Perceptions of caring for children with disabilities: Experiences from Moshi, Tanzania

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Background: Although there exist laws, policies and standards in Tanzania that serve to protect and improve the lives of children with disabilities, the individual human experiences and feelings of the carers and parents still remain the realities of caring for children with disabilities. There is a lack of qualitative studies examining experiences in a developing context. This research aimed to fill that gap.

Objectives: The objective of this research was to gain an insight into how having a child with a disability impacts upon participants lives and to examine both negative and positive experiences of care through the use of qualitative methods.

Method: This was a qualitative, exploratory study and followed a phenomenological method. Purposive convenience sampling methods were used to recruit 14 carers in Moshi, Tanzania. Qualitative, semi-structured interviews were undertaken with all 14 participants.

Results: Five main themes emerged from the data which shed light on the carers experiences, namely, objective challenges in terms of financial challenges, employment issues and demands of care; subjective challenges in the form of stigma, isolation and pity; positive experiences such as the child's progress, respect and happiness; material and financial needs; and coping mechanisms which included beliefs, support and attitudes.

Conclusion: The findings of this research were that objective challenges are common and more significant than subjective challenges. Positive experiences were not as easily identified by the participants as the challenges faced. However, having analysed the data, carers do not experience their roles as entirely negative. They simply need the resources to deal with objective challenges which in a developing context are not easily attainable.

Introduction

Problem statement

Informal caregivers are a crucial element of society in taking on the continuous and demanding task of providing care. They perform a job that saves the taxpayer money thereby decreasing pressure on service providers and enabling the family unit to stay together. According to the International Labour Organisation (ILO) over 9% of the population in Tanzania have a disability and informal caregivers are vital to society (ILO 2009). Adequate support is required for caregivers. As stated by Kittay (2001:575), when the support is inadequate 'either the cost of care is borne by the caregiver alone' or the recipient of care suffers. Understanding the lived reality of carers is important so that support systems and interventions can meet their needs and local and national organisations can provide them with vital support in order to continue to provide care.

In Tanzania, there are a number of policies, laws and standards that have been implemented to protect the rights of people with disabilities (PWD) and in the 1977 constitution, discrimination against PWD was prohibited. Whilst these aspects of legislation serve to improve the lives of PWD, it is still vital to understand the individual experiences of the carers and parents of children with disabilities (CWD) and provide an insight into the realities of caring for a CWD.

Research examining carer burden, coping strategies and experiences of carers and parents of CWD in low-income countries is not common, with little research in the African context (Gona *et al.* 2011). In the last decade, several qualitative studies have been conducted in various cultural contexts to examine the lives of parents who are raising a CWD but many more quantitative studies which do understand 'the richness of these parents experiences' (Gona *et al.* 2011:456) have been conducted. There is a need for more qualitative studies to provide rich insights into the realities of care.

Previous studies have focused on negative aspects of carers' experiences creating an unbalanced view of parents experiences with 'serious gaps in our understanding of the social experience

of disability' (Green 2007:151). Green (ibid:151) notes that studies have primarily focused on the subjective burden of care and have failed to understand the objective burden and the positive aspect of care. Resch *et al.* (2010) note that previous research has fallen short of capturing the entire perspective and experiences of carers. This paper aims to fill the gap by focusing on the perspectives of carers and parents of CWD. It explores negative experiences, both subjective and objective burden, positive experiences, needs and coping mechanisms, thereby providing a more balanced view of the situation. It also adds to the literature in the form of an additional and needed qualitative inquiry carried out in a developing country, namely, Tanzania.

Literature review

In examining the care of vulnerable children, Brannen, Mooney and Statham (2009) state that because of life experiences and events in peoples' lives, some may feel that they have a 'calling' to be a carer. Tronto (1993) lists four elements that lead to ethical practices in caring, namely, competence, responsiveness, responsibilities and attentiveness. However, both the structural context and the capacity of the individual are both factors in understanding the responsibilities of care and as stated by Brannen *et al.* (2009) actions are 'decided on the basis of what seems "right" under given social conditions' (Brannen *et al*. ibid: 378). In circumstances where people are faced with the task of caring there are many experiences to be noted.

Negative experiences identified in extant literature include carer burden and stress, financial and employment issues, stress, stigma and relationship issues. Lassetter *et al.* (2007) discuss themes found in research based on the experiences of caring for CWD, namely, stress, effect on the mothers' employment, spiritual growth and finding the positives. The severity of the disability, the socioeconomic situation of the family, support systems available and marital relationships all impact on carers' experiences (Gona *et al.* 2011). Hartley *et al.* (2005) identify four challenges in caring for a CWD through a study they conducted in Uganda. These four challenges were poverty, communication issues, impact of the disability and the burden of care. As Resch *et al.* (2010) state, the responsibilities of carers are physically demanding, affect social and family relationships, and adversely affect employment. Indeed, the 'person-environment interaction' affects carer well-being (Resch *et al.* 2010:140). Research has primarily focused on specific tasks and the challenges associated with caring but failed to capture the full picture. As Kittay (2001) states, because of the demands of the role, the caregiver can be vulnerable to exploitation. In this respect, an understanding of their experiences is essential.

Little attention has been given to the nature of carer burden. Green (2007) divided the 'burden of care' into:

- objective burden – possible financial issues, tasks and time involved in caregiving

- subjective burden, the perceived impact of the objective burden or internal emotional distress.

Burden is associated with stress. Pelchat, Lefebvre and Perreault (2003) discuss how stress causes doubts in carers minds when it comes to evaluating their skills, resulting in greater stress. Peoples' socio-economic situation can be a cause of stress (Dempsey *et al.* 2009). Mitra, Posarac and Vick (2011) discovered that a higher proportion of expenditure in households with disabilities is spent on health care in Kenya and Malawi. Significant outpatient costs are associated with caring for a CWD (Gona *et al.* 2011). Hartley *et al.* (2005) discovered in Uganda that poverty affects coping because external resources are unattainable.

