Demystifying Caregiving for Children with Disability in Botswana

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ABSTRACT

The intention of this study is to establish the kind of support available for caregivers in rural communities to be effective in their responsibility and if not, what can communities do to assist caregivers emotional, socially, spiritually, and to some extent economically to cope with the challenges of caregiving. This qualitative study used in-depth interviews to gain insight into the 30 caregivers' experiences and 7 key informants in Mopipi who participated in the study. A questionnaire was administered face to face to caregivers who were purposively selected, and the data was collected in August 2014. The caregivers were interviewed at their own residences to accord the researcher the opportunity to observe the care dynamics as they unfold. This method made easier for the researcher to probe further for clarity and appreciate the daily challenges of care. The empowerment theory informed the general structure of the study, the design of the interview guide, and the conclusion. The primary data were analysed using the qualitative method and techniques of data analysis by deriving themes from the objectives, data transcribing, and observation. It was found that children in Mopipi area have different types of disabilities ranging from physical to intellectual disabilities. The majority of caregivers were unemployed while others were dependent on income gained from the Ipelegeng project, which is a seasonal form of employment. Furthermore, the services to children and their caregivers are limited to food provision and at times transport to referral hospital. The condition of programmes and services are complex and usually result in the total lack or not receiving necessary assistance on time. In conclusion, caring for children with disabilities is a mammoth task as caregivers in Mopipi faced several challenges that end up affecting the lives of their children such as poor nutrition, lack of educational support. In addition caregivers end up having compassion fatigue as they do not have informal support systems. Therefore, it was caregivers need appropriate and timely interventions, community support groups, and training in order to provide effective care for children with disability.

Keywords: *Disability, Caregivers, children, social workers*

INTRODUCTION

The study on caregivers of children with disability in Mopipi was motivated by the dearth of information on caregiving to special groups and related challenges in rural communities. Research in Botswana has in the past concentrated on urban and peri-urban areas and

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with emphasis on people with disability but not caregivers. It is extremely beyond argument that caregivers play an important role in the lives and welfare of children living with disabilities. Therefore, disregarding the caregiver is like sentencing the person with disability to peripheral lines far beyond redemption. Caregiving is and must be recognized as a lifelong commitment without which the incremental development of a child with disability will be impossible. However, caregivers are usually faced with situations that are emotionally and socially draining, stressful, and economically disabling. They are characterized by low income, high stress levels, sickly conditions (high blood and diabetes) and lack communal and social support. These are complicated further by additional stressors that impact negatively on the care of children with disabilities.

Caregivers play an important role in the well-being of children with disabilities. The quality of and the availability of a healthy and economically strong caregiver determines the welfare outcome of the child. It is then crucial to explore the quality and the support the caregivers receive to strengthen their care giving role. As such, understanding their needs is of utmost importance for programme design by social workers and other professionals in the rehabilitation field. The study on caregivers of children with disabilities in Mopipi was motivated by the dearth of information on caregiving to special groups and related challenges in rural communities. Research in Botswana has in the past concentrated on urban and peri-urban areas and with emphasis on people or children with disabilities but not their caregivers. It is extremely beyond argument that caregivers play an important role in the lives and welfare of children living with disabilities. Therefore, disregarding the caregiver's needs is like sentencing the person child with disabilities to peripheral lines far beyond redemption. Caregiving is and must be recognized as a lifelong commitment without which the incremental development of a child with disabilities will be impossible (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall and Todd, 2009).

Caregivers of children living with disabilities experience high levels of parenting stress which has direct and indirect effect on the children. Some of these on the children are school absenteeism, truancy, educational under-performance, psychological and emotional problems as well as compromised transitions to adulthood. Therefore supporting caregivers requires the identification and assessment of the disability of the child, the support they need, and their unmet needs (Rossetti, 2004). There is limited research in Botswana on caregivers of children with disabilities. It is equally important to sensitize and mobilize stakeholders and the community at large regarding possible strategies to support caregivers of children with disabilities.

