

Role of Young Carers of Parents with a Disability in Sierra Leone and Cameroon: an Explorative Study

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ABSTRACT

Purpose: *This study aimed to get insights into the role of children who are caring for their parents with a disability in Sierra Leone and Cameroon.*

Method: *Quantitative and qualitative data were collected using two different questionnaires that were distributed among parents with a disability and community fieldworkers. The parents were asked to answer questions about their personal life and the roles that their children, other family members and aid organisations play in their lives. The fieldworkers were asked about their experiences and opinions regarding children's roles as caregivers for their parents.*

Results: *It was found that children supported their parents in performing domestic chores, childcare, and intimate and general caregiving. They also gave emotional support, mostly by showing compassion. Most parents wanted more help in raising their children, as well as financial support. Fieldworkers judged the caring roles of children as a responsibility, a blessing, or a burden.*

Conclusion: *This study indicates that children play diverse roles in caring for their parents with a disability. Future research could map cultural norms and expectations about a child's caregiving responsibilities, and focus on the possible consequences for a young carer, like dealing with poverty or being unable to attend school.*

Key words: *children, caregiving, low- and middle-income countries, emotional support, poverty*

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INTRODUCTION

Global estimates suggest that around 15% of the world's population lives with some form of disability (World Health Organisation, 2011), with disability being more prevalent in low- and middle-income countries (World Bank, 2021). Disability affects not only the individual, but also the social environment (Parnes et al, 2009). In low- and middle-income countries especially, where poverty limits the access to rehabilitation and health-care facilities (Department For International Development - DFID, 2000; United Nations, 2020), families and communities play an important role in caring for their family or community member with a disability (Elwan, 1999). When parents have a disability, it might be up to their children to take care of them.

According to Skovdal et al (2013), there is an urgent need for clarification regarding when caregiving by young people is or is not appropriate. A young carer is defined as "a person under 18, who provides or intends to provide care for another person. A person is not a young carer if the person provides or intends to provide care (a) under or by virtue of a contract, or (b) as voluntary work" (The National Archives, 2014). Becker (2007) suggests that this definition makes it possible to distinguish between children who are substantially and regularly more involved in caring, who would classify as young carers, and children who are involved in particular aspects of caring which are neither substantial nor regular. The latter do not experience any negative or damaging outcomes of the care they provide, whereas young carers will experience these negative outcomes (Becker, 2007).

The exact impact that caring for a parent has on a child is dependent on the extent of the caregiving, the nature of the caregiving, the time that is involved in caregiving, and the restrictions that this causes for social and educational participation (Becker, 2007). These can include restrictions in educational attainment, restrictions in participation possibilities, and restrictions in general development (Becker, 2007).

Negative outcomes for young carers include more worries and problems concerning their well-being, than for children who do not provide or intend to provide care for another person (Gibson et al, 2019). Another negative outcome is that caregiving work is negatively associated with schooling outcomes for young carers. Less time for schooling activities due to working for a longer period of time can lead to school failures and early school dropouts (Zabaleta, 2011). Whereas

children who are not carers might experience lack of money as the main barrier to fulfilment of their future ambitions, young carers additionally experience the responsibility of caring for their family members and the lack of qualifications due to lack of education (Warren, 2007). It should be acknowledged that for some households the only strategy for survival is to have the child(ren) care for their parents or to have the child(ren) work (Robson, 2004). Young carers are usually caregivers because they have no other choice (Becker, 2007).

Caregiving by children can include domestic chores, childcare, intimate caregiving and general caregiving (Robson et al, 2006). Firstly, domestic chores can include tasks like cooking, washing clothes and dishes, fetching water and cleaning the house. Secondly, childcare can include washing school uniforms and accompanying siblings to school. Thirdly, intimate caregiving can include helping the care recipient to walk, bathe and dress, as well as giving the care recipient medication. Intimate care can also include providing the care recipient with emotional support (Skovdal et al, 2013). Even though emotional support is mentioned in some frameworks describing the roles of children in caring for their parents (e.g., Becker et al, 2001; Warren, 2007; Skovdal et al, 2013), what exactly the provision of emotional support means is not elaborated on. Finally, general caregiving can include bringing the care recipient to the hospital or other healthcare facilities, buying medicine, and giving the care recipient food (Robson et al, 2006).