Other studies noted that caregiving is time intensive and leaves little time to seek employment (Lassetter *et al.* 2007). This is corroborated in an Australian study by Green (2007) who states that unavailable, unaffordable and unsuitable child care decreases carers job opportunities. In 1963 Goffman identified that parents of CWD experience 'courtesy stigma'. This is 'stigma of affiliation that applies to people who associate with stigmatised groups' (Gray 2002:735). Green (2007) cites authors who conclude that social isolation and increased emotional distress are attributed to courtesy stigma (Alban 1990; Blum 1991 & MacRae 1999). Stigma and burden are not mutually exclusive. Green (2007) identified in her study that subjective burden increased alongside perceived stigma and Mitra *et al.* (2011) concluded that stigma results in increased isolation and restricted participation in activites.

Family units are crucial for those members who are dependent, namely, children, the elderly, the sick or people with disabilities (Kittay 2005). Family relationships impact on maternal caregiving (Huang, Kellett & St John 2011), for example, when CWD are accepted by family members, parents feel more satisfied. Gray (2002) discovered that mothers of CWD were more prone to stigma than fathers were because mothers are attributed more responsibility for their child's behaviour than their spouses and are typically the primary carer. Hartley *et al.* (2005) discovered that the onus of care falls on mothers in Uganda. There have been studies carried out that conclude a lower stress level amongst carers is associated with a healthy marital relationship and spousal support. Hastings (1997) cited in Gona *et al.* (2011) states that extended family support decreases stress. Susan Whyte (1991) cited in Ingstad and Whyte (1995), found that the care of a person with 'retardation', 'epilepsy' or a 'mental illness' in Tanzania was left to the family and was not seen as a responsibility bestowed on the wider community. She goes on to state that because families are large, care could be shared thereby reducing the burden. According to Hartley *et al.* (2005), however, extended family systems are breaking down in Africa and caregiving tasks are usually the responsibility of a female carer. Indeed, studies in Zimbabwe and Botswana have found that the old, the young and the ill are left to care for the PWD because able-bodied family members have been migrating for work (Ingstad & Whyte 1995). Therefore, it seems that the literature available about family support in African countries varies and further investigation is warranted.

Positive experiences and parenting competence are lacking in the literature (Hastings *et al.* 2002). Hastings *et al.* (2002) recognise how little attention has been given to positives, both with regard to perceptions of the child and the impact the child has on the family. Rehm and Bradley (2005) discovered that closer bonds with extended family, close relationships with care providers and increased time with their children because of their inability to work outside the home were identified positives. Personal growth, family closeness, increased sensitivity to others, less materialistic attitudes and opportunities to expand ones social and political activities and contacts were identified (Hastings *et al.* 2005). Kisler and McConachie (2010) identify that raising a CWD is also as rewarding and positive as raising a 'normal' child. It is noted that Rehm and Bradley (2005) and Hastings *et al.* (2005) carried out their research in a developed setting and that different impacting factors were present. For example, Rehm and Bradley (2005) carried out their research on a population of European American or Hispanic heritage; 48% of their population had an income of more than $55 000 and all had access to healthcare.

Taunt and Hastings (2002) bring attention to the fact that although positive experiences are reported, they occur in tandem with the negative experiences. Other studies by Ferguson (2001), Landsman (2003), McKeever and Miller (2004), Read (2000), all mentioned in Green (2007), conclude that positive attitudes amongst carers is unrealistic and that positivity actually arises from a failure to accept their circumstances; in other words, they are in denial about their situation. Green (2007), however, discussed how such conclusions only serve to discourage carers to find the positive aspects of care, denying them the potential positive consequences. Seminal authors such as Kittay (2005:126) argue against comments by authors such as McMahan (1996) who states that people who are 'profoundly cognitively impaired are incapable ... of deep personal and social relations ... aesthetic pleasures and so on ...' Kittay (2005) argues against this. He says that there is joy to be found in caring for people who are severely disabled. Indeed, the disability movement, including authors cited by Watermeyer (2009); Abberley (1993); Oliver (1990); Morris (1989) and Lonsdale (1990), reject the logic of 'disability loss' where there is a 'constant awareness of what has been lost or was never had' (Watermeyer 2009:92).

Not all studies find positive experiences. Johnson, O'Reilly & Vostanis (2006) discovered through a qualitative study that isolation, conflict, a limitation of lifestyles and self-blame were common themes and not the positives of social contact, opportunities, harmony and increased self-esteem. Both Hastings *et al.'s* (2002) and Taunt and Hastings's (2002) findings support that positive perceptions are used as a mechanism for coping. However, the external factors of social support and difficulties of care were controlled in each of these studies. Folkman and Moskowitz (2000) suggest that psychological models that examine coping need to include both negative and positive affects. This will help in validating the positive experiences in the investigation as well.

Swartz and Watermeyer (2008:187) discuss the perception of disability throughout history and that 'disabled people have a history of being viewed as not entirely human'. In examining previous studies from Africa it becomes apparent that carers are stereotyped because of the perception of disabilities. In Uganda and Kenya the perception that disability is the work of evil spirits or a curse or god's punishment results in CWD being hidden (Gona *et al.* 2011). Hartley *et al.* (2005) carried out a study in Uganda which revealed that carers of CWD are subjected to stress. In examining the Maasai people, however, it is interesting to note that disability is not used as criteria with which to classify people (Ingstad & Whyte 1995). The Maasai's perceptions and attitudes vary but do not focus primarily on inability. In examining the extant literature it can be seen that there is a wide range of experiences from various contexts.

Research method and design used
Participants

Fourteen parents and carers of children with disabilities who live in the Moshi region, Tanzania were interviewed for this study. Participants were selected based on their children's attendance at day care centres run by Building a Caring Community (BCC). Parents and carers refer to either the parents of a child with disabilities or a carer who spends a large proportion of their time caring for the child. Throughout this manuscript the words 'carers' or 'parents' refer to parents and carers as described above, unless otherwise stated.