Disability is categorised in a variety of forms including mental retardation, visual and hearing impairment, communication disorder, learning disorders, and cerebral palsy, which affect not only the person's physical and intellectual functioning but also their effective functionality with others in the society (Morales and Sheafor, 1995). The World Bank (2004) states that disabled persons are among the poorest, most stigmatized, and marginalized of all the world's citizens. Furthermore, conditions of poverty like poor nutrition, lack of access to health services or safe living, and working conditions, create barriers that can occur from birth to old age until death (Maripe, 2010). The concern is that discrimination of children with disabilities multiplies the barriers their caregivers have to deal with in order for them to live a normal dayto day life.

Disability in Botswana

Disability is characterized by complex social and economic factors that challenge the person to confront and overcome in a positive manner. For example, stigma, discrimination, illiteracy, poverty, unemployment, and marginalization are common features of society. People with disabilities are usually faced with situational characteristics that could increase their vulnerability such as lower income than the non-disabled, and living outside caregiving institutions (Wisner, 2002). In consequence they suffer the social distance or stigma associated with being labelled ‘disabled’ or ‘sick’ in a society valuing self-sufficiency and independence. In Botswana services for people living with disabilities are pioneered by the government through the Office of the President. On the contrary, the implementation and provision of most services are done by non-governmental and community based organizations supported by the Ministry of Health through the Botswana Council for the Disabled (BCD).This means that the challenges faced by people living with disabilities in Botswana are not addressed adequately. According to Kajevu (2013), in Botswana, the rate of people living with moderate or severe disability is estimated to be between 11 and 15% (or 58 716 to 96 125) of the entire population. These numbers are too high for a country with a population of just over 2 million people.

Children with Disabilities

According to the United Nations (1990), globally, 180 million young people between the ages of 10-24 years live with a physical, sensory, intellectual or mental health disability, significant enough to make a difference in their daily lives. The vast majority of these young people (150 million) which constitute 80% live in the developing world. Children with disabilities are usually faced with the need for education, job training and inclusion for participation in the cultural, social, religious and economic affairs of the community. Due to the distinctive needs of children with different types of disabilities, they historically remain a forgotten group in society.

Caregivers

According to Rossetti (2004) a caregiver is defined as someone who provides care and support for a family member, friend or neighbor with a disability, is frail, aged or has a chronic mental or physical illness.Caregivers who may be the children‘s parents, siblings, aunts, relatives or even neighbours are the most important people in the lives of children with disabilities. Globally caregiving tends to be a role that takes a major toll on women as carers compared to men although there is a significant increase in number of men who are becoming caregivers (Surbone, 2003). Similarly, a study conducted among caregivers for veterans with trauma injury in Minneapolis, United States of America, attest to the fact that there are lower numbers of men who are caregivers as it revealed that 90% of caregivers were women (Phelan, 2011).

Caregiving is a crucial service in society which often times is offered without pay and preserves the health of people with disabilities, and aged citizens (Talley & Crews, 2007). According to Singer, Biegel, & Ethridge (2009), caregivers support family members who experience disabilities related to much physical and cognitive impairment that restrict normal functioning. These disabilities can first become evident at any time, ranging from birth, in the case of children born with some developmental disabilities, to advanced old age, in the case of family caregivers for relatives with dementia (Nyanguru, 2007). In the United States and Canada the family is now the main provider of long-term care, even for people with severe disabilities". In these countries caregiving usually takes place in a home setting as caring in institutions may be costly or full.

Caregivers' Needs

Historically caregiving duties were performed by women as they were not working outside the home. However, currently women have joined the work force and still find themselves being caregivers. Although the society has not taken this issue into consideration, there are no adequate solutions to assist women in this regard. This leads to women being overwhelmed with stress in an attempt to juggle work, household duties, and caregiving (Gray & Edwards, 2009; Carmichael, Hulme, Sheppard, & Connel, 2008; Cass, 2006; Pavalko & Henderson, 2006; Cummins, 2001).African society believes that a person with disabilities has to be provided with support for physiological needs, social integration, and emotional wellbeing by their family (Cummins, 2001). On the contrary, due to the erosion of the extended family structures in cosmopolitan African societies, there is a high possibility that caregiving for children with disabilities may not be available or burdensome (Clausen, 2000). As such, caregiving places greater demands on the nuclear family structure to care and provide for children with disabilities. This leads to health and social consequences related to stress and burnout resulting from failure to have regular breaks or gain assistance from other family members (MacDonald & Callery, 2007). Since caregiving is required on an ongoing basis it taxes the physical and emotional strength of the family or caregiver (Cass, 2006).

