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Psychosocial needs of carers of children with cerebral palsy in Lesotho

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Abstract

There is considerable incidence of childhood disability in Lesotho. However, statistical information and documentation of realities of families of children with disabilities in Lesotho is scanty. This study set out to consider psychosocial needs of carers of children with cerebral palsy in Mokhotlong, Lesotho. Data were collected using in-depth face-to-face interviews from a snowball sample of 12 carers of children with cerebral palsy. The study found that carers of children with cerebral palsy did so largely on their own and many complained of at least 3 symptoms of a depressive disorder. Parents were blamed for their children's disabilities and systematically isolated from the communities they resided in. Some parents abandoned their families after receiving children with cerebral palsy while some men denied paternity of such children, casting blame on mothers for having children with cerebral palsy. There is urgent need for respite care for carers of fully dependent children with cerebral palsy along with family therapy for parents and carers of concerned children.

Key words

Cerebral palsy; depressive disorder; Lesotho; marriage breakdown; parent blame.

Key points

- 1. Many carers of children with cerebral palsy in Lesotho do so without support, potentially giving rise to depressive disorders.
- 2. There is systematic social isolation and ostracisation of children and parents of children with cerebral palsy in Lesotho.
- 3. Parents in Lesotho are blamed by birth and marital families for their children's disabilities.
- 4. There is urgent need for respite services for carers of children with disabilities in Lesotho.



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Introduction

Cerebral palsy (CP) is an early-life onset, permanent, and non-progressive neurodevelopmental disorder affecting cognition and motor skills. While disability type-disaggregated data could not be accessed, Lesotho's 2016 population and housing census reported that out of a total of 847, 300 children aged up to 19 years old, 5,802 had at least one type of disability. Due to its high resource and care demand, caring for children with CP (CwCP) is a risk factor for stress, depression, and anxiety on the part of carers with the children's sole carers and single parents at heightened risk. Regardless, mothers and teachers of children with disabilities (CwD) in South Africa, Tanzania, and Zimbabwe revealed that available psychosocial support services for CwD focused on concerned children's needs, overlooking that of their carers. Carers' neglected psychosocial needs undermines care quality and gives rise to harmful behaviour towards children. That notwithstanding, services for families of CwD in Lesotho are undermined by weakened family structures and emerging social services. The article presents a brief literature review followed by findings pertaining to the situation of carers of CwD in Sub-Saharan Africa and CwCP in Lesotho, respectively. Lastly, needs of carers of CwCP are identified under recommendations for support of carers of fully dependant CwCP and other disabilities in Lesotho.

Psychosocial situation of carers of children with disabilities in Sub-Saharan Africa

In Sub-Saharan Africa, psychosocial conditions emanating from care of CwD are aggravated by factors such as poverty, parent blaming, and spousal conflict (Kveremateng et al., 2010; Gona et al., 2010; Singogo et al., 2015). Consistently, participants of studies in Ndola Zambia, Limpopo South Africa, Harare, and Bulawayo Zimbabwe said they were divorced after receiving CwD with some becoming destitute as a result (Chibvongodze, 2018; Mbanjwa & Harvey, 2023; Mukushi, 2018; Singogo et al., 2015). Furthermore, participants in Singogo's (2012) Zambian study highlighted non-acceptance of concerned children, negative influence by extended family, and weak spousal support as contributing factors to their marital problems. The participants added that extended families did not protect them or the CwD when spouses evicted them from their homes (Chibvongodze, 2018; Nyante & Carpenter, 2019; Singogo et al., 2015). Siambombe et al. (2020) further noted that fathers of CwD in Binga Zimbabwe took no direct care responsibility for such children but performed provider roles only. The fore cited Binga study added that instead of fathers', mothers roped in siblings' input in caring for CwD (Siambombe et al., 2020). Some children helped to shift their siblings with disabilities while others taught the mentioned siblings who could not travel to school. The study omitted to acknowledge that such tasks could better be performed by fathers for all children's wellbeing and optimal psychosocial development (Siambombe et al., 2020). More concerning, some study participants from Mahalapye Botswana, Gauteng and Limpopo South Africa, as well as Ndola Zambia reported negative attitudes and disparaging statements relating to their children's disabilities from health care professionals (Dangale, 2019; Diseko, 2017; Madzhie et al., 2022; Phumudzo et al., 2021; Singogo, 2012; Singogo et al., 2015).