Setting

Moshi is a market town in the Kilimanjaro region of Tanzania. Much of the employment in Moshi takes place through selling goods at the markets. BCC is a local Tanzanian NGO that has several day care centres in the Moshi area that provides care for CWD.

Design

This research was qualitative-exploratory in nature which allowed the researcher to uncover new ideas (Stebbins 2001) and to examine the complexities of the experiences of caring for a CWD. Qualitative research helps the researcher to understand the human realities of the situation (Morse 1995). A phenomenological approach was used because as Denscombe (2007) says 'phenomenology is an approach that focuses on how life is experienced'. This approach allowed the researcher to explore how respondents viewed their situation. This approach follows one undertaken by other similar studies (Gona *et al.* 2011) and (Hartley *et al.* 2005). An interpretivist orientation was followed which enabled individual interpretation of phenomena (Denscombe 2002).

The researcher acknowledges the limitations associated with the interpretivist orientation, namely, that results cannot be generalised (Poston *et al.* 2003). The researcher ensured rigour by following a systematic approach (Denscombe 2002) and clearly showing the steps in the research (Barbour 2001).

Procedure

Participants were selected through their status as parents or carers of a CWD by a purposive convenience sampling method. Access to the study population was negotiated through the organisation BCC who allowed use of their premises to carry out data collection. Recruitment was facilitated by staff members at the centres. Possible participants were introduced to the principle investigator and were given an information leaflet to consider for 7 to 10 days. If a participant chose to take part, they were then required to sign an informed consent form before taking part. Participation was completely voluntary with no remuneration or conditions attached.

Semi-structured interviews (SSIs) were used for data collection and each participant was interviewed once. A guide that was

followed for the interviews is included in Box 1 below. An audio recording device was used so that the researcher could observe non-verbal behaviour (Davies 2007). Using SSI's gave the respondents freedom to illustrate important concepts and to respond to the interview in whatever way they wished (Morse 1995). Interviews took place in a secluded area within the day care centres so that the respondent's child would be cared for by the staff. Although there was much background noise, no other setting was deemed appropriate. Staff at the centres were on hand should participants become upset or distressed during the interview process.

Interviews were conducted in the local language, using a translator and lasted between 25 to 50 minutes. Transcripts were augmented with non-verbal gestures and emotional reactions from field notes in order to capture the true essence of phenomena being discussed.

Analysis

This research employed an inductive approach; theory was developed from the data (Rudestam 2007) through manual analysis. An example of a theme emerging from the data is included in Table 1 below. Phenomena identified in the literature review which were deemed important were followed up in interviews. Data, in the form of transcripts was analysed systematically with a constant comparison approach. Recordings, field notes and transcripts were all used to triangulate the data. Congruence was found amongst all verbal and non-verbal data.

BOX 1: Interview Guide.

> **Interview Schedule:**
> - What is your name?
> - Where do you live?
> - Are you single/married/widowed?
> - How many children do you have?
> - Is your child that is disabled the youngest/oldest or middle child?
> - Tell me about your child who is disabled.
> - How has your life changed since having a disabled child?
> - What percentage of your day is dedicated to caring for your child?
> - Describe your typical day.
> - Tell me about a positive time with your child.
> - What is the most positive time with your child?
> - Tell me about a negative time with your child.
> - What is the most negative time with your child?
> - What are your strongest feelings and emotions about your child's disability?
> - Do you go into the community with your child?
> - How is your child treated in the community?
> - How is your child treated within your family?
> - Tell me about the difficulties you face.
> - Tell me about a time when things have gone well in your family.

TABLE 1: The theme of objective challenges and the resulting subthemes are shown in the table below.

Theme: Objective Challenges		
Subtheme	**Key Language**	**Examples of Supporting Data**
Burden of Care	Time spent caring	'So I could say maybe on Saturday and Sunday I will always have Lucy. In the middle of the week she is coming home from 6 in the evening. so that is when I am caring for her' (A).
		'From Monday to Friday from the evening until the morning because she comes to this centre. And then on Saturdays and Sundays all together at home' (K).
		'From 3 pm up until the morning until I bring her here again' (M).
	Demands of care	'The most difficult thing is when he falls sick because he is more grown up now and so when I have to carry him to Mawenzy hospital in town it is very difficult so I have to take a taxi' (N).
		'I used to have to find him, I didn't know where he is so I would go house to house to find out where he was' (H).
		'I can't walk too far from Adam, this is a problem, I have to be near him' (H).
Financial Challenges	Lack of money for necessities	'I used to rent houses but it becomes [sic] difficult to find the rent for those houses' (H).
		'The most, the worst thing I experience is about the pampers for John to get the money for the pampers and sometimes to get clothes for John because I am the mother, the father I am everything so that's what experiences I get' (E).
		'My economic situation is very hard. Sometimes I can't get enough food for her' (A).
	Lack of money for healthcare	'Sometimes when John gets sick I can't get the money for the treatment' (E).
		'When Grace falls sick, at that time I feel like I have a very big burden because I can't afford to pay money for her surgery in KCMC it's very expensive ... '(K).
		'The most difficult thing is when Maggie falls sick. Taking her to hospital is very very expensive. Maybe she will be admitted for week and this will be 60 T shillings' (M).
Employment Issues	Lack of time	'I can't do a job that is a full day job because of my child because I have to come here to bring him and again take him back home' (E).
		'Sometimes I want to go to work and I have to leave Maggie at home there so like those neighbours say 'no you can't leave Maggie in our hands' because it's very difficult to give her food, she eat slow, very slowly so it's just like, they don't like that they say like 'you have to stay there you can't go where you want to go' [sic] (M)
		'I used to work making bed nets so then when I get this disabled child I had to stop it. Once I used to employ a certain nanny but she couldn't take good care of that baby' (H).
	Low income jobs	'What I experience is that ... sometimes when my husband when he comes home maybe he doesn't have money because of his poor job' (B).
		'... all of them they are living in low income, they are poor all of them, so they can't support him but they accept the disabled child' [sic] (H).
		'And also the other child goes to school but it is a very difficult time because of the low income of the family' (N).

