

Supporting Parents in Caring for Children with Disability in Ghana

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ABSTRACT

Purpose: *This study assesses the factors that influence the well-being of caregivers and their children with a disability, in a rural and an urban site in Ghana. The well-being of parents, not surprisingly, influences the well-being of their children. A better understanding of the role and challenges faced by parents in caring for their child with a disability will help to improve existing services and support for children with disability.*

Methods: *Twenty-five parents of children with different disabilities participated in a PhotoVoice study. Photographs taken by parents, to show the challenges they experienced in childcare, were explained and discussed during focus group discussions. The Cantril Ladder was used to discuss subjective well-being.*

Results: *The photographs and discussions with parents indicated that the extensive time spent on their child, the child's poor health status, and lack of educational opportunities had a negative influence on the well-being of both parent and child. Parents struggle to earn an income to provide for a child with disability. This often causes them to sink into (even deeper) poverty, and further increases the challenge to provide the (specific) care that a child with disability needs.*

Conclusions and Implications: *If governments, non-governmental organisations and community-based organisations want to contribute to the well-being of children with disability, they should be aware of the immediate context of the child, namely the family, and of the specific needs of the parents. Since the well-being of parents can affect the well-being of the child, and a child with disability may often cause further poverty in the family, relieving parents from some of the demands of childcare could help them to generate income, to the ultimate benefit of the entire family. Organisations working for children with*

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a disability should actively involve parents of these children in designing and implementing interventions.

Key words: *Subjective well-being, PhotoVoice, child health, childcare, upbringing, parenthood*

INTRODUCTION

“Parents, legal or customary guardians have the primary responsibility for the upbringing and development of the child. But so do governments, non-governmental actors and community-based organisations” (UN General Assembly, 1989: Convention on the Rights of the Child).

An estimated 100,000 children in Ghana live with a disability (Ghana Statistical Service, 2012). In most cases their parents and families take care of them. Within the setting of family life, parents provide the physical and emotional care that children require to grow up and develop (Sameroff and Fiese, 2000; Piškur et al, 2015).

A child with a disability is generally associated with a variety of potentially negative health outcomes in caregivers, including decreased maternal employment, increased time spent on childcare and housework, and financial pressures (Lukemeyer et al, 2000; Brehaut et al, 2004; Davis and Gavidia-Payne, 2009). Moreover, several studies indicate that parents of children with a disability report high levels of stress, anxiety, isolation, stigma, physical tiredness, and lack of time to complete everyday tasks (Cadman et al, 1991; Kronenberger and Thompson, 1992; Mobarak et al, 2000; Guillamón et al, 2013; Zuurmond et al, 2015; Dambi et al, 2016). Both the general psychological literature and specific studies of children with disability show that parental distress and family functioning impacts children in numerous ways, affecting their cognitive, behavioural and social development (e.g., Richman et al, 1982; Wallander and Varni, 1998). Thus the well-being of children cannot be safeguarded separately from the well-being of families, and maybe even communities (Lund, 1997).

The inextricable link between the well-being of parents and children calls for development programmes designed to improve the well-being of both the parent and the child. As of the present, organisations often fail to sufficiently accommodate parental perspectives and priorities concerning development interventions (Daly et al, 2015).

Objective

The aim of the current study was to gain an in-depth understanding of parents' well-being by determining the factors that influence their life and the life of their child with a disability. The research adopted a participatory approach to gain insight into parents' perspectives of interventions that could support them in the care and upbringing of their child with a disability.

METHOD

Study Setting

The study was undertaken in two research areas for the purpose of comparing a rural setting (Amansie West) with an urban setting (Accra) in Ghana. The research took place from December 2014 till May 2015. In Accra, the parents who participated in the study are connected with a rehabilitation project where the children receive physiotherapy on a regular basis. Participating parents in Amansie West do not receive support from any organisation or project.

Study Design

PhotoVoice, a participatory action method, was the central approach. In addition, a mix of other qualitative methods were used, including focus group discussions, informal interviews and Cantril's "self-anchoring striving scale" (1965) (hereafter referred to as the Cantril Ladder) to measure subjective well-being.

