Understanding the lived experiences Caregiving for Children Living with Disabilities in Mukuru Slums, Kenya; Implications for Health and Wellness in Caregiving

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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. This study investigated the health and wellbeing challenges experienced by caregivers of children living with disabilities and to explore the coping mechanisms employed by caregivers of children living with disability. It 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 Max Qualitative Data Analysis Software Version 12. Authority to collect the data was sought from county government Embakasi Constituency. The study established health consequences of caregiving included physical activity limitations, physical exhausted during caregiving, side effects of some of the medications and risks of developing high blood pressure, ulcers and depression. The study concludes that caregivers of Children Living with Disability face unique social, economic and health and wellbeing experiences. The study therefore recommends programs aimed at addressing such challenges as a necessary public health initiative.

Key words: Disability, Health, wellbeing, Health Consequences.

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Introduction

Across the world, about 15% people live with disabilities (WHO, 2016)[40]. In Africa, it is estimated that 10% of the general population live with disabilities, but possibly as high as 20 percent in the poorer regions[36]. The current statistics of disabilities in Kenya reveal a 4.6% prevalence with 2.3% being children. These numbers are accompanied by equal numbers of caregivers. Children living with disabilities form a considerable proportion of persons living with disability in Kenya (about 63.58%) (KNSPD, 2008). Such children require considerable proportion of caregivers. However, caregiving in most parts of the world is often relegated to the parents and other relatives. Besides, with the changing economic structures, male members of the family, who hitherto were not involved in caregiving, are today involved in caregiving[1-5]. In cases where proper attention including legislative measures as well as appropriate social support system are put in place, caregiving becomes less challenging for the caregivers. However, in majority of cases in Kenya, the caregiver receives little or no form of deliberate support either financially, emotionally, physical health, nor in skills of caring. The state of Caregivers of children with disabilities in Kenya has not received much attention even in legislations[6-8]. Few studies on caregiving have been done in Kenya. Gona.et. al, (2011) and Geereet.al, (2010) are among those who have explored experiences of the caregivers of children with disabilities but focused on stigma, discrimination and exclusion [16]. In Mukururslums in Nairobi, the providers of services for PLWD are the Association for the Physically Disabled of Kenya that offers community-based rehabilitation services in collaboration with the government of Kenya, among others[9-12]. These agencies focus on the needs of the CLWD and but little on the state of the caregiver. With a population of about 700,000 persons living in 2.3 square kilometers of land, the area has high numbers of PLWD given that 4.6% of Kenyans are PLWDs (KNSPD, 2008)[19,20]. These persons live with caregivers whose experiences...
are not properly understood and documented due to lack of similar studies in the area. With the general tendency for poverty levels on the rise particularly among the slum dwellers like in Mukuru and where many of the caregivers being poor mothers, the negative experiences from caregiving if not explored and addressed only serves to make them more unproductive in the community[13-14].

Literature Review
Health and wellbeing experiences of caregivers of CLWD
Health has been described as the level of functional or metabolic efficiency of a living organism [31]. In humans, health is generally taken to imply the ability of individuals or communities to adapt and self-manage when facing physical, mental or social challenges [31]. The World Health Organization defined health in its broader sense in its 1948 constitution as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”[15-18] Policies, programs and practices in the health sector have an impact on the rights of PLWDs, and yet most development initiatives ignore the needs of caregivers of PLWDs. The UN Convention on the Rights of PLWDs emphasizes the importance of mainstreaming disability issues for sustainable development. Attention to health and its social determinants is essential to promote and protect the health of PWDs for greater fulfillment of human rights (UNSD, 2010) [39].

Candice (2011) carried out a study on The Impact on Mothers of Raising a Child with Significant Disabilities in the Developing World. This study was a literature review of 39 articles from the developing world that dealt directly or indirectly with the impact on mothers of raising a child with significant disabilities. Candice had noted that although much research had been done on this topic in North America, Europe and Oceania, comparatively little has been done in the developing world, and only one study had. This study aimed to compare mothers’ situation across cultures and secondly to see if John Friedman’s model of social empowerment could be helpful and adequate to shed light on these mothers’ situations [19-22]