In many African countries, domestic chores and childcare are seen as normal tasks that children can undertake, whereas intimate caregiving and general caregiving are specific tasks of young carers (Robson et al, 2006). When deciding on the appropriateness of these caregiving tasks, cultural norms and expectations of the role of children in the household should thus be taken into account (Skovdal et al, 2013). What is considered to be harmful in one culture might be considered a normal part of childhood or a normal responsibility for a child to have in another culture (Ribbens McCarthy & Gillies, 2017). For example, in many Western cultures there is a construction of childhood as a phase in life that is 'sacred' and should be protected, and mainly be spent playing, whereas in many other cultures it is considered to be normal for children, from a very young age, to carry out the same household duties as adults (Becker, 2007; Skovdal et al, 2013). Anecdotal evidence from various African countries suggests that the children who are caring for their parents are often between 8 and 11 years old, since older siblings are more likely to leave home in order to work and provide financial support for the family (UNAIDS, 2000).

In low-income countries, children whose parents have a disability often have to care for their parents because of reduced access to healthcare and lower incomes (Robson, 2004). Most young carers come from families that are likely to be living in poverty, are disadvantaged and socially excluded (Aldridge & Becker, 2003; Warren, 2007). Healthcare might be unavailable or unaffordable for the family. Furthermore, the community might not recognise the family's need for care (Becker, 2007). It has been suggested that the need for young people to care for their parents is a result of reduced healthcare from the state (Becker, 2007). The absence of public utilities, welfare services or social security requires caregiving children in Africa to perform many time-consuming and strenuous household labours that their parents are incapable of doing (Laird, 2005). Helping their family in meeting survival needs, and caring for them in times of sickness, is underpinned by a value system that sees it as an obligation for children (Laird, 2005).

There is a limited amount of literature available on parents with a disability (Olsen & Clarke, 2003). Research is often either on parents raising their child with a disability or on parents with a disability being cared for by their adult children. There seems to be limited attention to the situation where the person with a disability is both responsible for care and dependent on care (Olsen & Clarke, 2003). Even though insight into the role of young carers seems to be lacking the world over (e.g., Becker, 2007; Darling et al, 2019), low- and middle-income countries seem to be underrepresented in the currently available research. Despite several existing frameworks that describe the roles that children can have as young carers (e.g., Becker et al, 2001; Robson et al, 2006; Warren, 2007; Skovdal et al, 2013), there is limited information available about the factual roles that children have in caring for their parents with a disability and the relationship to poverty.

Objective

This research study aims to provide more insights into the role of children in caring for their parents with a disability in Sierra Leone and Cameroon.

METHOD

Study Design

Quantitative and qualitative data were collected, using two different questionnaires containing both open-ended and close-ended questions. These

questionnaires were specifically designed in order to get a clearer insight into the role that children have in caring for their parents with a disability in Sierra Leone and Cameroon. The first questionnaire, designed for parents with a disability, included questions about the parent's culture, disability, personal life, and the roles that their children, other family members and aid organisations have in their lives. The second questionnaire, designed for fieldworkers working with parents with a disability, included questions about the fieldworkers' experiences and opinions regarding the roles undertaken by children in caring for their parents with a disability.

Data Collection

Data collection took place in December 2020 and January 2021. The two different questionnaires were sent to professionals attached to organisations involved with people with disabilities in Sierra Leone and Cameroon. These professionals helped to distribute the questionnaires among 23 parents and 5 community fieldworkers. The study included parents with a disability who were living with at least one child. The age and gender of the children were not taken into consideration. No distinction was made between different kinds of disabilities (e.g., innate or acquired; physical, intellectual, sensory, or others). Since the questionnaires were in English, the community fieldworkers assisted the parents in understanding and filling them in.

Data Analysis

The quantitative data obtained from the close-ended questions was analysed using IBM SPSS Statistics (Version 27). Manual coding was used to categorise the responses that were given to the open-ended questions. The responses were analysed and reviewed by the two researchers, separately, before making a comparison. This was done to reduce the effect of personal filters that might affect the interpretation of the responses given.

Ethical Considerations

All respondents gave their written consent to participate in this study.

RESULTS

Questionnaire for Parents

The questionnaire for parents was completed by 23 respondents. Two parents did not meet the study's inclusion criteria and were excluded. The remaining 21 respondents included 3 parents from Sierra Leone and 18 parents from Cameroon. While 10 of the 21 parents had innate disability, 16 of them stated that their disability requires someone else to care for them. The respondents had between 1 and 13 children ($M = 4.0$; $SD = 2.86$).

Although 9 of the 21 respondents had a job, none of the respondents reported having an income that could meet their own or their family's basic needs. In addition, 10 of the 21 respondents had a partner, but none of them reported that their partners had a job.