The foregoing was in part attributable to women supposed "natural" childbearing role among Africans along with perceptions attributing childhood disability to prenatal wrongdoing such



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as not upholding traditional pregnancy prescripts (Chibvongodze, 2018; Dangale, 2019; Diseko, 2017; Gona et al., 2010; Mukushi, 2018; Ndlovu, 2016; Omoniyi-Oyafunke et al., 2014). Similarly, the South Africa and Zimbabwe based studies showed that mothers shouldered the greatest blame of their children's disability (Phumudzo et al., 2021; Dambi et al., 2015). Not only were the mothers blamed by their spouses, in-laws, and community members, but sometimes they blamed themselves for their children's disabilities and not doing better to prevent it (Ndlovu, 2016; Olawale et al., 2013). It was further observed that participants of almost all studies reviewed for the present research, spoke of father under or non-involvement in caring for their CwD (e.g Chibvongondze, 2018; Kyremateng et al., 2020; Jansen-van et al., 2023; Mbajwa & Harvery, 2023; Nyante & Carpenter, 2019; Siambobe et al., 2020).

Lastly, a study conducted among low-income carers of children with physical disabilities by Pelea (2016) in Mafeteng Lesotho, was consistent with the above-cited studies highlighting financial constraints faced by concerned families. The study's participants indicated that they struggled with procurement of the children's necessities such as diapers, wheelchairs, and special food, adding that up to 60% of their household income went to procurement of the children's needs (Pelea, 2016). Moreover, the carers had to forgo full-time employment to care for the CwD, with one participant indicating that on account of resource limitations, she had not had running water in her yard for 5 years (Pelea, 2016). This effectively exacerbated the care demands as the participant and her other children collected water from distant water sources (Pelea, 2016). Necessity of a reliable water supply for people with most types of disabilities needs no deliberation. As pointed out, Pelea's (2016) study was focused on children with physical disabilities. Possibly because of that, almost all (9/10) of the children whose carers participated in the study had acquired or were in the process of acquiring primary education (Pelea, 2016). However, Pelea's (2016) study was conducted in the low-lying parts of the country where travel and transportation were not as encumbered as Mokhotlong, while present authors note that there are no schools for children with special learning needs in Mafeteng Lesotho, where the study was conducted. Thus, care of CwD in Lesotho is complicated by factors ranging from finance and weak social services which are further compounded by the endemic poverty and difficult terrain. Regardless, it was encouraging to note that at least 4/10 of participants in Pelea's (2016) study reported having present and supportive spouses. That notwithstanding, little is known about the realities of caring for CwD in harder and hardest-to-reach parts of Lesotho. This article therefore considered psychosocial needs of carers of CwCP in Mokhotlong Lesotho, one of the country's administrative districts with vast hard-to-reach areas.

Methodology

The study was granted permission by the National University of Lesotho and was conducted in February to April 2022. The study population was carers of CwCP in Mokhotlong, Lesotho recruited through snowballing (Strydom & Ventor, 2011). The sampling process led to Seate (2 participants), Mphokojoane (2 participants), Sanqebethu (2 participants), Menoaneng (4 participants) and Mokhotlong Urban (2 participants). The first participant was referred to the first author by a South Africa based service organisation which works with clients from



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Lesotho. Upon receiving the referred participant's consent to participate, the participant then sought permission from further prospective participants in Mokhotlong to divulge their contact information to the first author and the snowballing continued in the same manner from there (Strydom & Ventor, 2011). The process yielded 19 potential participants, 12 of whom met participation criteria and agreed to participate in the study. Inclusion criteria for participation were adult carers of children with CP and residents of Mokhotlong for at least a year prior to the time of the study. The data was collected through face-to-face in-depth interviews in Sesotho using an interview guide and audio recording (Khupe & Keane, 2017; Greef, 2011). All interviews were conducted by the first author. The longest interview lasted one hour and fifteen minutes, while the shortest lasted thirty-five minutes.

The following six steps of thematic analysis were followed in the process of data analysis: data familiarisation, generating initial codes, searching for themes, reviewing themes, defining themes, and writing up (Braun & Clarke, 2006).