The health of a caregiver can influence or be influenced by process and outcome of caregiving as explored by McIlvennan et.al, (2015) [28]. He looked at health among caregivers of children with health problems in Canada. The purpose of his study was to examine how caregiver health was related to poor child health broadly defined, at the population-based level. He hypothesized that health of caregivers of children with health problems would be significantly poorer than that of caregivers of healthy children, even after we controlled for relevant covariates. Caregiving can influence the health of the caregiver negatively. A study conducted by Geere et.al. (2010) in Kilifi Kenya which aimed to explore the potential links between providing care of a child with moderate-severe motor impairments and the physical health of caregivers as well as to identify ways to improve the situation for 20 caregivers and their families. This study used qualitative and quantitative methods and a sample size of 20 recruited a purposively. The data collected was grouped into themes of; 1) symptoms related to physical health , 2) Symptoms that indicate particular conditions commonly affect their physical health, 3) demands of caregiving relating to own physical health and 4), suggested support by caregivers.[23-27]

Findings from this study indicated that caregivers commonly reported chronic spinal pain of moderate to severe intensity, which affected essential activities self-care and house wife responsibilities. All caregivers reported chronic pain as their main complaint, affecting all for more than 50% of the time in the previous month (one reporting >95% of the time). Only three reported that their symptoms were improving. Most had widespread pain in multiple areas, particularly in one or more regions of the spine and/or a limb [28-30]. The caregivers were identified as facing environmental challenges because of where they lived and were deemed by the physiotherapist to have psychosocial factors affecting their clinical presentation. Many caregivers also reported feeling generally unwell, recent weight loss, and that they were taking medication. They described the physical difficulties they faced in caring for their child, particularly difficulties in carrying their child with a disability. All except one rated the activity most affected by musculoskeletal impairment as being an essential activity of daily living [31-33]. On how they can be supported the findings showed that caregivers need help in enabling children to attend school, or when they remain at home, providing some additional supervision and also need for suitable equipment, such as wheelchairs or calipers, and shoes to facilitate their child’s mobility and reduce the need for carrying, as well as support through additional income or food.

The authors concluded that caregivers of children with moderate-severe motor
impaired health challenges. While routine assessments lead to diagnosis of simple musculoskeletal pain syndromes, the overall health status and situation of caregivers may be more complex. Reports of spinal pain may also indicate the presence of other medical conditions and expanded roles for rehabilitation therapists may be useful to optimize service provision in supporting caregiver’s health and physical functioning. They recommended that the role of rehabilitation therapists may need to be expanded to effectively evaluate and support caregivers' health needs and there is need for staff capacity building in Kilifi. The provision of equipment to improve their child’s mobility, respite care or transport to enable school attendance is likely to be helpful to caregivers and children alike[34-36]. Some researchers have investigated the positive aspects of caring, such as the satisfaction experienced by caregivers in performing their caring role. Important positive aspects of the caregiving role include giving pleasure to the care recipient, maintaining the dignity and maximizing the potential of the care recipient, experiencing enhanced relationships, meeting perceived responsibilities, sharing mutual love and support, and developing personally[24]. Caregivers in other studies also indicated some benefits of caring, such as a sense of closeness to the care recipient, and enhanced self-esteem (Brand, Barry & Gallagher, 2016). It is likely that these positive aspects of caring would impact positively on the caregiver’s overall mental health[37-39].

Methodology
The study adopted a simple descriptive cross-sectional study design to explore the caregiver’s experiences in caring for their children with disabilities. Qualitative phenomenological study approach was thus employed to explore the experiences of caregivers of children with disabilities. Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The rationale for a phenomenological approach in this study is that such an interpretive inquiry enables material to be collected and analyzed within the specific context of the subjective realities of primary caregivers of the children. It was conducted in Mukuru slums, a home to over 700,000 people living in an area of about 2.3 km square. The study populations were primary caregivers of children with disabilities aged zero to fifteen years. The study utilized purposive sampling to sample all households with children living with disability. Individual participants were identified purposefully and picked from the APDK program register were interviewed each in his or her own rented house where they lived with the CWD and family[40,42]. The study utilized Key Informant Interview Guide to collect qualitative data from caregivers. All audio recorded interviews were transcribed and analyzed using MAXQDA version 12 computer software.