The participants were asked to describe how they thought their children could or should support their parent with a disability. One respondent did not specify the type of support wished for and another respondent mentioned that his/her children were too small to provide support. Fourteen of the 19 respondents who specified the kind of support their children could or should provide, mentioned domestic chores like preparing food, fetching water and cleaning. One of the 19 respondents mentioned childcare, like assisting some of their children with school needs, as a type of support. In addition, 5 of the 19 respondents mentioned intimate caregiving, like helping the parent with a disability to walk and giving advice. General caregiving like providing financial support and running errands was mentioned as a type of support by 7 of the 19 respondents.

When asked about the emotional support provided by their children, the respondents often answered that they experienced this when their children encouraged them, helped when needed, and showed compassion. Parents also received emotional support when their children reassured them, showed affection, or obeyed them.

Fourteen of the 21 parents stated that their children attend school, while 5 parents said that some of their children attend school. Among the reasons for not attending school were poor results and dropping out in order to provide money for the family. Of the 19 children who did attend school, 16 were doing well in terms of grades in school and comprehension, as reported by their parents. It should be noted that it is unclear whether any of the children performing well in school also had a role as a young carer.

Seven of the 21 respondents reported that their children work. The work that children performed were domestic tasks, like fetching water and cleaning houses,

helping in the business of their parents, or farming. The main reason for working was to support the family in basic needs. One parent mentioned that the child works for fun. Only 3 of these 7 respondents answered the question “How many hours does your child work per week?”, so this question has been excluded from the data.

Kind of Support

Nine of the 10 respondents who had a partner stated that their partner/spouse helped in raising the children. Their help in child-rearing involved preparing food, washing clothes, taking care of their children whenever the children were sick, and helping their children in education by paying for schooling, transporting the children to school or helping in the process of education itself. Fourteen of the 21 parents also reported that their children received support from other people, such as family members, friends, aid organisations or community members, even though the kind of support was not specified.

Except for one parent, the rest of the 21 respondents felt they needed more help in raising their children. It is noteworthy to mention that the one respondent who indicated there was no need for more help, however wanted more livelihood support for business. Two respondents did not specify what kind of help they wished for. Seventeen of the 19 respondents who answered the question “What kind of help do you wish for?” asked for some kind of financial support. They would use this support either to expand their business, which would enable them to provide their family with basic needs, or to finance their children’s education. Besides financial support, 2 respondents wished for a personal assistant to either support their children in school or to support them in their business so their children can focus on their education. Three of the 19 respondents wished for support in obtaining resources like books and clothes.

Six of the 21 parents mentioned that an aid organisation was helping them. Four of these respondents received financial support to start up or grow their business, and the other 2 respondents mentioned receiving livelihood support. One respondent added that a mobility aid like crutches was received.

Only 10 of the respondents noted that healthcare was available for them and their families; however 18 respondents stated that they could not afford healthcare.

Questionnaire for Fieldworkers

The questionnaire for fieldworkers was completed by 5 respondents – one was a fieldworker from Sierra Leone and 4 were from Cameroon. All 5 of them had worked with children who had parents with a disability.

Two of the 5 fieldworkers considered that caring for parents with a disability was the responsibility of the child. One respondent stated:

“One gets blessed if you serve your parent. If one’s parent has a disability, you see it as your responsibility to do your best for them so you get blessed. It’s a common practice”.

The respondent from Sierra Leone said that children should give their parents any kind of support they may need, depending on the severity of the impairment. This answer was similar to the answers given by some of the fieldworkers from Cameroon. However, the other 2 fieldworkers from Cameroon mentioned that this can be regarded as a burden on the children. This indicates that the fieldworkers have diverse opinions.

If the child caring for a parent with a disability is under 18 years of age, 3 of the 5 respondents would consider this as child labour. When a child is 18 years or older, none of the respondents would consider caring for a parent with a disability as child labour. It should be noted that the respondents did not specify what kind of care they considered to be work.

There were mixed answers regarding whether girls or boys were more likely to take financial care of their parent with a disability. Two fieldworkers felt that daughters were more likely to do so, whereas 1 fieldworker attributed this task to sons. However, 2 fieldworkers mentioned that daughters and sons were equally likely to take financial care of their parents with a disability. Interestingly all 5 fieldworkers mentioned that daughters and sons were equally likely to take care of their parents at home. One respondent noted that the sex of the parent influenced whether their sons or daughters took care of them. Male children seemed to be carers for their fathers, while female children seemed to take care of their mothers.

