Original Research Article

SOCIO-CULTURAL AND ECONOMIC CHALLENGES FACING CAREGIVERS OF CHILDREN WITH PHYSICAL DISABILITIES SUPPORTED BY MAWAKI IN KILOLO DISTRICT, TANZANIA

Abstract

The well-being of children with physical disabilities is highly dependent on the absence or reduction of the caregiving burden on caregivers. This study aimed to investigate the social, cultural and economic challenges facing caregivers on provision of social well-being to children with Physical Disabilities supported by MAWAKI organization in Kilolo District, Iringa region, Tanzania. The study adopted a cross-sectional research design where interviews and Focus Group Discussions (FGDs) were used to collect information from the caregivers of children with physical disabilities, MAWAKI organization staff and Village Executive Officers (VEOs). The content analysis was used to analyse qualitative information collected from the respondents. From the study findings it is concluded that the social challenges facing the caregivers of children with physical disabilities include inadequate availability of social programs, marriage conflicts and poor family relationships. The cultural challenges identified by study to affect caregivers of children with disabilities were negative attitude, perceptions and beliefs towards children with disabilities. On the other hand, the existence of poor financial support, high cost of health and transport services were concluded as the economic challenges facing caregivers of children with physical disabilities. Therefore, the study recommended that caregivers needed to be provided with affordable social and economic support services together with the existence of effective implementation of the government policies and laws related to disabilities people in Tanzania.

Key words: Caregivers, Physical Disabilities, Challenges, Socio-Cultural, Economic

1.0 Introduction

Well-being provision to people with disabilities is a global challenge. Children with disabilities are among the most marginalized and discriminated group in societies. They have been experiencing day to day prejudice in the form of alienation, lack of affection, unfavorable guiding principles and biased legislation, hence excluding them from being recognized for their potential in healthcare, education and survival (UNICEF, 2016). According to Resch *et al*., (2010), the responsibilities of caregivers are physically demanding, affect social and family relationships, and adversely affect employment. These roles of the caregivers to the children with disabilities expose them to the greater risks of being of over-exploitation. For example, the study by Whyte (1995), revealed that the care of a person with ‘retardation’, ‘epilepsy’ or a ‘mental illness’ in Tanzania was left to the family and was not seen as a responsibility bestowed on the wider community. According to Hartley *et al.,* (2005), however, in the situation of a family breaking down normally caregiving tasks usually remained as the responsibility of a female caregiver.

The empirical literature has observed the existence of a limiting number of studies undertaken in the area of social, cultural and economic challenges facing caregivers of children with physical disabilities This study, therefore was undertaken to fill the identified knowledge gap by informing relevant authorities about improving the planning and implementation of the laws, policies and programs on people with disabilities using a case of caregivers of children with physical disabilities supported by MAWAKI organization in Kilolo District, Tanzania.

2.0 Description of Study Area and Methodology

2.1 Description of the Study Area

The study was conducted in Kilolo District as one of the four Local Authorities forming the Iringa Region. The district extends between Latitude 7.0° and 8.3° South of the equator and between Longitude 34°& 37° east of the Green- which. The district borders Mpwapwa and Kilosa districts to the north, Kilombero District to east, Iringa District Council to the west and Mufindi District to the south. The district is divided into 3 divisions, 24 Wards, 106 Villages and 555 hamlets with 46,002 households, with only one parliamentary constituency. With the exception of a few plateaus, the district is mountainous with Udzungwa Mountains and several steep slopes and lies at an altitude of between 900 metres to 2,700 metres above sea level, covered by alluvial soil. Udzungwa Mountain ranges are the common features of Kilolo District and divide the district into East and West. Udzungwa Mountains separate Kilolo District and Kilosa District of Morogoro Region in the east. According to the report of the United Republic of Tanzania (URT) Census done in August 2012 Kilolo district has a total population of 218,130 inhabitants of whom 105,856 are male and 112,274 are female. (URT, 2012). The villages covered by the study were Lukani, Mtitu, Isuka, Kitowo, Ng’uruhe, Ukumbi and Kihesa Mgagao of Kilolo division as shown in Figure 1.