Study Findings

Demographic characteristics of the participants
The demographic information considered included gender, age and religion. The results were as shown in Table 1. below

<table>
<thead>
<tr>
<th>Gender</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>93</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-25</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>26-30</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>31-35</td>
<td>8</td>
<td>50</td>
</tr>
<tr>
<td>36 and above</td>
<td>2</td>
<td>13</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religion</th>
<th>F</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christian-Protestant</td>
<td>11</td>
<td>69</td>
</tr>
<tr>
<td>Christian-Catholic</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>No religion</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>100</td>
</tr>
</tbody>
</table>

In most African societies, caregiving is a preserve of the women. This study on the other hand did not assume the caregiving role to be that of the mothers or female members. In cases where both male and female participants were present during the study, the researcher made conclusions on the caregiving role based on how the two answered the questions asked.
The respondent who addressed most of the needs of the child at home qualified as the primary caregiver. This was done through code weighting. The findings of the study revealed that most of the caregivers (93%) were female. From the study, most of the caregivers, 8 out of 15 were aged between 31-35 years. Only 1 caregiver was aged above 36 years while 2 of them were between 20-25 years of age. The rest of the caregivers, 4, were aged between 26-30 years. Of the sampled informants (69%), majority were Christian Protestants. The other, 25% were Christian Catholics. About 6% had no religion they subscribed to. This was as shown in table 4.1 above.

Experiences relating to health and wellness. There are several health consequences that come with caregiving. Most caregivers are confined to the duty of caregiving and this could limit their physical activities, the extra financial burden of caregiving may also affect their nutritional status, they would become physically exhausted while caregiving and, in most cases, would suffer from poor emotional health. In other instances, conditions of the child might require specialized medicines with side effects to the third parties. These were as presented in table 2 below

<table>
<thead>
<tr>
<th>Essential themes</th>
<th>Thematic statement</th>
<th>Number of passages</th>
<th>Percentage of cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health and wellbeing experiences</td>
<td>Selfcare in case of sickness</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Isolation</td>
<td></td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td></td>
<td>9</td>
<td>56</td>
</tr>
<tr>
<td>Marital dissatisfaction</td>
<td></td>
<td>10</td>
<td>63</td>
</tr>
<tr>
<td>Weight Loss</td>
<td></td>
<td>9</td>
<td>56</td>
</tr>
<tr>
<td>Medical Complications</td>
<td></td>
<td>11</td>
<td>69</td>
</tr>
<tr>
<td>Effects of medication</td>
<td></td>
<td>9</td>
<td>56</td>
</tr>
<tr>
<td>Physical exouston from caregiving</td>
<td></td>
<td>7</td>
<td>44</td>
</tr>
<tr>
<td>Stress</td>
<td></td>
<td>8</td>
<td>50</td>
</tr>
</tbody>
</table>

Medical complications
Health complications facing caregivers are a result of the physical demands that come with caregiving. During the interviews, it emerged that most caregivers developed back pains, numbness of hands and high blood pressure in the course of their caregiving. Though the conditions could not be directly linked to caregiving, the caregivers perceived that such conditions developed as a result of their caregiving. Eleven caregivers attributed various health conditions they had to their caregiving experiences. One caregiver contended that “There are several health experiences we go through as caregivers. Our health is affected in many ways. for example now carrying a child like this, my hands lost strength, even now”.

Another caregiver posed that “I think a lot, blood runs quickly... and I was sick with chest problems...I have ulcers because of him...I keep on thinking where I could get help because indeed my role as a caregiver is faced with several challenges”. Effects of medication
As caregivers of CLWD, one of the critical role is to ensure good health for the CLWD including proper medication if prescribed. During the interviews, it emerged that some of the CWD used medicine which sometimes produced undesired effects to the caregivers. Use of inhalers and other drugs that were not revealed to the researcher had negative effects on the caregivers. Nine respondents indicated that their children used menthoplus and that they did not like the smell of the medicine and that besides that, it had undesirable smell. One respondent posed that “The child has a problem of allergy. Since there is alot of cold here, he is often on menthoplus and you know this thing has a smell. It sometimes irritate me”.

Depressive symptoms
Caregivers become depressed when they have nowhere else to turn to. Their worries are not only limited to the conditions of their children but also begin to question themselves as why such a thing had to happen to them and not to someone else. Nine caregivers mentioned instances where they had depressive symptoms. During the interviews, the researcher encountered three cases of caregivers who seemed depressed. One of them posed “I don’t have any body to tell anything and who might help me...even if I cook in my house.... I will cook but I won’t eat with joy. I spend most of my time alone and keep on
wondering why this had to happen to me. But God knows why”. Another caregiver who was in business had similar sentiments. You know how it is when you slightly wrong someone he/she will even stop buying from your shop and now take that advantage?

Interviewer: so then... explain what you do when this happens.