Findings

Demographic information

Twelve carers, 10 women and 2 men, participated in the study. Their ages ranged from 18-years to 73-years, with most participants (10/12) between 23- and 54-years old. Six of the participants were the children's mothers; 2 were their fathers; while 3 and 1 were their grandmothers and grandaunt, respectively. The older participants (ages 54; 70; and 73) were the children's grandmothers. Majority (8/12) of the participants were unemployed. One of the mothers of the CwCP in the care of those other than mothers was deceased while the other 3 were migrant labourers, reportedly all supporting their children financially. The father whose child was in the care of a grandaunt was financially supporting his child while other fathers were not. Table I below reveals the whereabouts of parents whose children were with carers other than their parents. The youngest CwCP under the participants' care was 3-years old while the oldest was 17-years old. Additionally, 1 carer cared for 5 other children, 3 carers each cared for 4 other children, 2 carers each cared for 2 other children, while 2 carers cared for no other children.



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Table 1: Whereabout of parents whose children were with carers other than parents

Carer and	Biological parents' whereabout	
relationship	Biological mothers' whereabout	Biological fathers' whereabout
to child with		
CP		
CG1	Died when the child was 6 months	Whereabouts are known but he does
Maternal	old.	not take care of the child, nor is he
Grandmother		involved in any way. He claimed that
		the child was not his, since in his
		family they have never had any one
		with a disability.
CG6	Domestic Worker in Republic of	Resident in the same village as child,
Maternal	South Africa, KwaZulu Natal.	but not involved in caring for the
Grandmother		child.
CG7	Works and resides in Maseru.	Was not married to the child's
Maternal		mother. He is not involved in caring
Grandmother		for the child.
CG10	Separated from father and	Works and resides at a nearby village.
Paternal Aunt	understood to be residing in the	He supports the child financially.
	Republic of South Africa.	

Participants' psychosocial situation

To determine participants' needs, it was considered worthwhile to understudy their psychosocial situations. Discussed hereunder, themes which emerged under this category are: sole caregiving to dependent children from which implications of sole caregiving to dependent children – symptoms associable with depressive disorders emerged as a subtheme; inadequate spousal, friend, and community support; hurtful comments/treatment and disparaging names; marriage breakdown; and parent-blaming. Below, CG denotes caregiver.

Sole caregiving to dependent children

Most of the participants said they were sole carers to the CwCP in their families adding that this gave rise to chronic stress on their part. The stress was compounded by lack of support and mother blame. Some of them said:

"You know when you have a child, the hope is that one day the child will grow up and be able to take care for themselves and do other things for themselves. [This situation is different]. I have to think on his behalf, because he cannot speak or hear, this stress is killing me. I don't have other people to take turns while caring for this child, it's me throughout. My other daughter does assist me time and again, but she also has a family of her own". (CG6)



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"It is so stressful to care for a child at the age of 17 years, she depends on me for everything, and it stresses me because I can't get some time to rest. Every minute I have to do this and that for her". (CG9)

Implications of sole caregiving to dependent children - Symptoms associable with depressive disorders

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), (2013) lists the following as identifiers of most depressive disorders: low mood, chronic sadness or hopelessness, chronic fatigue, irritability, diminished interest in pleasurable activities, change in weight, eating, and/or sleeping habits, as well as change in energy and/or movement patterns. The fore-listed symptoms were common among the study participants, suggesting likelihood of one of the types of depressive disorders. Accordingly, CG1 and CG2 reported episodes of insomnia and hopelessness, respectively, while CG8 and CG12 complained of frequent irritability, frequent episodes of fatigue, diminished appetite and need for as well as social isolation saying:

"When my stress is high, I cannot even sleep. I spend the whole night turning and tossing, and I will just be thinking of so many things". (CG1)

"I sometimes look down upon myself, doubting whether I could really impact the wellbeing of this child. [I question my usefulness] so much that sometimes I wish I could just wake up dead because I am really struggling as I have no one to help me". (CG2)

"During the time when I am stressed, I feel so irritated by anything so much that even this child I would feel like I could be so far from her. I would just find everything irritating me and I become so rude towards people". (CG8)

"Sometimes I don't know what to do. I cannot cope. I will be feeling tired. Tired in my mind, tired or unable to think right. Feeling tired. The moments I feel like that, I feel annoyed by anything.... There are times when I take about two days without eating, when I am stressed. One time I was going through a lot because of this child. I literally did not want to talk to anyone. I just felt like I wanted to [run away and not return] or be in the wilderness, on my own. Caring for a child with this condition is so stressful." (CG12)

Inadequate spousal, friend, and community support

In this category, participants reported inadequate spousal support as well as friends and community non-support, discussed in turn below.

