Open Access Journal of Nursing

Volume 1, Issue 1, 2018, PP: 33-39

Caregiving for Children Living with Disability in the Informal Settlements in Kenya: Exploring the Social Experiences of the Urban Poor Living in Mukuru Slums in Nairobi

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Abstract

Caregivers are entrusted with provision of the needs of those who are incapacitated by disabilities in the society. However they face many challenges in the process of caregiving. Understanding the experiences of caregivers would be instrumental in addressing the challenges faced in the process of caregiving. The study investigated the social experiences of caregivers of children living with disability. The study was guided by Friedman's social (dis) empowerment which highlights 8 areas of (dis) empowerment during caregiving. The study adopted descriptive cross sectional study design and a qualitative phenomenological method of data collection. In-depth interviews were conducted to collect data from sixteen (16) primary caregivers of children with disabilities. Data were audio recorded, transcribed and analyzed using MAXQDA Version 12. The study established that caregivers of children living with disabilities face challenges in acceptance, lack of public awareness, burden of caregiving, stigma, embarrassments, inadequate social services as well as socio-psychological challenges. The study therefore recommends programs aimed at addressing such challenges as a necessary public health initiative.

Keywords: *caregiving; disabilities; informal settlement.*

INTRODUCTION

Caregivers are individuals entrusted with ensuring needs of an incapacitated individual are met (Clifford Simplican, 2015). Due to the number of persons with disability and the social context in which they occur, state health systems would be unable to provide adequate coverage to the persons with disabilities without the caregiver contributions (Seligman & Darling, 2017). A care giver in this study is an individual such as a parent, foster parent, or head of a household, who attends to the needs of a child with a disability. Caregivers support family members who experience disabilities related too much physical and cognitive impairment that restrict normal functioning (Clifford Simplican, 2015). As in most countries, the care of seriously disabled children most often falls to the parents or family of the child and reduces the use of institutional care for the child (Adithyan, Sivakami & Jacob, 2017). A family caregiver and informal caregiver refer to an unpaid family member, friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care (Feinberg, Reinhard, Houser, & Choula, 2011).

Traditionally, women have been attributed primary responsibility for family work in most societies (Benería, Berik & Floro, 2015). Women's massive entry into the work force, combined with diversification of families has however today shifted the dynamics of gender in caregiving as men are also getting involved (Coontz, 2016).

For a family member who cares for a child with a disability, combining personal, caregiving, and everyday needs can be challenging. To most care providers , caregiving isn't a job or a duty but is an obligation that they have to contend with (Shapiro, 2015). Unfortunately, few people have the time, resources or ability to care for their disabled loved one without assistance or support. It is important for caregivers to know their limits, take care of themselves, know their resources in the community, and understand the wants and needs of the person needing care. Successful caregiving means finding a balance between providing the necessary care and encouraging the care receiver to be as independent as possible. Gona*et al.* (2010) states that caregivers of children with disabilities have repeatedly highlighted their feelings of discrimination, stigma and exclusion in many domains of their lives and that there is little research from Africa addressing these issues. Zarit and Zarit (2015) also notes that caring for a disabled family member can be challenging, potentially impacting caregivers' health, mental health, work, social relationships, and quality of life. The aim of this study was to explore social caregiving experiences of caregivers of CLWD in Mukuru slums, Nairobi, Kenya.

LITERATURE REVIEW

Experiences and challenges in caregiving for CLWD vary from one context to another. Social experiences refer to those experiences relating to such factors as social support, religious connections, and sense of community that caregiver face in the process of caring for CLWD. Several social experiences may occur during caregiving. Lokwet (2013) Studied challenges faced by parents of CLWD from pastoral communities in conflict zones and found out that social experiences of parents caring for CLWD include the prevailing societal attitudes about disability which they attributed to myth created around the concept of disability, superstition, and self-blame. His study also highlighted the fact that CLWD are enrolled and retained in schools where social challenges still persisted.

Another study conducted by Ambikile and Outwater (2012) revealed that caregivers of CLWD are often stressed by caring tasks and having worries about the present and future life of their children. They had feelings of sadness, and inner pain or bitterness due to the disturbing behaviour of the children. They also experienced communication problems with their children due to their inability to talk. The caregivers pointed inadequate social services for their children, stigma, burden of caring task, lack of public awareness of mental illness, lack of social support, and problems with social life. A study by Gona et.al,(2011) generated two main themes as; Shattered dreams and Expectations from health care staff. The analysis revealed that caregivers to not have adequate time for other responsibilities and are isolated from community activities. Their study also revealed that community members often speculated about the cause of disability and this often interpreted pejoratively. Such situation build stressing environments for caregivers of CLWD.