According to several studies, caregivers report not getting enough sleep, not participating in exercise routines not eating regular and nutritious meals, and failing to seek medical attention for themselves resulting in clinical depression, isolation from social activities high stress, and low quality of life (Cummins, 2001; MacDonald & Callery, 2007; Talley & Crews, 2007). As a result, caregivers experience health and social consequences due to their caregiving responsibilities (MacDonald & Callery, 2007). Studies indicate that, regardless of age, ethnicity or gender, caregivers are at risk of major stress, anxiety, and depression (Rhee YS, Yun YH, Park S et al., 2008). According to a study on caregivers for youth with HIV and AIDS, caregivers faced similar challenges to those caring for children with disability. The results indicated that almost all 330 participant caregivers experienced depression with 73.1% were low energy, 69% reported feeling sad, and 59.7% said were lonely (Smith Fawzi, et al., 2010). There is a need to take good care of caregivers to help them function effectively through programs, services and interventions designed specifically for them. Furthermore, when caregivers cope well with caring for the children with disability it enhances the social and cognitive adjustment of the child under care (Gross, 2004). Children with disabilities need services that will support not only their physical needs, social integration and emotional well-being but also those they rely on to meet their basic care needs (Floyd & Gallaher, 2007, Cummins, 2001). The purpose of this study are to:

i To assess the socio-economic status of carers of children with disabilities in Mopipi area
ii To identify the type of disabilities of the children under care
iiv To identify suitable support programmes for these carers
iv To identify the programmes and services for children with disabilities and caregivers in Mopipi.

METHOD

The empowerment theory is relevant to this study that deals with disability, gender, and poverty because of the prevailing unfavourable economic conditions, societal attitudes, and prejudices especially in Africa.Generally, people with disabilities are discriminated against, marginalized, and denied the very services meant to improve their welfare. Their voices are hardly ever heard by the communities, leaders, policy makers, and whistle blowers and this kind of treatment applies also to their caregivers. Theories of empowerment, therefore, explain the fundamental philosophies that characterize the relationship patterns, perceptions, and reactions by several societal actors against the powerless. Empowerment theories define the processes of dealing with oppression and discrimination of society as well as social action, social justice and social equity (Robbins *et al,* 2011).

This study adopted the qualitative paradigm to explain, explore, and describe the life situation of caregivers of children with disabilities in Mopipi (Alreck, 1995; Dawson, 2006). The qualitative approach was appropriate for the study to conduct in-depth face to face interviews as the medium of data collection (Anslem, 2004). In this regard, the study sampled 30 caregivers of children with any form of disabilities in the village of Mopipi (Babbie, 2004; Babbie, 2007; Babbie, 2008; Babbie & Mouton, 2001).The researchers visited the Social and Community Development Office in Mopipi to obtain a list of people living with disabilities from which a sample of 30 participants was randomly selected and conveniently leading to carers(Locke, 2001; Babbie, 2007).Thus, collected data was arranged according to verbatim accounts of participants and then into themes for easy analysis (Grinnel, 2001; Babbie, 2008).The proposal was subjected to ethical clearance by the Faculty of Social Science Research committee and after its approval; it was sent to the Ministry of Local Government and Rural development which granted the research permit (Babbie and Mouton, 2001).