The second author independently conducted an inquiry audit trail following the process laid out by Halpern (1983), cited in Lincoln and Guba, (1985). The audit of the study materials established the credibility, confirmability and dependability of the investigation by reviewing techniques employed in the study, including coding of the data and triangulation of data (Anfara, Brown & Mangione 2002; Lincoln 1995; Lincoln & Guba 1985).

Results

Five main themes (Table 2) were identified, namely:

1. objective challenges
2. subjective challenges
3. positive experiences
4. needs identified
5. coping mechanisms.

The results of this research highlighted both the challenges experienced by carers as well as the positives.

Theme 1: Objective challenges

Objective challenges are challenges related to objective burden and cannot be dealt with through emotional means. Demands of care, financial challenges and employment issues were objective challenges identified. The demands of care experienced were the tasks and time involved in caring. Some parents spent all their time caring. Many parents, however, acknowledged that when the child spent time at the day care centre they did not spend time care-giving. Participant K said, 'from Monday to Friday from the evening until the morning because she comes to this centre. And then on Saturdays and Sundays altogether at home'.

The tasks of caring identified varied based on the type and severity of the disability. Physically carrying the child in the

TABLE 2: The table below shows the themes and subthemes that emerged from the data.

Theme	Subtheme	Key Language
Objective Challenges	-Demands of care	• Time • Tasks
	-Financial Challenges	• No money for necessities • No money for healthcare
	-Employment issues	• No time for work • Low-income jobs
Subjective Challenges	-Stigma	• Rejection • Discrimination
	-Isolation	• Lack of support • Worry
	-Pity	• Being shown pity • Reactions to pity
Positive Experiences	-Child's progress	• Independence • Ability to do tasks
	-Respect	• How respect is shown • Reactions to respect
	-Happiness	• Interactions • Health
Needs Identified	-Financial help	• Sponsors • Loans
	-Supplies	• Supplies
Coping Mechanisms	-Beliefs	• God • Hopes for the future
	-Support	• The centre • Other people

case of children who were unable to walk was difficult, 'the most difficult thing is when he falls sick because he is more grown up now and so when I have to carry him to Mawenzy hospital in town it is very difficult so I have to take a taxi' (N). Another issue faced by parents was finding their children having left them alone, 'I used to have to find him, I didn't know where he is [*sic*] so I would go house to house to find out where he was' (H).

Lack of money for necessities was a financial challenge. Necessities included food, clothes, nappies and shelter or housing. Participant H explains how she could not afford rent, 'I used to rent houses but it becomes [*sic*] difficult to find the rent for those houses' (H). Lack of money for nappies or 'pampers' was inevitably a response confined to those who cared for incontinent children, 'the pampers are sold like [*sic*] 10,000 per dozen, one packet, one packet is 10,000' (L). Stemming from the issue of unaffordable pampers, was unaffordable clothes or bed sheets. One participant expressed her inability to afford food, 'my economic situation is very hard. Sometimes I can't get enough food for her' (A).

A lack of money for healthcare was a major financial challenge. Hospital fees and transport were unaffordable, 'Sometimes when John gets sick I can't get the money for the treatment' (E), a sentiment also expressed by participant K, 'When Grace falls sick, at that time I feel like I have a very big burden because I can't afford to pay money for her surgery in KCMC. It's very expensive …' (K).

A mix of low-income jobs and lack of time resulted in employment issues. The more dominant challenge was the lack of time to work. Only a couple of parents managed to use the time their children were cared for to do some work, 'when it comes to the morning, I just bring him here so I have to go and find some moneys and things like that' (F). One woman had to stop working because of the demands of care '… I used to work making bed nets so then when I get this disabled child I had to stop it' (H). Participants who didn't work because of the time they spent caring brought attention to the low income of their husbands' jobs, 'what I experience is that … sometimes when my husband when he comes home maybe he doesn't have money because of his poor job' (B).

Theme 2: Subjective challenges

Subjective challenges are emotional challenges and are intangible. Stigma, isolation and pity were identified. Rejection and discrimination were manifestations of stigma. Some participants spoke of rejection in general terms, 'they all run away after knowing that I am having [*sic*] a disabled child …' (C). But nearly half of all participants mentioned this specifically in relation to their husbands or his family, 'after giving birth and he was seeing [*sic*] how John is, he runs away' (E). Two participants reported rejection on the basis of blame, 'in our family we don't have such kind of diseases' (H). In one extreme case an aunt who wanted a relationship with the child was subsequently rejected, '… after she accepted Jack the other family of the father, they also rejected the auntie, they don't need her…' (F).

Stigma or discrimination was shown in gestures such as pointing, laughing and staring, 'they just see him the way he is and they find out he is disabled so they're just laughing at him' (F) or, '… in the fathers side they point' (A). Another way stigma is shown is by people avoiding the child, '… maybe Alex he can go anywhere and see the door open and just come in so they say that this is our house and we don't want him … ' (L). Stigma directed at parents at social gatherings was reported, 'I used to go with John to celebrations but some people are stigmatising [*sic*] towards him. Then they say that maybe the children is having asthma and the mother is just doing farts… ' (E).

Lack of support and worry contributed to isolation. In some cases spousal or immediate family support was absent with some participants experiencing blame, '… so sometimes even my mother used to blame me that I don't teach Alex how to go to the toilet and also the husband used to tell me "you don't teach Alex how to go to the toilet"' (L). Sentiments expressed indicated that isolation was an experience of many, 'Oftentimes I am alone' (N). Participants worried about the future, '… I also feel that maybe one day I will die one day … so I afraid to think what will happen because I am the only one who can help Grace, so Grace will be just living like street children …' (K). Others worried about the near future '… I just worry about her when she goes to school because she can't talk straight and that other people cannot understand her … ' (A).