METHODS

The study adopted descriptive cross sectional study design to explore the social experiences of caregivers of children living with disability (0-15 years) in Mukuru Slums in Kenya. Qualitative phenomenological study approach was thus employed to explore the specific social experiences of such caregivers. Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The study utilized purposive sampling to sample all households with CLWD. Individual participants were identified purposefully and picked from the APDK program. Data was collected using Key Informant Interview guides. All interviews were audio recorded. The audio records were transcribed and translated from Kiswahili to English. Qualitative data analysis, a range of processes and procedures aimed at understanding individual experiences for a consolidated explanation, understanding or interpretation of the situation investigated (Silverman, 2016). All the transcripts were uploaded into MAXQDA software and themes identified through text analysis approaches. Identified themes included lack of acceptance, lack of public awareness, embarrassments, burden of caregiving, stigma as well as inadequate social services.

FINDINGS

Social experiences of caregiving for CLWD are the experiences relating to such factors as social support, religious connections, and sense of community. This includes social support structures, relationships impact, social isolation and social stigma and embarrassment that the caregivers had faced from the family and society in various walks of life. Table 1 below represents the frequencies of themes identified from data analysis.

Table 1. *Frequencies of thematic statements*

Essential themes	Thematic statement	Number of passages	Percentage of cases
Social Experiences	Discrimination	10	63
	Child activities	2	13
	Blame from spause	4	25
	Understanding the condition of disability	13	81
	Inadequate Social Services	9	56
	Embarassment	8	50
	Stigma	13	81
	Societal attitude	6	38
	Public awareness	7	44
	Acceptance	9	56
	Soccial services	11	69

Experiencing the "Disability'' in the Child

While caregivers live in the hope that their children would one day become better, they are also frustrated by the inabilities of these children. However, they become dissapointed that their children are not able to do basic things like eating on their own, talking, toiletry or making decisions. They are often left wondering what future holds for their children. About 81% of the informants indicated that they were generally disapointed with the condition of their children. In an interview with a female caregiver, before breaking into tears, she said

"Yes I take him to school, but he does not understand anything...he cannot do anything that other children who are in the same school with him are doing"

Another caregiver posed that

"I pleaded to the teacher to just let him stay in school even though he was not making progress because even if he stayed at home, he would not be ableto do anything... he was just lying there on the floor and would not do anything. He cant help himself, he cant talk, he cant go to the toiletets... this was difficult for me"

Stigma

Most CLWD and their caregivers have to live with stigma due to the conditions of their children. From the interviews, it emerged that caregivers are stigmatzed in the community they live in, the health facilities they attend as well as the schools where they children would attend. A caregiver whose child had polio narrated the stigma she went through in a health facility.

"When I went to a health facility two years ago, I explained the condition of the child to the doctor... he started writing in the computer and did not even look at the child. For me I knew he did not like the look of my child"

Another parent caregiver also narrated how she was stigmatised in a school where she had wanted to enroll her child in;

"When I took him to school, people were surprised what kind of problem is this..they looked at the child and wondered. Personally, I felt bad because they seemed to be holding hate a gainst me and my child. This is the situation a faced with the child from the time I entered the school compound"

It also emerged that most caregivers were stigmatised due to the condition of their CWD. One caregiver posed that

"the first thing is, it becomes hard to engage with other parents and even with friends. sometimes those other parents they are my friends but they put me aside because of my child"

Discrimination

Discrimination occurs when an individual is treated or considered of, or made a distinction in favor of or against, based on the group, class, or category to which that person belongs rather than on individual merit(Emens, 2017). About 10, 63% of the informants mentioned instances where children under their care were discriminated against. Those who discriminated against the children were neighbors and family members who thought that disability was infectious. One care giver mentioned that;

"My neighbours do not want to visit my place because they think coming to my house or sending their children here....my son will infect them. They avoid me and treat me differently because of the condition of my child...it is also abig problem with my family members. I thought they could come up and help me raise this child. This did not happen becase they soon statrted avoiding me when they realised the condition of my child. So i had to carry the burden of raising him myself.

