well, if I'd known this ahead of time it would have been easier.' You know, the honeymoon phase and then testing out lasts this long... –55 year old foster mother

While many felt that each child is different, so they would have never been completely prepared, they all felt that some kind of material to prepare them would have been helpful.

Discussion

This study shows that the family is the most accessible and utilized form of support available to foster carers. Community support is hardly available to foster carers of HIV positive children in South Africa. This is consistent with the studies conducted by Nixon [1], Durand [2] and Brown, et al.[3] who also found that family support was the most frequently used form of support by foster carers.

The finding that religious communities were not seen to be supportive links to the study by Kiggundu and Oldewage-Theron [4] but stands in contrast to studies by Simpson [5] and Durand [2] who found that churches in particular are often a significant form of support to foster carers and caregivers in general. It is possible that the foster mothers definitions of support, as well as their particular religious affiliations could have influenced the way in which they perceive the support, or lack thereof, that they receive from these communities.

Organizational support was reportedly very helpful to foster carers consistent with findings by Durand [2] that support for foster carers is more likely to come through formal sources such as organizations rather than from informal sources. The areas of greatest need identified by foster carers were reportedly financial support, emotional support and training needs. This is consistent with prior research that found that when these needs are met, foster carers are better equipped to provide care for their foster children [2]. The finding that the foster carers have a desire for a support group in which to discuss their concerns and challenges links to the study by Kiggundu and Oldewage-Theron [4] who found that such groups are the most effective form of support for foster carers.

Conclusion

It was apparent from this study that many of the foster carers of HIV positive children in South Africa do not feel well supported in their caregiving role. Family support, organizational support, and a belief in God are the most important support mechanisms for the foster carers of HIV positive in children. Community support (from neighbors and friends) and support from the foster mothers religious groups was reportedly lacking. To be more effective in their caregiving role, foster mothers of HIV positive children in South Africa could benefit from a comprehensive package of evidenced-based interventions incorporating financial and psychosocial support mechanisms.

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