Selection of Participants

In addition to having a child with a disability, the selection criteria included willingness to: (a) allocate time for participation in this study, (b) offer insights into their life, and (c) raise awareness and advocate for the rights of children with a disability.

On this basis, the research team selected a total of 25 parents (in two cases, caregivers) of 26 children between 4 - 20 years of age. Thirteen parents were selected from Amansie West and 12 from Accra. One parent had two children with a disability.

Participants were asked to indicate what type of disability their child has (self-report), which resulted in four categories: cerebral palsy, intellectual disability, physical disability, and a combination of physical and intellectual disability

(Table 1). While some categories overlap and might not be entirely correct from a medical point of view, these categories have been used throughout the article since the perspectives of the parents are being assessed.

Table 1: Self-reported Disability Type, Gender and Age Distribution

Self-reported Type of Disability	Gender Distribution				Age range of Children (years)
	Children		Parents		
	Male	Female	Male	Female	
Cerebral Palsy	7	1	2	6	4-20
Intellectual	2	2	0	3	5-10
Physical	4	6	1	9	6-18
Physical and Intellectual	2	2	3	1	10-16
Total	15	11	6	19	

Data Management and Analysis

Data comprised of photographs taken by the parents, stories explaining the photographs, notes of focus group discussions, and ranking forms of the Cantril Ladder. After selection of the research team and participants, the researchers attended a two-day orientation workshop on research design and data collection. Participants attended a two-day workshop in which PhotoVoice and the use of cameras was explained, and gave their ranking of the Cantril Ladder.

Participants gathered photos from February – May 2015. Local researchers then visited them to discuss data collection and select photos according to the issues that required the most attention as perceived by the parents. At each research site a focus group discussion was held with the participants, to discuss the photos and jointly select additional issues that were relevant in caring for a child with a disability. The focus group discussions were a method to extract more nuanced and richer insights to complement and clarify the stories that were depicted by the photographs. In the last phase of the research, the researchers and all the participants selected photos to be shown at an exhibition for the community, media and policy-makers. Finally, a wrap-up meeting was organised for the participants to evaluate the research project.

Cantril Ladder

The Cantril Ladder (Cantril, 1965) is known for its usage in the Gallup World Poll (Helliwell and Barrington-Leigh, 2010; Khaneman and Deaton, 2010). Participants are asked to think of a ladder with rungs numbered from '0' to '10'. The bottom of the ladder represents "the worst possible life for you" and the top indicates "the best possible life for you". Participants are asked on which rung of the ladder they currently stand. The Cantril Ladder can also be used for evaluation purposes at a later stage. In this study, the Cantril Ladder was chosen in preference to more in-depth tools such as the WHO-QoL, because it is simple, accessible to non-educated people and helps to discuss rather than measure well-being. The Cantril Ladder has been used before by, amongst others, Regensteiner et al (2008), Bailey et al (2009) and Helliwell et al (2013).

Ethical Considerations

Written informed consent was obtained from the participants. Informed consent included awareness of project activities and significance, specific potential risks and benefits, the voluntary nature of participation and the understanding that no photographs would be released without written consent of the participant.

RESULTS

This section presents the scores of parents on the Cantril Ladder, followed by a discussion of the photographs and stories with a focus on the identified essential themes: health, educational opportunities and time spent on childcare.

The Cantril Ladder

Participants scored, on average, a 1.2 on the Cantril Ladder, which is far below the average score of 5.091 for the general population in Ghana (Helliwell et al, 2013). A score below 4 indicates well-being of someone who is more likely to experience lack of food and shelter, physical pain, stress, worry, sadness and anger (Helliwell et al, 2013). Table 2 shows that 19 out of 25 parents scored below 4.