Acceptance

From the time of birth to later periods in life, parents who are also caregivers in most cases have to face the reality of disability in their children. From the initial stages of life, parents are mostly optimistic that the condition of their children would become better. However, as days go without any observable change in the condition of their children, they become disillusioned. In the study, informants revealed that caregivers took time before they begun to accept the fact that their children were disabled. In one interview, a male caregiver posed that;

"The mother had an accident and passed out ...she was then pregnant and the doctors suggested that an abortion be procured but the mother declined...when she finally delivered, the child was affected. We kept on waiting and praying that the condition of the child would improve...however, we had to finally accept that she was different from the other children and that she would be with this condition for the rest of her life"

Experiencing Need to Monitor Child activities

Children with mental disabilities require close monitoring. About 13% of the informants indicated instances of their CLWD causing disturbance to the neighbors. The study revealed that caregivers were cautious over their children's whereabouts lets they stray into their neighbor's households and cause disturbance. This experience was mentioned to be quite disturbing to the caregivers who had to be physically around where for caregiving or carry their children along if they were to attend to any form of errand. One caregiver narrated that;

"this child does not calm down, he runs, jumps up and down and when he cant, he drools. He is ever like that. And another thing is that he doesn't like other children... he beats them and they also beet him. This kind of disturbance does not make my neighbours happy. It strains my relationship with them. So it forces me to be around...in this place all the time and if I have to leave then I leave with him"

Experiencing Deviations from Ideal Family Expectations

Every family formed expects a fairy tale of their marriage life. Diseases are least expected and when they come, explanations are sought from every body of knowledge. This experience was recounted by about 25% of the informant. One informant narrated how the husband could not stay with her after giving birth to 3 children with disability.

"The issue with this child affected my marriage. My husband took off after a gave birth to our last born... the baby I am holding now. He mentioned to me that none of his relatives had ever given birth to a disabled child and that I was the cause of all these. He said that he could not father such children. He even threatened to beat me up...so he left and now I have to take care of these children alone..."

In another perspective, over 80% of the informants indicated that their family members were equally disapointed with the condition of their children. They mentioned that the family had never had such children before. One caregiver mentioned that a member of the extended family mentioned that ;

"I have had social challenges emanating from the family in which I am married (in-laws) ..they started saying that they have not had a child like that, and that

I was the first to give birth to such a child in the entire lineage...could this be true...they just blamed me..."

Experiencing Disability in the Public opinion

Public understanding on disability involves not only understanding it causes but also being in a position to accomodate and empathise with the disabled. When disability is not understood by the public, stigma and sicrimination occurs. From the study, it emerged that most people do not understand what disability entails. This lack of awareness was found even among the caregivers. About 7 out of the 16 sampled informants mentioned instances of lack of awareness. During one of the interviews, a respondent indicated that;

"When I realised that his hands and legs were twisted, I did not understand what was going on...you see most people do not know about disability...when we took the baby to the hsopital...we din't understand, they did not tell us whether the baby had problems and he was our first born"

This lack of understanding puts alot of pressure on the caregivers. During the interviews, it emerged that the apparent lack of public awareness made people reluctatnt to participate in caregiving. One caregiver posed

... *you can't find somebody to leave the baby to they won't accept even if you pay them".*

SUMMARY OF FINDINGS

Experiences relating to the social lives of caregivers of CLWD from the study included disappointments with the conditions of the child, stigma, discrimination, acceptance, child causing disturbance, blame from the spouse, and lack of public awareness, inadequate social services and embarrassments. The study established that caregivers of CLWD often find it difficult to accept their situation as caretakers of CLWD. Further the study established that the public is not well informed about the issues of disability and therefore are not able to offer the required support to the CLWD as well as their caregivers. Because of this, caregivers go through difficult moments trying to address the challenges of their CLWD. On the other hand, the study also established that there are inadequate social support services for the caregivers of CLWD. The available services are mostly initiated by the caregivers themselves. The few available services are poorly organized and inadequate. Community members themselves were also found to be reluctant towards providing support to the caregivers.

Socially, the caregivers in the study also expressed their state of disappointment in the condition of their children which they lived in hopes of improving. Most of the caregivers found it frustrating that the CLWD under their care had to be assisted in doing everything. Further, most of the caregivers had to contend with the stigma labeled against then in the society due to the condition of their children. This stigmatization was found to be at school, at home as well as the health facilities. In the society, the study revealed that poor attitude also exist and that these misconceptions results into myths, self-blames as well as superstitious claims labeled against the parents of the CLWD who are in most cases also the caregivers.

The study also revealed that most of the caregivers were stressed by caregiving. Due to lack of support from the society, caregiving was burdensome to them and that they hardly even understood the needs of the CLWD. Caregiving from the study was viewed as a burden that the mother had to bear alone. Besides, the caregivers also indicated that they did not even have enough knowledge on caregiving. The study thus finds caregiving for CLWD as a tasking exercise which if not well understood and addressed may complicate both the social life of the caregivers predisposing them to lifestyle diseases.