RESULTS AND DISCUSSION

The table 1 shows that caregiving is provided mostly by women more over age of 56. There was only one male aged 69 who was interviewed as a caregiver in the study. Younger women in Mopipi from the ages of 19-35 who provide care for children living with disabilities were only five. It has been concluded from the study that older women form a majority caregivers in Mopipi village. This may be due to the fact that most of them are not working either due to old age or the fact that they have retired from formal jobs to farming and cattle rearing (Davis & Gavidia-Payne, 2009). This trend may also be a consequence of the fact that younger women leave villages to look for greener pastures in towns and big villages. The nature of caregiving may also be a deterrent for younger women because it is demanding and requires a great deal a lot of patience. Respondents shared that younger women would rather stay with their boyfriends than to be confined to one place where they have to provide twenty four hour care to their children. On the other hand, Mopipi is a traditional village, and caregiving has always been done by older women.

Out of the 30 participants interviewed, only 6 reported to be working. The fact that most of the caregivers were not working is not surprising as caregiving is a full time job. Singer, Biegel & Ethridge (2009) stated that caregivers support family members who experience disabilities related to physical and cognitive impairment that restrict normal functioning. When a child has a disability, in most cases it means that they are limited with regard to performance of normal functions. This makes it impossible for them to be left alone without any supervision. Therefore caregivers in most cases cannot have a full time job as this would mean neglecting their children.

Among the six that reported that they were working, one is a caretaker at S&CD and she indicated that her child was at a boarding school. This explained why she was able to work on a full time basis because she did not have to provide full time care. The only male caregiver who was interviewed in the study worked as a security guard, and thus went to work at night and the mother of the child was able to provide care for the child. Four of the women worked in the Ipelegeng project, which is temporary employment. The most prevalent type of disability in Mopipi was mental illness and deformed limbs. A significant number of caregivers also take care of children with paralysis.

Challenges Faced By Caregivers of Children with Disabilities in Mopipi

Some of the caregivers indicated that the caregiving process was too demanding for them. They have to be home all the time and one of them mentioned that every time she has to go to the lands, she has to take her child with her as there was no one to take care of her in her absence. This was costly for her as she does not have transport of her own. One caregiver revealed that, *"I cannot even plough because my child does not attend school as the schools do not cater for her type of disability*". In another case, a caregiver lamented that she takes care of two grandchildren who are blind, and it was difficult for her as she was 82 years of age. She had to fetch water from the standpipe, cook for them and even take them for their monthly medical check-ups which are on different days. She stated that, *"I am all alone because the mother of these children is married and stays elsewhere with her husband, and this child is my burden"*.

Some caregivers provided care to children who were immobile and they indicated that their major challenge was that they had to bath them, and even take them to the toilet every single day which was exhausting. In some cases there was a shortage of napkins from the local clinic for those patients who needed them and that made life even more difficult for the caregivers. Those who took care of mentally ill children and those with fits indicated that the children wandered from the home and they have to go around the village looking for them. Their fear was that they will be hit by moving vehicles or even get lost. Some indicated that in some instances the children ran away at night which was dangerous for them. One mother pointed out that her child could not speak; she uses sign language which family members cannot understand so that has been a problem when trying to communicate with him. One of the challenges faced by a majority of caregivers was lack of transport to take patients to the clinic or other necessary places. One caregiver mentioned that her child puts on special shoes that are only found in Marina or Nyangabgwe hospitals and it is difficult for her to go from Mopipi to Francistown or Gaborone. She pointed out that:

> *"sometimes I go to Nyangabgwe hospital using my last money, only to be told the shoes are only available in Marina, which means that I have to take another trip to Gaborone. Sometimes when we get there, we are told to wait several days for the shoes"*.

One problem that troubled caregivers was the fact that there are no schools in the area which admit children with special needs in their area and as such their children have to stay at home because of the stigma from other children in normal schools when they cannot do school tasks. In other cases, children need the help of physiotherapists but because there are none in the area, they end up unable to walk even in instances where the abnormalities could have been corrected. The area social worker also viewed this as the most troubling challenge because children with disabilities are unable to access educational facilities. Some caregivers decried the lack of a proper diet for their children. Since they are not working, it has been a mammoth task to provide for their relatives, except in cases where the Department of Social and Community Development (S&CD) assists. It is evident from the findings that caregivers experience considerable stress ranging from emotional to psychological and financial stress. This is related to fatigue associated with the caregiving job which is consistent with the findings of several studies conducted on caregivers.