Table 2: Cantril Scores of each Participant

Part. ID	Gender part.	Gender child	Age child	Disability type child (self-reported)	Research Site	Cantril Score
1	F	F	7	Physical	AW	0
2	F	M	16	Physical and Intellectual	AW	0
3	F	M	7	Intellectual	AW	10
4	F	F	8	Physical	AW	0
5	F	F	5	Intellectual	AW	0
6	F	M/M	7/10	Physical/Intellectual	AW	0
7	M	M	12	Physical	AW	0
8	F	F	18	Physical	AW	4
9	M	F	13	Physical and Intellectual	AW	0
10	F	F	10	Physical	AW	0
11	F	M	10	Physical	AW	0
12	F	F	9	Physical	AW	0
13	M	F	10	Physical and Intellectual	AW	0
14	M	M	7	Cerebral Palsy	Accra	0
15	M	M	13	Physical and Intellectual	Accra	0
16	F	M	4	Cerebral Palsy	Accra	0
17	M	M	16	Cerebral Palsy	Accra	0
18	F	F	20	Cerebral Palsy	Accra	4
19	F	M	4	Cerebral Palsy	Accra	0
20	F	M	5	Cerebral Palsy	Accra	0
21	F	F	8	Intellectual	Accra	4
22	F	M	6	Physical	Accra	4
23	F	M	11	Cerebral Palsy	Accra	0
24	F	F	14	Physical	Accra	4
25	F	M	5	Cerebral Palsy	Accra	0

Only one parent, the mother of a 7-year-old boy with an intellectual disability in Amansie West, indicated her life as the best possible life for her. Five other mothers, of whom four were from Accra, rated a Cantril score of 4. This could suggest that females have a more positive perspective of their well-being than males, and that females in Accra (urban setting) are more positive than males and females in Amansie West (rural setting).

The 8 parents of children with Cerebral Palsy (CP) used words like “*high pressure*”, “*suffering*”, and “*life is hard*” to describe their well-being and their choice of the lowest rung. Some parents explained that their child had a negative effect on their happiness and living circumstances:

“My child takes away my happiness, everything about me. At times I just pretend everything is well, but it is not well” (Mother of a 5-year-old boy with CP, Accra, Cantril score 0).

“Life is not easy, because of the children I need to work hard. The father said that the children’s issues do not concern him anymore, and for our child with a disability he said if she will live or dies it does not matter for him” (Mother of a 14-year-old girl with a physical disability, Accra, Cantril score 4).

“At first we were living in a nice house, but because of my child, the father and his siblings sacked me out of there, so because of my child I don’t know happiness”(Mother of a 5-year-old boy with CP, Accra, Cantril score 0).

Only one caregiver mentioned that her child was a gift of God and that this knowledge gave her patience to take care of the child.

Health of Children with a Disability

Recurring themes represented by the photographs and stories were often health-related. Some parents portrayed their child’s weak health, showing the child lying on the lap of the mother, taking medicine or while vomiting. Furthermore, parents of children with an intellectual disability reported periods of aggressiveness, panic and of shivering. Other parents mentioned that their child wandered around, without interacting with others. This was illustrated by a photograph in which the child is playing with mud and sitting all alone outside.

Parents explained that when their child is sick, they take the child to the hospital, prayer group and/or to a traditional healer:

“When I took him there, what that person said was that it was spiritual, so he made three marks on her; you can still see the mark on her. When he added medicine on the mark, it took about 3 minutes and she started sucking breast milk. And since then the child is a living being and not dead” (Father of a 13-year-old girl with intellectual and physical disabilities, Amansie West).

Parents mentioned that every time their child was taken to the hospital, the medical officer failed to take a proper look at the medical condition. In consequence,

there was no satisfactory answer to the child's health problems. For example, one parent expected her child with an intellectual disability to be cured after the child was given tranquilizers for a period of time:

"So I sent her to the Bakwi hospital and the doctors gave me medicine for her to calm her mind down, but since one year it is the same problem" (Mother of a 5-year-old girl with an intellectual disability, Amansie West).

There seemed to be a general lack of understanding among parents about the medical causes of their child's disability. This is probably a result of inadequate information from health professionals and could increase the negative impact of having a child with a disability. Parents stated that disappointment over the lack of support from health professionals was a reason not to return to the hospital when fever or other health problems arose. This could affect the child's health and aggravate the disability. Poor health of the child with disability also affects other aspects of well-being. In some cases, illness had prevented the child from going to school:

"She was going to class three, but because of her illness she repeated the class because she did not write exams" (Mother of a 7-year-old girl with a physical disability, Amansie West).