Inadequate spousal support

Inadequate spousal support was common among the carers. CG4 and CG11 described their husbands' support as limited while CG3 said she did not receive any support from her exhusband.



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"It is true that [my child's] father and I divorced, but he does not do anything for the child. I was even advised by one of my friends to take him to court, because he is working and all he does is staying with other women, iyooh! (clapping hands and shaking head). I do everything for this child by myself. I do thank God that I receive a grant [on behalf of the CwCP] from [Ministry of] Social Development, otherwise I would be going up and down the streets with madness". (CG3)

"In as much as his father still gives me support, he does not do that fully. He is not as involved as one would expect, and you could see and feel that sometimes he is annoyed when he has to do something for the child. For instance, when I request him to feed the child while I am busy with something else, the man will sulk for the whole day, he will be quiet and will not even talk to me or our other child". (CG4)

"I can't even expect [my husband] to do anything for this child. I cannot even say he has a child [with a disability]. I am alone. When I take the child to the clinic, I am alone. Only the community members can assist me with transport. When the child has nothing to eat, I am alone. If I even tell him that the child needs this or that, you will hear him [shouting/complaining]". (CG5)

"My husband still helps me, but he is just not [fully] involved, I sometimes wonder if it is because men were truly not meant to be carers. But when two people have a child, we need to offer each other support at all times. I play the biggest role in caring for this child." (CG11)

Friends and extended family non-support

Similarly, "friends" and extended family members were not supportive to the carers, instead they spoke negatively of concerned CwCP.

"Instead of supporting me, [the friends] will be asking if I ever wish my son were dead considering how I struggle. It is hard to respond to such [nonsensical questions]. It used to make me sad, [but] I have noticed that they say those things to deliberately hurt me." (CG3)

"I still have friends, but most of the time I hear them speaking negative things that dishearten me about my child. That hurts me. One would think that a friend is someone who will always be by your side, but that's not the case with some of my friends, they are just friends by name, and only come to me when they think I can be of help to them". (CG5)

"For an old person like me who is caring for a child with this condition, people are not really helping me. Some will be saying they have nothing. This condition is so demanding that I keep begging for assistance from other people in the community, so I think people get tired of me". (CG6)

Hurtful comments/treatment and disparaging names

CG2 and CG3, said they faced hurtful comments from estranged husbands' family members and community members, respectively. CG4 and CG9 on the other hand said they had been



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called disparaging names to their faces numerously. CG2 and CG4 added that they had opted to withdraw from social interaction due to the unpleasant treatment saying:

"[My husband's family] say things like, [my] womb is full of disabled children hence I brought them bad luck, as if I chose to have a child with this condition. It is hurtful (shaking her head in apparent helplessness). I no longer attend these gatherings of theirs because they stigmatise us. [At family gatherings] they [make statements like] ""so and so whose child can't walk was performing that [task]"". [Or] ""nothing touched by a woman whose child is lame can ever work out"". Such utterances, which you feel that no! no! I cannot keep up with that." (CG2)

"During family gatherings, [people from my community] don't allow me to do anything, they tell me to sit and tend to my child with a disability. It really feels bad because having a child like this is as if I am bound to always be seated. I seem like I am the one with the disability now, there is no longer anything that I can do or help with". (CG3)

"It is not like I asked to have a child like this, but people will be using those Sesotho names like, ""sehole"", ""seritsa"", ""sebopuoa"", (all listed terms are demeaning words for person with disability) knowing that it was not my wish to have a child like this. It hurts. So much that I sometimes respond angrily and start insulting them.... I ended up not going to ceremonies around here, because of what people kept saying to me with reference to my child". (CG4)

"They call me ""'Maseritsa"" (loosely translated as mother of the lame one) it is not so good to be called that, but you find that other people just seem to be enjoying making you feel bad because of having a child with this condition". (CG9)

"My in-laws discriminate against me because I have a child with this condition, you will find that it gets worse when there are some family ceremonies". (CG11)

Marriage breakdown

Twenty-three, 31-, and 30-years old CG2, CG3, and CG8, respectively, said their relationships with ex-partners broke down after receiving CwCP. CG3's ex-husband said "he could not produce a child with a disability" while CG8's estranged wife left for work and did not return to her marital home despite visiting her maiden home – in the same area as the marital home – frequently.