Assistance Given to Carers

Participants were asked whether they received some kind of help from the government or the private sector and the majority answered that they were not receiving any assistance from government (Beresford, 1994). Some indicated that they got assistance from good Samaritans who would help them in time of need. One of them stated that" *one businesswoman has volunteered to buy my child toiletries every term and also transports her to and from school. I do not pay her anything"*. Others acknowledged that the Department of Social and Community Development (S&CD) provided them with support, such as food ration and transport. Family members and relatives were also seen to provide emotional and material support to caregivers in few instances.

Type of Assistance

Some caregivers reiterated that the clinic assists them with disposable napkins and also with medication whenever the children are sick. Those who are assisted by S&CD indicated that they received food, toiletries, and blankets, and one participant added that she has been given goats. In another instance one participant stated that the S&CD Department also helps her with transport to and from school since her child is deaf. Relatives also assisted in some cases in helping to relieve the caregivers when they need to do something outside the home.

Limitations of The Study

i Since the researchers were using a list from the social workers office, they might have missed other children who might not be in the list who would otherwise have also provided valuable information for the study.

ii Lack of adequate resources did not allow the researchers to frequent the area as many times as possible to observe the lives and cultural context of the community

iii Some caregivers were working in the fields far away from Mopipi and could not be followed by the researchers

iv Insufficient time in the field did not permit the researchers to observe all the necessary day to day interactions of caregivers with institutions, cultural beliefs, and attitudes, and services provided.

Table 1: Distribution of participants by age

Age	Frequency	Percentage
19-23	1	4
24-28	2	7
29-35	2	7
36-40	4	14
41-45	2	7
46-50	6	21
51-55	1	4
56+	10	36
Total	28	100

NB: The age of 2 respondents is missing because they were not sure of the exact birth dates.

Table 2(a): Employment status of participants

Employment	Frequency	Percentage
Employed	6	20
Unemployed	24	80

Table 2(b): Type of employment and income for participants

Type of employment	Salary
Ipelegeng	P500
Security guard	P1000
S&CD Caretaker	P2800

Table 3: Type of disability

Type of disability	Frequency
Mental illness	8
Deformed limbs	8
Epilepsy	2
Blindness	3
Paralysis	6
Speech problems	2
Deafness	1
Downs syndrome	1

CONCLUSION AND RECOMMENDATIONS

The study has revealed that there is a great need to have a support system for the caregivers of children with disabilities in Mopipi. Challenges such as clinical depression, isolation from social activities, and high stress, and low quality of life are some of the challenges caregivers are faced with in their daily lives. In addition, there are limited services for children with disabilities such as schools in Mopipi and therefore, caregivers struggle with transportation issues when government delays to take the children to and fro the urban area where schools are located. Caregivers need systems that promote their wellbeing and reduce stress, which includes, church, support group, and extended family members. When these systems are functional they are vital components of effective intervention as they become a source of respite care for families. The study also found out that the health status, socio economic status and emotional well-being of caregivers had a direct impact on the children they were taking care of. Children whose parents were not working tended to have poor nutrition, not well clothed and could not access basic amenities due to lack of resources. It is without doubt that when caregivers receive proper support and resources they can provide quality care to children with disabilities. The following are not exhaustive recommendations for the caregivers in the research site because there are so many challenges that need immediate attention. There are no community based organizations or Non-governmental Organizations offering services to people with disability and their caregivers. The recommendations are as follows:

i Social workers to establish community support for caregivers of people with disability where they can discuss challenges, share experiences, and organize themselves in seeking assistance

ii Traditional leadership in terms of Dikgosi, Headmen, and Wardmen should encourage the residents of their respective Administration points to support families of people with disability with related activities and services.

iii The Rehabilitation Offices should establish units in the respective communities within the district to link people with disability, their caregivers and the social welfare officers with the main office.

iv There is a need for a continuous community education, outreach, and assessment on disability and the changing needs of both the caregiver and the cared for.

v There is a need for further research on the subject covering other areas in Letlhakane Sub District for a comparative analysis and appreciation of the situation and condition of people with disabilities and their caregivers.

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