The poor health of some children with disability motivated teachers and other children to exclude them from participation. These children were bullied or were advised by the teacher not to come to school anymore. Parents considered such situations to be disempowering. They stated that they wanted to prevent their child from being hurt by others and therefore preferred to keep their child at home.

Educational Opportunities for Children with a Disability

Parents explained how the lack of educational opportunities for their child had an influence on their life. According to them, lack of education not only affected their child's development but also made it difficult to perform household tasks, as the child needed care during the day. Parents regarded school as a place for the child to learn and be looked after.

Almost all the parents of children who did not attend school explained that they had tried unsuccessfully to get their child enrolled at a local school. They were refused admission for diverse reasons. One parent was told that the child should be independent before the school would allow the child to join the class;

other parents were sent away by the teachers because their child was not able to communicate. In a considerable number of cases, the parents decided to keep the child at home because of the lack of support from the school and maltreatment by fellow pupils.

The stories about problems in getting an education were illustrated by photographs of children remaining idle at home or sitting alone outside. Two cases were more positive, showing a child who learns with and from other children living in the neighbourhood:

"I am not good myself in educational activities so her friends come to teach her at times" (Mother of a 5-year-old girl with an intellectual disability, Amansie West).

Of the children in this study, only two who have a physical disability attend school and are on track with their education. The other children either did not attend school, had dropped out of school or, in two cases, remained in the nursery school or in the first or second class of the primary school. Photographs of these children in school revealed that they were much older than their classmates. The stories mentioned parents who guide their child to school and sometimes stay in the classroom as personal assistant to their child. Most parents are concerned about the future of their child and foresee a lack of opportunities for children to earn an income or be capable of looking after themselves.

Time spent on Caring for a Child with a Disability

Most parents indicated that caring for their child curtails their activities outside the home, especially with regard to employment and going to the market. Parents of children with CP and multiple disabilities spend considerable time in providing direct care to their child:

"Sometimes I spend the whole time for him; sometimes when you divide the time in three, two out of the three is for him because sometimes I have to wash when no one is around, I have to cook for him, I will do some little things around the house; even with that I check on him so my time is for him" (Mother of a 5-year-old boy with CP, Accra).

Parents who spend only one hour on childcare have relatively older children and have training in activities of daily living. These parents proudly talked about the independence of their child. However, the majority of the parents explained that they were occupied with daily living activities of their child, such as helping in going to the toilet, bathing, dressing, and assisting the child to eat. Some parents of children with CP mentioned that feeding their child takes up to three hours a day. Sometimes other family members are also affected:

"She (sister of a child with a disability) turned down the scholarship that she got for schooling because she says she wants to stay with her mother to help her to take care of our child with CP"(Father of a 16-year-old boy with CP, Accra).

Parents of children with intellectual disability spend a lot of time in preventing their child from walking away, or protecting their child from harm such as emotional, physical or sexual abuse:

"From morning to evening, if I am in the house, I have all the time for him. I see to him that no one beats him" (Father of a 12-year-old boy with multiple disabilities, Amansie West).

"If my wife wants to go somewhere I need to waste my time to be with her (the child). I don't go anywhere to be with her. To enable my wife to go to the farm, I will be in the house looking after her to prevent her to move around" (Father of a 10-year-old girl with multiple disabilities, Amansie West).

Most parents do not receive support to look after their child. Without additional support from their (extended) family or the community, the parent- usually the mother - is the child's only caregiver. Mothers mentioned that this made them feel like a prisoner in their own house. Some mothers were sent away from the village because of their child with a disability. It was stated by some parents that they could arrange proper care, healthcare and education for their child if only they had more money:

"Now everything is about money; if I have money and get a school to send my child, so after work I know she is in school, if I get school for her I will be happy" (Mother of a 20-year-old girl with CP, Accra).