Most participants experienced pity, 'then I tell them that Jack has a syndrome and then they say "ok, sorry, we just pray to God that he will get better someday" or something like that' (F) or when participant M discloses about her child's disability, 'they just feel sorrow' (M). There are mixed reactions to being shown pity; it negatively impacts on some participants, 'I don't feel good. I feel sad because people do this' (B) but others found it helpful and it made them happy 'I feel very happy because I feel it's better that a person feels sad for you more than stigmatizing towards you' (N).

Theme 3: Positive experiences

The child's progress, respect and happiness were positives identified. Most talked about seeing their child's progress in terms of independence and ability to do tasks. Participant I states that, 'I can tell her to go to the shop and bring this. Emma can go and bring it so that is a positive thing' or indeed as participant K tells, '… so she can go to the shop and take beans and come back at home so I am very happy'. In those children whose disability was more severe, the ability to do simple tasks such as speaking or counting were seen as positives, 'Jack growing up little by little. Sometimes he can say "mama" maybe sometimes "mama school", things like that so that feels good' (F) or indeed counting, 'when Emma sometimes can just come and counting [*sic*] 1-10 and write it down and she can come and show me like "father just look here" so that's a positive thing' (I).

Most carers felt respected and were shown respect by members of the community by being compared to others,

'we like you because you like your child who is disabled, some of the mothers used to hide their child inside the house and they didn't give them food …' (D), 'they just say that I have a good heart because I am taking care of my child, if it was another they would have thrown him away … so they respect me' (E). Most felt happy when they were shown respect, one carer even indicated she put added effort into caring for her child, 'I am feeling good and I am adding effort in taking care of Grace' (K).

Interactions and health were sources of happiness. Happiness was reported when children are at home and interacting with the family, 'she is always happy. When we cook she eats together with us. She is happy with her family' (M). Some parents indicated that the positives they experienced with their child were 'all the time, every day' (I). Two carers stated that simply seeing their children alive was a positive experience, 'Alex is alive, I can see him walking, going there and coming here so this is a positive thing' (L). When the child was not sick was also reported as a positive time, 'when Maggie is not sick, she is ok, she is always happy, all the time she is happy when she is not sick' (M). This is confirmed by others, 'When Diana is not sick, it is just positive but when she is sick I am feeling very sad' (C).

Theme 4: Needs identified

Financial help and the need for supplies were major needs identified. Financial help in the form of sponsors and loans was needed. Participant H details why she needs a sponsor and the experience of trying to secure one:

> I don't have the school fees for those children because of this one, the disabled one. And I was also advised that I can take that child to the boarding school where he can learn things at the boarding school but I am not having [*sic*] money so I was told to fill out a certain form for sponsors so I am still filling this, I don't know if I will get a sponsor or not.

Participant J simply states, 'If I could get a sponsor for the children for Alan to go to the boarding school it will be better'.

Some participants identified the need for financial support in the form of loans to build a house or to start a business, '... so I feel like having a compound for building a house where I can live with my family but I can't because most of my time I take care of Anna ...' (B). 'I feel like if I could get maybe, like having my own house, it would be if also I could get some loans, some governmental loans ... get the capital for starting business ... ' (J).

Some parents indicated that they need supplies including nappies and clothes, 'Alex needs pampers, he needs a lot of pampers so maybe when we go to hospital or he goes somewhere ... ' (L).

Theme 5: Coping mechanisms

Beliefs in God and spirituality, support sought through prayers and hope for the future were identified as coping mechanisms. Some parents were more spiritual than others,

however, many parents referred to God, 'I don't worry so much because like I leave everything to God so it's ok' (F). Others believe that God will help them through their problems, 'God is the one who knows everything in this world so he will just help me' (K). Some asked God for strength, 'I asked God to give me strength, that's how' (J). Hopes and beliefs for the future were mentioned by at least seven participants. All relate to the child making progress, changing or getting better, 'I hope that Sean will be normal as other children' (C) or as in sentiments expressed by participant E, 'I believe one day he can go to school and he will walk, that's what I believe' (E).

The centre and other people were sources of support, 'all the time I feel good all the time and more thing that the child has been brought here ...' (N). The support the centre provides has allowed many parents to earn a small living which enables them to cope. 'Before I take Diana here in this centre it was a big problem for me to do my works [*sic*] because I had to take care of Diana ...' (D). Throughout the interviews parents acknowledged that at some period they receive support from neighbours, their other children or family members, 'The neighbours, neighbours or friends around the home they used to help me sometimes maybe when I would leave the home I would just tell them to take care of him. And also sometimes they used to give me some clothes for the child because he is incontinent' (N). Participant A indicated that she received help from the child's siblings, 'They do help me when I need help. They feed her when she needs' (A).

Ethical considerations

Ethical approval was received from the Health Policy and Management/Centre for Global Health Research Ethics Committee (HPM / CGH REC) of the University of Dublin.

Potential benefits and hazards

Participants could benefit from any programmes that may be put in place as a result of this research or by knowing that they are not alone in their feelings and experiences in caring for a CWD. The respondents may be seen as a vulnerable group because of possible stigma and discrimination resulting from their association with children with disabilities. The participants remained anonymous at all times throughout the study to eliminate this.

Recruitment procedures

The researcher used a gatekeeper (staff at the centre) to access participants as she was previously unknown to them. Participation was completely voluntary. If potential participants decided to take part having read the information leaflets and signed the consent form they still had the right to withdraw at any time from the study and were informed of this.

Informed consent

Possible participants were provided with information leaflets to consider for 7 to 10 days. Prior to commencing an interview the respondents were reminded of their right to withdraw and that the interviews would remain anonymous. If a participant chose to take part they were required to sign a consent form prior to being interviewed.

Data protection

All data was only accessible to the researcher and was kept secure and destroyed appropriately. TrueCrypt encryption software was used to encrypt data collected. Any information that identified participants was destroyed and soft copies were deleted. Hard copies of data collected were shredded. Consent forms and recorded data are stored securely in the Centre for Global Health in Trinity College Dublin. Translators never had open access to the data, only under the supervision of the researcher. All files will be destroyed after five years.