Fieldworkers had different ways of defining the provision of emotional support by children. Four of them regarded showing compassion as a sign of emotional support. Examples cited were of children taking an interest in the disability, showing that they were proud of their parents, and accepting the parent’s condition. Furthermore, 2 participants stated that offering encouragement and providing help were aspects of emotional support. One participant thought a show

of affection, such as hugging, was also emotional support. All the respondents felt that more research was needed on children who have to care for their parents with a disability. In addition, all of them believed that NGOs had to do something to prevent children under 18 years from working. The fieldworkers stated specific actions that NGOs could take, such as provision of financial support, livelihood support, provision of personal assistants to the parents, educational support for the children, and support from community members.

DISCUSSION

This research article aimed to answer the question: “What is the role of children in caring for their parents with a disability in Sierra Leone and Cameroon?” .

It was found that children take on several roles when caring for their parents with a disability. With regard to the types of support that parents with a disability believe their children could or should provide, support most often mentioned was help with domestic chores like preparing food, fetching water and cleaning. Other types of support mentioned were intimate caregiving, like helping the parent to walk and giving advice; childcare, like assisting their siblings with school needs; and general caregiving, like providing financial support and running errands. Emotional support that parents received most often took the form of children’s encouragement and helping when needed, and showing compassion. They also experienced emotional support when children reassured them, showed affection, or obeyed them.

As to the effect that the caring role has on children, most children reportedly were able to attend school, even though some parents could only send some of their children to school. The reasons for not attending school were poor results and the need to provide money for the family. Caring for parents was not found to have an impact on children’s achievements at school since most of the children were reportedly doing well academically. However, as mentioned before, it is unclear whether those who were performing well in school were also parental caregivers. One-third of the parents reported that their children work, the main reason being to support the family’s needs. Even though nearly half of the parents worked, none of them earned enough to meet their own basic needs or the needs of their family.

All but one of the respondents believed that more help in raising their children was needed, despite help received from partners, family members, friends, aid

organisations or community members. The majority also wished for some kind of direct or indirect financial support to expand their business or finance their children's education. In the minority were parents who had received financial or livelihood support from an aid organisation. Healthcare was found to be available for about half of the parents, but only a few could actually afford it.

To supplement the data collected from the parents, a questionnaire was also completed by fieldworkers. The fieldworkers interpreted the caring role of children in different ways, judging it variously as a responsibility, a blessing, or a burden. Regarding the gender specificity of tasks, no clear conclusions could be drawn. Similar to the parents' opinion, the fieldworkers defined emotional support by children as the showing of compassion and affection, and the provision of help as well as encouragement. About half of the fieldworkers felt that it was child labour if children under the age of 18 years were caring for their parents with a disability. All the respondents believed that more research had to be done on children who are caregivers for their parents with a disability. Possible actions that NGOs could undertake to prevent underage children from working were mentioned, such as offering financial or livelihood support, providing a personal assistant for the parents, supporting the children in their education, and increasing the support from community members.

Implications

This study has shown that in low- and middle-income countries such as Cameroon and Sierra Leone, children are often caregivers for their parents with a disability. The roles that children can have are diverse. They are expected to undertake domestic chores, and provide childcare, intimate caregiving, and general caregiving. These roles correspond to the roles found in previous research (Robson et al, 2006). However, unlike previous research (Robson et al, 2006), childcare was mentioned by only 1 parent in this study. A possible explanation for this finding could be that the parents were asked to describe the types of support that children could or should provide them, rather than the tasks that they in fact carry out. This could therefore signify a discrepancy between the tasks that children are expected to carry out and the tasks that are actually carried out. Future research could look into this possible discrepancy. Emotional support, which can be seen as part of intimate caregiving, has not been elaborated on in the previous research. Therefore, participants were asked for their definition of emotional support. It was found that parents mostly experienced emotional

support in the form of their children's encouragement, compassion, affection, reassurance, and obedience. Future research could take these components into account when investigating the emotional support offered by children.

It was found that the majority of the parents with a disability needed more help in raising their children. The implicit message is that parents would appreciate additional help so that their children might have to perform fewer caregiving tasks. Since no distinction was made in this study between small and large families, future research could look into the caregiving burden of large families (i.e., when there are more children sharing the caregiving burden, the burden may be smaller and thus affects them less, or at least in a less negative way). It has previously been suggested that the appropriateness of the provided care is dependent on the care that is provided, the intensity of the caregiving, and its frequency (Becker, 2007). According to Gibson et al (2019), when a young carer is identified, the local authority could inspect whether the care the young carer provides is appropriate or not (Gibson et al, 2019). Whenever the conclusion is that the care the child delivers is inappropriate, the local authority has to provide suitable support for the parent. If the parent receives support, this will lead to a reduction of the care the young carer has to provide (Gibson et al, 2019).