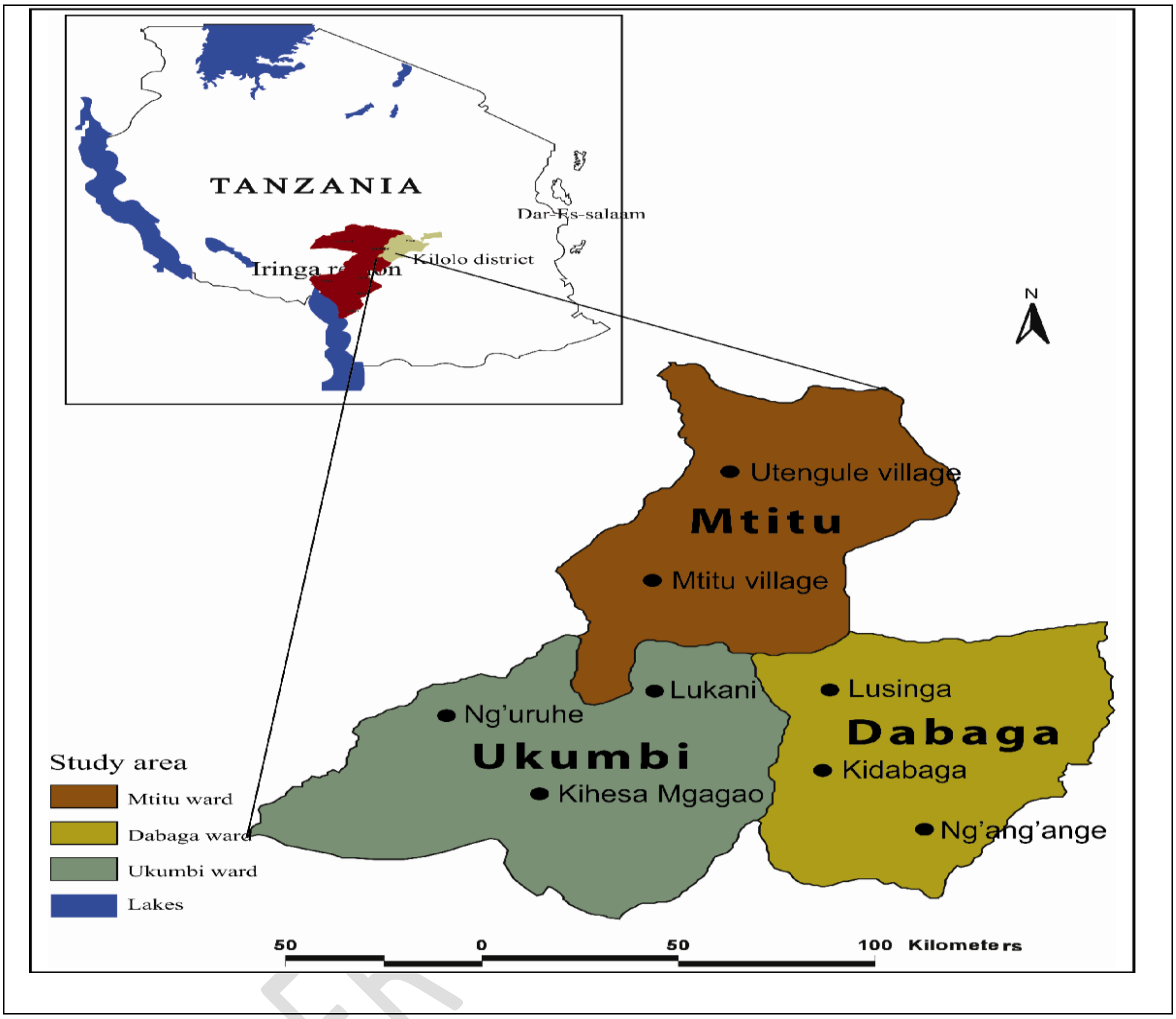

Figure 1: The Map of Study Area

2.2 Research Methodology

The study population for this study was caregivers of children with physical disabilities supported by MAWAKI organization in Kilolo District. A cross-sectional research design was used in the study in which data from respondents was collected at a single point in time. A purposive sampling technique was used to obtain divisions with the villages with the study population, whereas, the villages involved in the study and respondents were sampled accidentally. The villages covered by the study were Lukani, Mtitu, Isuka, Kitowo, Ng’uruhe, Ukumbi and Kihesa Mgagao of the Kilolo division. In-depth information on challenges facing caregivers of children with physical disabilities was collected through FGDs. The interview was conducted to 10 caregivers, 5 village Executive Officers (VEOs), and

5 MAWAKI staff in the study area. Content analysis was used to analyse qualitative information collected from the selected respondents.