Trustworthiness

The findings of this study are based on the human experience as experienced by the participants.

Reliability

Considering that this research is qualitative, it cannot be guaranteed that repeating this study would produce the same results.

Validity

Vailidity is the accuracy with which a method measures what it is intended to measure (Whittemore, Chase & Mandle 2001). Processes and steps in the study are detailed and the use of quotes validates the themes identified. Meanings were not extrapolated from data and conclusions were based on evidence. The results are an accurate representation of data developed from a systematic analytic approach. Internal validity referring to the rigour of the study is examined through the use of reflexivity, namely, examining the impact of the researcher being present and the perspective from which they carry out their research. Possible biases which the researcher has taken into account included being a 'Westerner' in a developing country because there may have been an expectation from participants that the researcher could provide assistance in some way.

Discussion

The main objective of this study was to examine the experiences of carers and parents of CWD in Moshi town, Tanzania. A range of findings emerged in the form of five themes: (1) objective challenges, (2) subjective challenges, (3) positive experiences, (4) needs identified and (5) coping mechanisms.

There are a number of insights that this study contributes to the literature:

• Although the demands of care are high, parents do not feel burdened or overwhelmed by their children.

- The parents do not see the child as the problem. It is the inability to provide for the child that creates the most stress.
- Carers have a clear idea of what they need in the present and the future to care for their child.
- Parents do not doubt their parenting abilities.
- In Moshi, objective burden impacts on carers more than subjective burden.

Outline of results

Objective challenges in the form of demands of care, finance and employment emerged. Lack of money for both healthcare and necessities are major challenges. Such lack of finances and experiences of poverty are supported in studies by Hartley *et al.* (2005) and Gona *et al.* (2011) who discuss the financial costs of caring and how external resources are unattainable. The financial issues stem from lack of employment. Lassetter *et al.* (2007) also concluded that mothers are constrained and have no employment. Green (2007) concluded in a study carried out in Florida that objective burden has a greater influence on 'the burden of care' than subjective burden. A large amount of data on financial challenges was collected; there may have been an expectation that the researcher could provide assistance to participants. Objective challenges emerged as one of the most prominent themes within the research, indicating that these issues are experienced regularly.

Emotional or subjective challenges that emerged from the data included rejection, stigma, discrimination, isolation, worry and pity. Rejection by fathers is a major issue which negatively feeds back into decreased job opportunities and increased financial difficulties. Hartley *et al.* (2005) concluded in Uganda that in many cases fathers were absent and mothers were primary carers. Carers described various experiences of stigma from a range of sources. In their study, Mitra *et al.* (2011) found that stigma results in carers being restricted in activities but only three carers referred to this. Most participants showed resilience and determination – they coped with stigma and there were no instances of any participants doubting themselves when they experienced stigma.

Many carers were worried about the future because of a lack of support. Many felt alone and that they were the only ones who understood the needs of their child. High levels of pity reported signify that many members of the community have an understanding that raising a CWD brings with it increased challenges, strains and stresses. On the other hand, it may be also be interpreted as stigma. The National Policy on Disability (NPD) reports high levels of pity, as does this research (Ministry of Labour 2004). Carers identified positive experiences. Lassetter *et al.* (2007) concluded that finding positives posed a challenge to parents of CWD. This was reflected in this research in the delay it took to answer some questions about positive experiences, infact, one interviewee paused and laughed.

The positives discussed by carers in this research were not as 'deep' as those seen within the extant literature, for example, personal growth, increased sensitivity and a less materialistic focus (Hastings *et al.* 2005). However, the positives discovered cannot be discounted. Abbot and Meredith (1986) cited in King *et al.* (2006) identified that positives are found in the small and simple things. This is reflected in this research. One example of a deeper positive experience by these carers, however, is respect. Carers of 'normal' children do not experience the level of respect that carers of CWD do.

In Uganda, Hartley *et al.* (2005) divided support into social and physical support. Nearly all needs identified in this research were of a material or physical nature, such as financial help and access to supplies, which are both objective. This indicates that the objective burden of care impacts on the carers more than the subjective burden. Indeed, when looking at field notes some participants became emotional when discussing objective challenges. A conclusion that can be drawn from the data is that a cause of stress to carers and parents is not being able to meet the material or physical needs of their child.

Divine interventions, sharing of experiences, learning new skills, external support and the search for a cure were identified by Gona *et al.* (2011) as coping mechanisms. The only overlap with this research was external support. A contradiction between this study and Gona *et al.'s* (2011) was participants' sharing experiences. An interesting coping mechanism that emerged was parents remaining logical when people reject them and stigmatised against them. These types of attitudes were not expected given the adversity these carers face.

Coping with objective challenges was difficult. Without money these cannot be minimised and in a low-income country where resources are limited and where services for CWD are few, coping with objective burdens is extremely difficult. The findings of this study confirm some findings of previous research, namely, stigma and isolation are common; the demands of care are high for CWD; financial challenges and employment issues are common; carers use various coping mechanisms to deal with the stresses and strains of having a CWD; support systems make caring for a CWD less stressful; the socioeconomic situation of a family impacts on the ability to provide for a CWD and lack of financial support causes stress.

Practical implications

The findings have practical implications and suggest that the design of support systems and peer support groups should be done taking the experiences of carers into account. Communication between service providers and carers is important so that the needs of CWD are met but also so that the needs of the parents are met.

Limitations of the study

Limitations include the possible failure to establish a rapport with participants in an unfamiliar cultural context. This was mitigated by spending several weeks immersed in the culture.

The translator used for this research was not a professionally trained one, but had proficiency in both English and the local language. A limitation of this, however, could be that at times there were discrepancies in translations. The researcher acknowledges that back translation should be used to ensure congruence between the source and target languages (Yu, Lee & Woo 2004). However, because of limited resources and time constraints back translation was not used in this research.

An additional limitation is that all participants were selected based on their children's, or the children they care for, attendance at day care centres run by BCC. It is not within the scope of this research to document reasons why other carers do not use the services offered by BCC.