"We ended up separating because there was no longer peace between us. Immediately after realising that the child had [this condition], he started spending nights, [sometimes] days away from home. [He did not provide for the family]. When he did come home, he would insult me and my child saying, ""Do this/stop this you mother of a lame one!"". I told myself it was better to leave while I was still alive, because all I desire is to live longer and care for my child, not to chase after a man to force him to take responsibility. No! I cannot do that, never!" (CG2)



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"[My ex-husband] never accepted my son [who has CP], saying he could not produce a child with a disability. [As a result], the marriage was unhappy until I decided to divorce him. I realised I would die from constantly being hurt. [In other words] my marriage ended just because of giving birth to a child with this condition". (CG3)

"We separated. My wife left for work, but never came back home. Even when she is [in this residential area], she never comes to see the child, and what I see is that she did not accept this child. We just separated like that. I have tried to talk to her, but she ignores me. [Hence], I had to leave her and focus on my child's future". (CG8)

Thirty-two years old CG11 was enduring her marriage "because of the children", but said her husband rallied with his birth family to ostracise her because of their child's condition. The couple had 2 other children apart from the CwCP.

"I am just staying in this marriage for the sake of it, it is not nice. My in-laws and husband say [unpleasant things about me], simply because I have a child of this kind. A normal person would expect that a husband would be on my side, but he is the one who is strongly against me. I remember when we were told of the child's condition, he started blaming me. If it was not for these children, I would have divorced him but there is nothing I can do because I need him. I am just staying in this marriage for the sake of my children other than that nothing would have kept me here". (CG11)

Parent-blaming

Parents were blamed by spouses and extended families for receiving CwCP. For example, 23-years old CG2's relatives said her child's disability was because she got married – and had a child – too young, while blame from her ex-husband continued even after CG3's divorce. Some of the persecutors such as CG11's mother-in law cited "traditional beliefs" to justify their parent blame.

"My relatives blame me for the child's condition, they tell me how I behaved recklessly by getting married at a young age. Of course, I got married at a young age because I was pregnant and my father didn't want me to stay in his house [in that condition], so my boyfriend and I decided to marry. [Also], this child was born prematurely, I think it was because of the stress that I was going through at that time". (CG2)

"Prior to the divorce and even now when I happen to meet [my ex-husband] he says I am the cause of this child's condition because in his family they have never had anyone with a disability. So, I constantly endure that blame. It is so stressful to always know that fingers are being pointed at you for something that is also puzzling you". (CG3)

"I am just in this marriage. I should have taken all that belongs to me and left a long time ago because of things done to me by my husband and his relatives. They say I gave birth to a child with a disability, yet they know that I was told that my pregnancy was a high risk and that there was a high possibility that my child will develop some disability, which indeed happened



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because shortly after birth I was told of this condition. [But] blaming me for the child's condition is a dagger I endure daily. Each time [my husband] gets drunk, he starts telling me how I give birth to children with disabilities, all sorts of hurting words and insulting me...". (CG5)

"My family blames the child's condition on me because they say I married someone with whom I have blood relations and was warned against marrying. [Hence], they say my child's [condition] is ancestral punishment, it is worse during family ceremonies because they do not consider him as part of them". (CG8)

"My mother-in-law constantly blames me for the child's condition because she says I did not follow the [marital] family's tradition. Because of that, I am mostly discriminated against in the family among other daughters-in-law. I do not know which tradition is that which I did not follow because during my pregnancy I did everything I was told to do. Is it my fault that they did not tell me everything? It is not everything that can be attributed to traditional rules". (CG11)