DISCUSSION

Lukemeyer et al (2000), Brehaut et al (2004), and Davis and Gavidia-Payne (2009) found that having a child with a disability generally affects families in terms of decreased maternal employment, increased time spent on childcare, and financial pressures. The current study confirms this with a number of examples. Parents mentioned that when their child does not attend school, it becomes difficult to perform household activities, to generate income or go to the market. While the vicious cycle between poverty and disability is often mentioned, for example by Braithwaite and Mont (2009) and Trani and Loeb (2012), one should realise that the disability of a child goes beyond the individual and may lead to poverty of the entire family. If parents receive support in caring for their child, they could

possibly generate more income, which would alleviate poverty and enable them to arrange proper (health) care and education for their child.

Moreover, it has been mentioned that the well-being of parents affects the well-being and development of their child (Lund, 1997; Dambi et al, 2016). The scores on the Cantril Ladder indicate that parents have a particularly low subjective well-being. Only mothers in the rural site seem to experience relatively higher well-being compared to other parents; no differences are found in terms of type of disability and gender of the child. Parents with relatively older children seem to score relatively higher on the Cantril Ladder. The only positive side of having a child with a disability, according to the parents, is the belief that children are a gift of God and that this gives patience to take care of the child. At any rate it is crucial to start paying attention to parents' well-being. Numerous non-governmental organisations that focus on children aim to: *"enable children to achieve their full potential and ensure their overall well-being"* (Plan International, 2016), *"build a world where every child can grow up healthy, protected from harm and educated, so they can reach their full potential"* (UNICEF, 2016), or *"give children a healthy start, the opportunity to learn and protection from harm"* (Save the Children, 2016). These goals cannot be achieved without ensuring that parents of children with disability receive the right support to care for their child. Furthermore, while the Convention on the Rights of the Child (UN General Assembly, 1989) refers to both the duties and rights of parents and caretakers, one may question to what extent governments feel obliged to make sure the rights of these parents are met. If the CRC were to be appropriately and effectively implemented, this could lift the heavy burden of parents to some extent.

Health professionals, teachers, the (extended) family and the community could also provide better support to parents. For example, if children with a disability attend school, their parents would have the opportunity to spend time outside the house, to earn an income, or to perform household tasks. Not only would this benefit the parent, but it could also contribute to the development and empowerment of the child. The case of the child who was learning with and from children in the neighbourhood shows how the social environment can easily contribute to the care of children with a disability. In all efforts to enhance the well-being of children with a disability, one cannot ignore the inextricable link between the well-being of parents and children. This study and an evaluation by UNICEF (Daly et al, 2015) both illustrate that organisations often insufficiently address parental perspectives and priorities.

Finally, parents mentioned that they would particularly like to be supported in terms of economic empowerment. If they could hand over the care of the child to some extent, they could generate an income, which would benefit themselves and their family both financially and emotionally.

Limitations

While this study aimed for a participatory approach to better understand the challenges and desired support in caring for a child with a disability in Ghana, participants were not involved at all levels of this study. In consequence, some of the challenges and needs of the participants may have been overlooked, as well as issues outside the focus of this study. In terms of participant bias, it can be expected that whenever a (representative of a) donor conducts a study on needs and challenges, participants will be more likely to report negative stories that could potentially generate continued or increased donor support.

CONCLUSION

Understanding the factors that influence the well-being of parents of a child with a disability is a first step towards developing interventions to support them in the care and upbringing of their child. The subjective well-being of participating parents in this study is exceptionally low. The parents felt that caring for their child afforded limited time for household activities, limited their job opportunities thereby causing poverty, and restricted them from going out of the home, for example, to the market. The lack of support and maltreatment by schoolteachers, fellow pupils, family and the community placed an even heavier burden on their role and responsibilities. If non-governmental organisations (and any other concerned actors) aim to enhance the well-being and quality of life of children with a disability, they should realise the context in which these children live and the fact that children are part of a family. Children with a disability whose parents feel burdened and alone in caring for their child are more likely to miss out on proper care, which may consequently aggravate the child's disability and inhibit development. While parents play the main role in rearing a child with a disability, the outcome of their efforts is also dependent on the performance of the government, non-governmental actors and community-based organisations. Mutual cooperation is absolutely essential.

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