3.0 Results and Discussion

3.1 Social Challenges Facing Caregivers of Children with Physical Disabilities

The results show that eight out of ten caregivers who were interviewed identified social isolation, marital breakdown and family disintegration as the main challenges affecting the children with disabilities. For example, the caregiver 1 of a disabled child with Cerebral Pulse (CP) has reported that:

> Breakdown of my marriage occurred soon after my husband found out that we have a disabled child. Before he promised to live with me and we were together until when I delivered a baby. Till this moment I don't know where is as his mobile number is no longer available (Caregiver 1)

The findings are similar to that of Singongo *et al*., (2015), whereby, some of the studies show that some of the marriages are broken up because of lack of acceptance of the children and humiliation especially by male relatives, thus poor spousal support and hence poor coping mechanisms. Furthermore, the study done by Hartley *et al.*, (2005) showed that characteristics of most parents who are mostly the primary caregivers varies and include self-blame, guilt, denial, withdrawal, grief, rejection, and acceptance are the usual parental reactions. Likewise, the study done by Gupta and Singhal in 2004, identified that acceptance has been noted to affect parents which results in them experiencing helplessness, feeling inadequacy, shock, anger and guilt whereas others go through moments of denial, self-blame and depression. A barrier to taking epilepsy medications was the lack of support from family members. One among the caregivers said "*You could be living nearby someone who owns a car and cannot even give you a lift to the hospital to take medicine especially when you are having insufficient bus fare despite being your neighbour. Sometimes I feel like they are afraid that my child may faint in the car so they do not want disturbance"*

The study findings also revealed that caregivers in the study area have been experiencing insults from the community and their family members for having a child with physical disabilities. They also reported that their children are stigmatized by their colleagues and they got the same challenges from their workmates, neighbours, community members as well as family members. The caregiver 4 with a stroke disabled child explained to feel ashamed by some family and community members because of having a child with disabilities. Sadly, she explained that:

> At the community meetings, I can get one attack and then my colleagues isolate me. My friend who used to help me has stopped

> sharing a seat with me, they say that when they sit with me. I would disturb them with my epileptic child who faints always. Surely, I am not comfortable going to community meetings because I feel ashamed of my child. (Caregiver 4).

Likewise, caregiver 3 reported that lack of support from families with children with disability and this has increased isolation felt by the children with epilepsy and the other disabilities in general. The caregiver explained that no one likes to have a child with Epilepsy or even other disabilities but no way out, they have to accept it and community or/and family members should not isolate them. The caregivers explained that they have been given nicknames associated with their disabled children. These names were disappointing to them because they did not want to have children with disabilities. The caregiver 3 with a child having Epileptic disability explained that:

> When you have this disabled child, people isolate you a lot and people start saying, "There is a way they call it that sounds so bad, "Epilepsy" or 'epileptic', caregiver. I would prefer a word like convulsions/seizures. These names are hurting because it is not our will to have children like these. It is a kind of joke that hurts so much although we cannot force them to stop joking like that (Caregiver 3)

The study also identified emotional and instrumental support as very important in facilitating caregivers for children. Parents felt that it is important to be healthy psychologically because in dealing with the well-being of a child with disability, a good mental state is important. On their side, all VEOs interviewed had reported the lack of special programs and services such as rendered directly from the government to the caregivers especially in the remote areas where there are poor social services like electricity. One of the VEO had this to say, " It is very difficult for our people in remote areas like this to access special programs and services which are available in town due to poor infrastructures." (VEO C)

The studies by Shirley, Amily, Zulhabari and Norashikin, (2017) and Suriati *et al.*, (2011) show that parents of children with physical disabilities are experiencing psychosocial problems including guilty, grief and discrimination from community members. Some of the challenging aspects of caring for these children include excessive caring burden, less quality time with family members, handling sibling problems, education and future concerns, as well as financial difficulties. The responses from the VEOs in five villages show that families with disabled children have depended on huge support from the MAWAKI organization. During interviews with MAWAKI staff, it was revealed that most of the caregivers lack social networks, isolated by their family members and unable to access transport services. One among the MAWAKI respondents said that *"caregivers really need time for themselves. They never had a chance to entertain themselves. They feel very tired of* *handling the situation. They really need a break from all of this and wish someone could help them in taking care of their disabled children as it is tough to handle it alone".*