Discussion

Consistent with previous studies on the continent (Dambi et al., 2015; Diseko, 2017; Phumudzo et al., 2021; Siambombe et al., 2020), care of CwCP in Mokhotlong Lesotho was a solitary undertaking for most study participants. Unlike in previous ones (e.g. Chibvongodze, 2018; Mbanjwa & Harvey, 2023; Siambombe et al., 2020), solitary caregiving affected both women and men in the present study. Even the carers in the study who had spousal support described the support as wanting while marriage breakdown was common after couples received CwCP. Notably, some of the participants in the present study were in their advanced age and caring for grandchildren with CP together with other grandchildren without CP, amplifying their care responsibilities. For instance, 70- and 73-years old carers 6 and 7, respectively, cared for 5 and 4 other grandchildren with CG6 revealing that she frequently asked for community support. Additionally, fathers of CwCP 1; 6; and 7, all in grandmothers' care, were uninvolved in the children's care. Understandably, many of the parents in the study struggled with accepting their children's diagnoses giving rise to abandonment of concerned children (e.g fathers of CwCP2 & CwCP3; mother of CwCP8).

The relationship between care of dependant CwD and carers' psychological concerns is well-documented (Moosa-Tayob & Risenga, 2022; Mukushi, 2018; Dambi et al., 2015). While the present study was not in a position to make diagnoses, it was concerning to find symptoms associable with depressive disorders among participants of both sexes. For example, 23-years old separated CG2 said she "wanted to wake up dead" while 40-years old widower CG12, who had one other child apart from the one with CP, reported going days without eating; wanting to give up; and frequent episodes of social isolation. The fore-listed are among the most serious psychological concerns which also carry adverse implications for careging (Gona et al., 2010; Moosa-Tayob & Risenga, 2022). Furthermore, comments such as "nothing touched by a mother of a lame child can work out" and encouraging mothers of CwCP to tend to their children at community events suggested effort to systematically isolate the parents. In addition to



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disparaging words and treatment against them, the parents were, in fact, treated as though their children's disability and/or bearing such children was contagious. This was likely influenced by prevailing disability superstitions among Africans (Madzhie et al., 2022; Mukushi, 2018; Ndlovu, 2016). Such systematic isolation was more worrying in this study because it encouraged the mothers of CwCP (e.g. CG2 & CG4) to self-isolate from their communities. The parents (e.g. CG3 & CG5) could not even depend on support from their so-called friends, giving way to more psychological concerns.

Lastly, some parents of CwCP (e.g. CG3 & CG8) were blamed for their children's conditions. Such parent-blame was used to ostracise CG8's child at family ceremonies while it was perturbing that even after breakdown of their marriage, CG3's ex-husband habitually made cruel utterances to CG3 about their child with CP. Such parent-blaming and insensitive treatment is understood to be widespread in Africa, calling for aggressive attempts to combat it (Dambi et al., 2015; Phumudzo et al., 2021).

Recommendations

The above-discussed psychosocial situation of carers of CwCP revealed widespread sole caregiving along with serious implications thereof. It also uncovered that some parents did not accept their children's CP diagnoses. Another concerning finding in this study was that of community ostracisation and non-support. Thus, indicated is an urgent need for integrated respite services for carers of fully dependent CwD such as CP in Lesotho. For immediate response, one such facility would be adequate for the whole of Lesotho and possibly two additional ones could be established in the long term. The proposed respite facilities could also provide psychoeducation and psychotherapy for families of CwD emphasising spousal corporation in care. Strong community education against superstitions relating to disabilities were also indicated. Lastly, American family friends and neighbours (FFN) initiative holds strong prospects for mitigating some of the challenges of carers of CwD in Lesotho (US Census Bureau, 2011). In the unlicensed, self-initiated approach, mothers take turns to care for others' children. The FFN initiative would further be appropriate as carers of children with similar care needs would have more experiences, be more empathetic, and compassionate towards children in their care (US Census Bureau, 2011).

Conclusion

Findings from the present study revealed profound psychosocial challenges faced by carers of CwCP, with high likelihood of adverse implications to both carer wellbeing and care quality. The psychosocial situation was exacerbated by spousal and community non-support. Even "friends" could not be depended on for support of carers of CwCP. Some evidence of deleterious superstitions pertaining to early-life onset disability also emerged, calling for closer empirical examination to inform intervention. Social services, spouses and communities should therefore be rallied to buttress care of CwCP in Lesotho.



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