The conclusions cannot be extended to well-resourced carers or under-resourced carers in a developed country. The nature of this research is qualitative and as such the results cannot be generalised to a wider population. By having more participants and a wider sample, more themes may have emerged from the data or more insights may have been gained into their situations. A bigger sample may have validated the findings further, however, thematic saturation was reached using the sample size.

Future Research

Further longitudinal studies to validate the findings of this study are recommended.

The use of focus groups in this type of research would provide further insights by providing an opportunity to study the way the respondents collectively make sense of issues.

Recommendations

Solomon *et al.* (2001), cited in Gona *et al.* (2011), identified that a key to coping amongst carers is the building of relationships with others who have the same experiences (i.e. a peer support network). A recommendation from the findings of this research is the setting up of a peer support network for the carers so that they can share their feelings in an open and supportive environment with people who have had similar experiences to them. Furthermore, there needs to be an extension of the hours of care provided by day care centres so that parents have more time to earn a living. Although there are many external factors that may need to be overcome to enable this, it would help carers deal with the financial issues and reduce the needs identified. It is acknowledged that extending the hours of care provided by the centres run by BCC has challenges, namely, additional staffing and operating costs. Setting up of peer networks also has its challenges, namely, finding carers or parents who are willing to be involved at the implementation stage may be difficult.

Conclusion

The objective of this study was to gain an insight into how having a CWD has impacted upon participants' lives, namely, (1) if participants have experienced any negative stigma or discrimination as a result of having a disabled child; (2) if participants experience carer burden and (3) the positive experiences of caring for a CWD. The research followed a qualitative research design using semi-structured interviews. It followed a phenomenological approach that allowed an exploration of how respondents viewed their situation. The research met its objectives and provides some rich insights into the experiences of carers of children with disabilities.

Negative experiences outweighed the positives in concluding the findings. The study was carried out in a low-income country where resources are scarce and people face adversity in their lives every day, apart from raising a CWD. It was found that the objective challenges of caring are more significant than the emotional challenges. The main contributions of this study are that parents are impacted more by objective burdens than subjective burdens. These carers love their children unconditionally and are dedicated to providing the best life possible for them in the face of adversity. They do not doubt their abilities to care for CWD and they do not feel overwhelmed. They simply have needs in terms of objective challenges. This study provides data to support the development of support programmes. A peer support network would be very beneficial, as well as an extension in the hours of care provided by the centres.

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Competing interests

The authors declare that they have no financial or personal relationship(s) which may have inappropriately influenced them in writing this paper.

Authors' contributions

A.M.N. and H.M. were responsible for the project design. A.M.N. carried out the field work, analysis and wrote the manuscript. H.M. carried out the audit and provided conceptual contributions.

References

Anfara, V.A., Brown, K.M. & Mangione, T.L., 2002, 'Qualitative analysis on stage: Making the research process more public', *Educational Researcher* 31(7), 28–38. http://dx.doi.org/10.3102/0013189X031007028

Barbour, R.S., 2001, 'Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?', *BMJ* 322, 1115–1117. http://dx.doi.org/10.1136/bmj.322.7294.1115

Brandon, P., 2007, 'Time away from 'smelling the roses': Where do mothers raising children with disabilities find the time to work?', *Social Science & Medicine* 65, 667–679. http://dx.doi.org/10.1177/0907568209335317

Brannen, J., Mooney, A. & Statham, J., 2009, 'Childhood experiences: A commitment to caring and care work with vulnerable children', *Childhood* 6(3), 377–393.

Davies, M.B., 2007, *Doing a successful research project: Using qualitative or quantitative methods,* Palgrave Macmillan, New York.

Dempsey, I., Keen, D., Pennell, D., O'reilly, J. & Neilands, J., 2009, 'Parent stress, parenting competence and family-centered support to young children with an intellectual or developmental disability', *Research in Developmental Disabilities* 30(3), 558–566. http://dx.doi.org/10.1016/j.ridd.2008.08.005

Denscombe, M., 2002, *Ground rules for good research: A 10 point guide for social researchers,* Open University Press, Buckingham.

Denscombe, M., 2007, *The good research guide for small-scale social research projects,* Open University Press, Berkshire, McGraw Hill.

Folkman, S. & Moskowitz, J.T., 2000, 'Positive affect and the other side of coping', *American Psychologist* 55(6), 647–654. http://dx.doi.org/10.1037/0003-066X.55.6.647

Ghai, A., 2009, 'Disability and the millennium development goals: A missing link', *Journal of Health Management* 1(2), 279–295. http://dx.doi.org/10.1177/097206340901100202

Gona, J.K., Mung'ala-Odera, V., Newton, C.R. & Hartley, S., 2011, 'Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience?' *Child: Care, Health and Development* 37(2), 175–183. http://dx.doi.org/10.1111/j.1365-2214.2010.01124.x

Gray, D.E., 2002, '"Everybody just freezes. Everybody is just embarrassed": Felt and enacted stigma among parents of children with high functioning autism', *Sociology of Health and Illness* 24(6), 734–749. http://dx.doi.org/10.1111/1467-9566.00316

Green, S.E., 2003, 'What do you mean "what's wrong with her?": Stigma and the lives of families of children with disabilities', *Social Science and Medicine* 57(8), 1361–1374. http://dx.doi.org/10.1016/S0277-9536(02)00511-7

Green, S.E., 2007, '"We're tired, not sad": Benefits and burdens of mothering a child with a disability', *Social Science and Medicine* 64(1), 150–163. http://dx.doi.org/10.1016/j.socscimed.2006.08.025

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M. & Chavuta, A., 2005, 'How do carers of disabled children cope? The Ugandan perspective', *Child: Care, Health and Development* 31(2), 167–180. http://dx.doi.org/10.1111/j.1365-2214.2004.00464.x

Hastings, R.P., 1997, Grandparents of children with disabilities: a review. *International Journal of Disability, Development and Education* 44, 329–340.