Participant: (Diverting from the question) now something like that me usually know is that there are always better people other than the one wanting to take advantage of my situation. it is like a mental problem, I could not understand myself .It affects me because thoughts become too much”

In other instances, poor emotional health resulting from the fear of having another child, emotional stress and stigma crops in and the caregivers become depressed.

Interviewer: Do you have another child?

Participant : NO!

Interviewer : And why? ..

Participant : you get the first one and has a problem, the second one too has the problem. The thought of having a disabled child troubled catetakers in the study area. A respondedt posed.

“some times it takes some time to note that Rehema is like this but if you would be always waking up to see her or getting in the house and remembering you have a disabled child”......

Weight loss
Weight loss occur due to mulnutrition, physical exhousion as well as emotional stress. Caregivers may suffer from malnutrition due to economic constraint associated with caregiving and emotional stress from the condition of the child. During the interviews, nine caregivers (56.25%) indicated that they suffered physical exhousion while caring for the CWD. The researcher also observed that out of the 16 mothers who participated in the study, 13 appeared underweight. One caregiver posed “I have to carry him even when I go to work and as result, I lose alot of energy...look at me...I have lost weight because of him. His condition is also stressing for me and I wonder sometimes when all these suffering will end”.

Physical exhousion from caregiving
Caregivers are faced with the challenge of having to physically carry their children even in cases where the child has been provided with wheel chairs. This occurs when they have to be helped in the washrooms, sleeping places as well as to and from school. It emerged from the interviews that the caregivers had to contend with the weight of their children. Seven caregivers (43.75%) indicated that they got exhoused with caregiving. One caregiver contended that “At her age she is very heavy ..since I am the only one who looks after him, I get tired carrying him. I feel some pain on my back and hands. I have to also carry his things as well, when I get to the house I will be tired, that day I won’t be able to do other things my back will be aching”.

Emotional stress of caregiving
Caregiving for CWD can be a source of stress for the caregivers. During the interviews it emerged that most of the caregivers were often stressed up by the fact that they had to spend a better part of their life caring for their CWD. Eight out of the sampled 16 caregivers indicated that they suffered emotional stress. One caregiver posed “you cannot understand her...you may not know what her problems her..I get stressed sometimes and just start crying. So as a mother, sometimes as a mother you have to leave things to God. The other thing is that people should accept the disabled and they stop mistreating us”. Caregiving could also be burdensome to the caregivers. During the interviews, it emerged that caregiving was a burden that the caregivers had to put up with. One female caregiver indicated that “she is heavy and this child you cannot leave in the care of another person... you have to move as a whole family... you have to sit with her and feed her because somebody else can feed her within 20 minutes and leave her...so when the father is off to work, I have to feed this one and the younger one wants to be carried also”.

Beside, some of the caregivers had not had any form of training on caregiving. As a result, they are not able to sufficiently cater for the special needs of the children due to lack of adequate caregiving knowledge. A caregiver complained of the frustrations she underwent “sometimes you do not know how to do the massaging...“sometimes when you do it, the doctor say that you did not do it like it’s supposed. So I am saying that I depend on myself... “

In other instances, the caregivers did not even know what steps to take when they discovered that their children had disability. “I did not know where to take him so that I get help...No one seemed to understand me” Health experiences of caregivers of CLWD. The study established that since most caregivers were confined to the duty of
caregiving their physical activities were limited. They did not have adequate time to exercise their bodies and therefore were at risk of lifestyle diseases. Further, most of these caregivers would become physically exhausted while caregiving. In the absence of wheelchairs, they would physically carry their children from one place to another. In other cases, they had to carry the CLWD along to work and this was found to be physically exhaustive.

The study also revealed that some of the CLWD used medicine which sometimes produced undesired effects to the caregivers. Such drugs would possibly create negative effects on the caregivers. The caregivers also had a risk of developing unhealthy conditions including high blood pressure, ulcers and depression. The study established that most of the caregivers were underweight, suffered depressions and sometimes had ulcers. The study also established that in the process of caregiving, caregivers are faced with the challenge of dissatisfaction in marriage life. Partners and or relatives engage in blames against one another on the cause of the disability.

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 and economic challenges that result in them being stressed and emotionally as well as physically ill. 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.

The male caregivers should be given specific attention as many of the times the community and society may not think about them. Traditionally and naturally caregiving roles have been more the work of women. There is need to identify women caregivers and make deliberate efforts to empower the men handling their primary caregiving roles to CLWD.

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.

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