When determining which children need extra support, it is important that people working in the field consider cultural norms and universal children's rights about a child's care responsibilities. In this study, it was found that caring for a parent with a disability is sometimes seen as the responsibility of a child. In Western cultures children are not expected to take responsibilities in substantial or regular caring (Becker, 2007), whereas this might be 'normal' in some cultures. To prevent an incomprehensible gap about whether caring for a parent with a disability is or is not appropriate, different cultural norms have to be mapped in future research and compared to children's rights and child protection.

Suggested ways in which NGOs can support parents with disabilities were by providing them with personal assistants or engaging them in sustainable livelihood programmes which are another way of empowering families economically (OneFamilyPeople, 2016). The provision of personal assistants might not be realistic due to the costs involved and the fact that it is not a long-term solution, unless it is possible to give parents a personal assistant for their whole lives. Economic empowerment through sustainable livelihood programmes might therefore be a more viable and sustainable option. Conforming to the empirical analysis, parents with a disability might be more independent when

they receive a business grant from an aid organisation. Besides, according to the empirical analysis, it might be helpful if an aid organisation assists with educational materials and housing. As has been mentioned by the fieldworkers, aid organisations can also help in providing general educational support and basic needs for the children. It is recommended that aid organisations or NGOs keep in mind the needs of parents when deciding on the kind of help to be provided, as well as the feasibility of certain solutions.

The empirical analysis showed that healthcare is not always available for parents. This finding is in line with that of Becker (2007) who stated that healthcare might be unavailable. In fact, even when healthcare is available, analysis showed that the majority of the parents could not afford it. Future research should focus on the availability of healthcare and assistive devices in different regions, the time people have to travel to get healthcare and the quality of the available healthcare. For parents with a physical disability an assistive device might make the parent more autonomous, relieving the child from providing extensive care. Future research should map the availability and usability of assistive devices in Africa. Service provision, such as from fieldworkers, should be included in future research as well, since it is sometimes one of the only alternatives for people in rural areas in low and middle-income countries who do not have access to healthcare. It is important to consider the possible obstacles to availing of healthcare (e.g., travelling time, access, financial issues). Financial issues have to be taken into account and families who cannot afford healthcare should get financial support to do so. Future research should investigate how poor families can get more financial support and thereby improve access to healthcare.

Since none of the parents reported having an income that meets their basic needs or the needs of their families, young carers might have to deal with poverty, which is in line with findings from the DFID (2000). When children live in poverty, they might not be able to pay for schooling. In addition, several parents had to let their children work in order to meet basic needs. However, there is limited literature available about this possible link. Future research should focus on the possible link between young people having to care for a person with a disability and child labour, and the possible link between having a disability and poverty.

Limitations

This study suffers from a few limitations. First, the largely open-ended questions in the questionnaires might have led to differing interpretations and consequently

to variations in the given answers. When big differences in the interpretation of a question were found, the question was judged to be invalid and was excluded from the results. However, some differences in interpretation might not have been spotted, and could therefore have influenced the results. Second, the questionnaire was in English, so some of the parents needed assistance from fieldworkers to complete the questionnaire. It is possible that since an intermediary was involved, the parents may not have answered some of the sensitive questions honestly. Another consequence of the language barrier could be that the questions may not have been understood in the way that was intended. Wherever any misunderstanding was obvious, the given answer was excluded from the results; however, this might not always have been obvious and could have influenced the results. Third, the results showed outcomes for children which were based on data provided by parents and fieldworkers, without taking into account the children's views. The viewpoint of children could be included in future research for a more complete picture. Fourth, the age and gender of the children were not investigated. Future research could give more clarity about possible gender-related differences in caregiving. Fifth, the interpretation of the given answers was done by just two researchers. Even though researchers did the coding of the results independently before comparing the results, bias or personal filters could have affected the way in which the given answers were interpreted. There was no significant difference between the two researchers. Lastly, this study was based on a limited sample size, so the findings should be interpreted carefully. In addition, since the majority of the respondents were from Cameroon, the results should be interpreted extra carefully for Sierra Leone.

CONCLUSION

Even though young carers are a large group, there is a lack of literature about the role of children in caring for their parents with a disability in Sierra Leone and Cameroon. When there is more insight into the role of young carers, they can receive help which might prevent negative effects. The research results show that children take on several roles when caring for their parents with a disability, like domestic chores, intimate caregiving, childcare and general caregiving. Parents with a disability wish for more help in raising their children. Young carers might have to deal with poverty and several parents let their children work in order to meet their basic needs. Future research should map cultural norms and expectations about a child's caregiving responsibilities, and focus on aspects that are associated with these tasks among young carers.

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