Hastings, R.P., Beck, A. & Hill, C., 2005, Positive contributions made by children with an intellectual disability in the family: Mothers' and fathers' perceptions, *Journal of Intellectual Disabilities* 9(2), 155-165. http://dx.doi.org/10.1177/1744629505053930

Hastings, R.P., Allen, R., Mcdermott, K. & Still, D., 2002, 'Factors related to positive perceptions in mothers of children with intellectual disabilties', *Journal of Applied Research in Intellectual Disabilties* 15(3), 269–275. http://dx.doi.org/10.1046/j.1468-3148.2002.00104.x

Huang, Y.P., Kellett, U. & St John, W., 2011, 'Being concerned: caregiving for Taiwanese mothers of a child with cerebral palsy', *Journal of Clinical Nursing 21* (1–2), 189–197.

International Labour Organisation (ILO), 2009, viewed 25 April 2011, from http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_111461.pdf.

Ingstad, B., & Whyte, S.R., (eds.) 1995, *Disability and Culture,* University of California Press, London.

Johnson, R.F., O'Reilly, M. & Vostanis, P., 2006, 'Caring for children with learning disabilities who present problem behaviours: A maternal perspective', *Journal of Child Health Care* 10(3), 188–198. http://dx.doi.org/10.1177/1367493506066480

King, G.A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P. & Bates, A., 2006, 'A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrom', *Child: Care, Health and Development* 32(3), 353–369. http://dx.doi.org/10.1111/j.1365-2214.2006.00571.x

Kisler, J. & McConachie, H., 2010, 'Parental reaction to disability', *Paediatrics and Child Health* 20(7), 309–314. http://dx.doi.org/10.1016/j.paed.2010.02.010

Kittay, E.F., 2001, 'When caring is just and justice is caring: Justice and mental retardation', *Public Culture* 13(3), 557–579. http://dx.doi.org/10.1215/08992363-13-3-557

Kittay, E.F., 2005, 'At the margins of moral personhood', *Ethics* 116(1), 100–131. http://dx.doi.org/10.1086/454366

Lassetter, J.H., Mandleco, B.L. & Roper, O.S., 2007, 'Family photographs: Expressions of parents raising children with disabilities', *Qualitative Health Research* 17(4), 456–467. http://dx.doi.org/10.1177/1049732306298804

Lincoln Y.S., 1995, 'Emerging criteria for quality in qualitative and interpretive research', *Qualitative Inquiry* 1(3), 275–289. http://dx.doi.org/10.1177/107780049500100301

Lincoln, Y.S. & Guba, E.G., 1985, *Naturalistic enquiry*, Sage Publications, Inc., Newbury Park, California.

McMahan, J., 1996, Cognitive disability, misfortune and justice, *Philosophy and public affairs* 25(1), 3–35.

Ministry of Labour, Youth Development and Sport, 2004, National policy on disability, United Republic of Tanzania, viewed 27 April 2011, from http://www.tanzania.go.tz/pdf/NATIONAL%20POLICY%20ON%20DISABILITY.pdf

Mitra, S., Posarac, A. & Vick, B.C., 2011, 'Disability and poverty in developing countries. A snapshot from the World Health Survey', *SP Discussion Paper*, Social Protection and Labor, The World Bank. http://dx.doi.org/10.2139/ssrn.1908128

Morse, J.M. & Field, P.A., 1995, *Qualitative research methods for health professionals,* Sage, London.

Pelchat, D., Lefebvre, H. & Perreault, M., 2003, 'Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability', *Journal of Child Health Care* 7(4) 231–247. http://dx.doi.org/10.1177/13674935030074001

Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., Wang, M. & Taylor, S.J., 2003, Family quality of life: A qualitative inquiry, *Mental Retardation* 41(5)**,** 313–328,392. http://dx.doi.org/10.1352/0047-6765(2003)41<313:FQOLAQ>2.0.CO;2

Rehm, R.S. & Bradley, J.F., 2005, 'Normalization in families raising a child who is medically fragile / technology dependent and developmentally delayed', *Qualitative Health Research* 15(6), 807–820. http://dx.doi.org/10.1177/1049732305276754

Resch, J.A., Mireles, G., Benz, M.R., Grenwelge, C., Peterson, R. & Zhang, D., 2010, 'Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities', *Rehabilitation Psychology* 55(2), 139–150. http://dx.doi.org/10.1037/a0019473

Rudestam, K.E. & Newton, R.R., 2007, *Surviving Your Dissertation. A Comprehensive Guide to Content and Process*, Sage Publications, London.

Stebbins, R.A., 2001, *Exploratory research in the social sciences*, Sage Publications, London.

Swartz, L. & Watermeyer, B., 2008, 'Cyborg anxiety: Oscar Pistorious and the boundaries of what it means to be human', *Disability and Society* 3(2), 187–190. http://dx.doi.org/10.1080/09687590701841232

Taunt, H. & Hastings, R., 2002, 'Positive impact of children with developmental disabilities on their families: A preliminary study, *Education and Training in Mental Retardation and Developmental Disabilities* 37, 410–420.

Tronto, J., 1993, *Moral boundaries; A political argument for the ethics of care*, Routledge, London.

Watermeyer, B., 2009, 'Claiming loss in disability', *Disability & Society* 24(1), 91–102 http://dx.doi.org/10.1080/09687590802535717

Whittemore, R., Chase, S.K. & Mandle, C.L., 2001, 'Pearls, pith and provocation: Validity in qualitative research', *Qualitative Health Research* 11(4), 522–537. http://dx.doi.org/10.1177/104973201129119299

Whyte, S.R., 1991, 'Family experiences with mental health problems in Tanzania', Acta Psychiatrica Scandinavia 83(364), 77–111

Yu, D.S.F., Lee, D.T.F., & Woo, J., 2004, 'Issues and challenges of instrument translation', *Western Journal of Nursing Research* 26(3), 307–320. http://dx.doi.org/10.1177/0193945903260554