3.2 Identified cultural challenges experienced by caregivers in study area

The VEOs were asked to state the cultural challenges affecting caregivers of children with physical disabilities in the study area. Four out of five VEOs who were interviewed had explained the existence of negative cultural beliefs and attitudes towards children with disabilities especially by male parents. In the case of families supported by the MAWAKI organization, the VEOs respondents argued that when they went to see the situation of the families supported by the MAWAKI organization there were only two men caregivers of disabled children. One disabled child explained to be valued more because her parents were government workers. The short story narrated by one of the VEOs revealed that acceptance of children with disabilities is really a big challenge to caregivers. One among the VEOs interviewed narrated that "*sometimes it is really surprising when mothers and fathers of a child do not agree to accompany their child with a disability to the hospital. I have received three cases from the MAWAKI organization about parents refusing to accompany their children to the hospital. Just because the MAWAKI is supporting them, they also allow its servants to continue staying in the hospital when their children get bed rest despite the fact the organization is paying for everything concerning the treatment. For sure as a VEO of this village I blamed and discouraged this kind of behaviour. The organization has many children to support. Why do the parents not understand this simple concept of cooperating with the organization that is paying for the treatment or even transport? Then what will happen if the organization does not agree to continue giving services to the child? What shameful is…? But I am happy that the MAWAKI organization servants are very tolerant despite those disturbances they never gave up* (VEO key informant B).

The study findings revealed that there is a relationship between the cultural knowledge and perceptions among caregivers of children with physical disabilities and their well-being. Poor beliefs and perceptions of the caregivers themselves and the whole community members had a great effect towards the well-being of children with physical disabilities.

3.3 Economic challenges facing caregivers of children with physical disabilities

An interview with caregivers in the study area had revealed that most of the caregivers interviewed are self-employed. Nine out of ten caregivers interviewed had reported to have limited financial support for caring for their children with disabilities. Most caregivers interviewed had reported that they find it difficult to care for their children because they have no clear job that can help them sustain their living. They are involved in small economic activities but most of the time they have to stay home with their children. One among the caregivers had this to comment:

> Financial support is very limited however; we cannot blame anyone because the life situation itself is very difficult to many of us who live in the villages. We mostly depend on small agricultural production to earn our living but the cost is higher these days. People are unable to buy fertilizers and other materials for agriculture hence they earn very little that is also sold with low prices… (Caregiver 5)

As a result of having economic hardship, most of the caregivers reported to face difficulties in accessing health services such as medical equipment; rehabilitation services and maternal health services. All caregivers interviewed in the study area had revealed that the costs of health services are higher and to a great extent unaffordable. They explained that the cost is mainly during the time of sending them to the hospitals for rehabilitation. Rehabilitation requires a higher cost that has led many caregivers not being able to afford and depending much on the support from MAWAKI organization. One among the caregivers' said that: *we are always unable to escape mentioning and appreciating the MAWAKI organization for the services that help us. We get transferred to Inuka (a place/center of disabilities found in Njombe region) whereby the MAWAKI organization sends our children to get some technical rehabilitation which costs much which in our normal economic situation is impossible to sustain…*

This finding is similar with the findings of the study by Sigalla *et al.*, (2017) who found that availability and use of social support services among members in various groups in any society is one of the critical areas that need attention. The employment or having a job to caregivers were explained to Carter for some requirements as further portrayed that, children with physical disabilities require more basic needs than the normal children.

4. Conclusion and Recommendations

The study found that the social challenges facing caregivers of children with physical disabilities in study areas are inaccessible to social programs, poor social support, poor family ties and services as well as marriage conflict which negatively affect social wellbeing to children with physical disabilities. On the other hand, the study has identified poor cultural knowledge, perceptions and beliefs as the existence of cultural challenges which are facing caregivers of children of children with physical disabilities in the study. Furthermore, the caregivers were found to face economic challenges such as unemployment, poor financial support, and health and transport costs that hinder the well-being of children with physical disabilities. In order to overcome challenges associated with caring for children with physical disabilities, parents needed reliable sources of social support and information as well as better implementation of government policies and laws. However, earlier identification of children with physical disabilities was presented to be very significant to ensure their well-being.

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