Conclusion and Recommendations

The conclusions that can be drawn from the study are that though the caregivers showed commitment to their responsibilities, they face several social challenges. These include difficulty in accepting the condition of the child as well as the burden of care. There are minimal support options for the caregivers such as counseling and respite care. Further, the needs of the caregivers for children with disabilities are not being met.

The study recommends creation of more centers for caregivers and their CLWDs, deliberate attempts of identifying unique challenges that face the caregivers of CLWDs, strategic programs aimed at empowering caregivers with information and resources to take care of their own health and wellbeing as they do the caregiving.

To address the social challenges of caregiving, caregivers can be aided in their journey to adjustment by providing solid social support structures that can be able to provide services aimed at respecting and addressing the caregiver's emotions of loss and grief, encouraging families to take time to heal, and by providing them with more facts about disabilities. Specific attention needs to be given to the attribution of blame and responsibility within the family, as well as possible spillover effects in the marriage relationship, parent-child relationships, and/or sibling relationships.

It was observed that most of the caregivers interviewed were in their productive years. This being the era where both sexes are bread winners, collaboration in establishing local training programs and day care centers where these people can train in various skills while their CLWDs are taken care of at the center. This could minimize poverty among them. Finally, since most participants in the present study were female, possible gender differences in male caregivers' experiences of raising CLWDs remain unexplored and further research can look into it.

ACKNOWLEDGEMENT

We acknowledge support from colleagues from Great Lakes University of Kisumu, all respondents from the study area and those involved in one way or the other in caregiving for CLWD.

REFERENCES

[1] Adithyan, G. S., Sivakami, M., & Jacob, J. (2017). Positive and Negative Impacts on Caregivers of Children with Intellectual Disability in India. *Disability, CBR & Inclusive Development*, *28*(2), 74-94.

[2] Ambikile, J. S., &Outwater, A. (2012). Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam-Tanzania. *Child and adolescent psychiatry and mental health*, *6*(1), 16.

[3] Benería, L., Berik, G., &Floro, M. (2015). *Gender, development and globalization: economics as if all people mattered*. Routledge.

[4] Bureau,U.(2018). *Census.gov*. *Census.gov*. Retrieved 16 February 2018, from https://www.census.gov/

[5] Chrisman, N., & Maretzki, T. (Eds.). (2012). Clinically applied anthropology: anthropologists in health science settings (Vol. 5). Springer Science & Business Media.

[6] Clifford Simplican, S. (2015). Care, disability, and violence: Theorizing complex dependency in Eva Kittay and Judith Butler. Hypatia, 30(1), 217-233.

[7] Coontz, S. (2016). The way we never were: American families and the nostalgia trap. Hachette UK.

[8] Cortiella, C., & Horowitz, S. H. (2014). The state of learning disabilities: Facts, trends and emerging issues. New York: National Center for Learning Disabilities, 2-45.

[9] Feinberg, L., Reinhard, S. C., Houser, A., & Choula, R. (2011). Valuing the invaluable: 2011 update, the growing contributions and costs of family caregiving. Washington, DC: AARP Public Policy Institute, 51, 1-28.

[10] Geere L., Gona J., Omondi F., Kifalu K. and Newton C.(2010).Caring for children with physical disability in Kenya: Potential links between caregiving and carers' physical health. USA. Blackwell

[11] Gona J., Mung'ala-Odera V., Newton C., and Hartley S. (2011).Caring for children with disabilities: What is the carer's experience. Nairobi. Blackwell Publishing Ltd.

[12] Kenya National Survey for Persons with Disabilities. (2008) (1st ed., pp. 23-27). Nairobi.

[13] Kenya National Survey of Persons With Disabilities, (2009). Nairobi. Government Press

[14] Lokwet, (2013). Parents balancing between insecurity and schooling needs of children with disabilities in Pokot north district, west Pokot county. Nairobi. Kenyatta University

[15] Seligman, M., & Darling, R. B. (2017). Ordinary

families, special children: A systems approach to childhood disability. Guilford Publications.

[16] Shapiro, D. A. (2015). Caregiver Stress: First Person Accounts of the Perception and Utilization of Support Services.

[17] Silverman, D. (Ed.). (2016). Qualitative research. Sage.

[18] Zarit, S. H., & Zarit, J. M. (2015). Family caregiving. In Psychology and Geriatrics (pp. 21-43).

Citation: **Eunice Ndirangu, Ronnie Midigo.** *Caregiving for Children Living with Disability in the Informal Settlements in Kenya: Exploring the Social Experiences of the Urban Poor Living in Mukuru Slums in Nairobi. Open Access Journal of Nursing. 2018; 1(1): 33-39.*