

CAREGIVER BURDEN AS DEPICTED BY FAMILY CAREGIVERS OF PERSONS WITH PHYSICAL DISABILITIES

Noreth Muller-Kluits, Ilze Slabbert

A significant number of people live with some or other form of impairment. These people often need someone to take care of them, the practice being known as caregiving. It is usually family members who assume the role of caregiver and they often experience the caregiver burden. The goal of this study was to explore and describe the caregiver burden as experienced by family caregivers of persons with physical disabilities. A qualitative study of an explorative descriptive nature was undertaken. Seven themes were identified regarding the caregiver burden, and relevant conclusions were drawn and recommendations made.

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INTRODUCTION

Most people will experience a form of impairment or disability (either temporary or permanent) in their lifetime (Hartley, Ilagan, Madden, Officer, Posarac, Seelman, Shakespeare, Sipos, Swanson & Thomas, 2011:3). Impairment in various forms could happen at any given moment: a baby is born with Down's syndrome, a soldier loses a leg in battle, or a person suffers a stroke and is left paralysed down one side. Kress and Herridge (2012:340) in their study added another physical disability in the form of a critical illness. This condition can persist for years or even a lifetime, requiring continuous assistance from family caregivers.

In 2011 the World Health Organisation estimated that around 10% of the world's population of around 700 million people live with some form of disability. Disability not only affects the person concerned, but also has an impact on the support network, i.e. friends and family. When a family member has a disability, whether physical disability, a psychological illness, chronic or life-threatening illness, care is generally provided by the family.

Blanes, Carmagnani and Ferreira (2007:401) found that about 90% of persons with chronic diseases are cared for by relatives, who generally live with the patient. The authors refer to a study by De Vivo and Fine (1985:501–504) of persons with spinal cord injuries (SCI), where it was found that the caregiver spends an average of 11,3 hours per day caring for the person with SCI and is also responsible for housekeeping tasks and the care of other dependent family members. The several challenges faced by the caregivers are collectively known as the caregiver burden, an umbrella term used to describe the physical, emotional and financial responses of a caregiver to the challenges and demands of providing help to a person with a disability (Jeong, Myong & Koo., 2015:619; Pangalila, Van den Bos, Stam, Van Exel, Brouwer & Roebroek, 2012:988).

Scholte, Reimer, De Haan, Rijnders, Limburg and Van den Bos (1998:1605-1611) observed that the burden of caregiving was described as entailing feelings of heavy responsibility, uncertainty about the patients' needs, constant worries, constraints in the caregivers' social life, and perceptions that patients rely exclusively on their care. Goldner and Drentea (2009:499) investigated the impact of caregiving on the caregiver and stated that most research shows that family caregivers often suffer negative outcomes. Another factor was that raising and taking care of a child with a physical disability is a full-time responsibility that either requires one of the parents to stay home or to hire a private caregiver. Again, the authors (Goldner & Drentea, 2009:499) emphasised the importance of analysing the effects of caregiving on the caregiver, to understand how disability affects the entire family, not just the person who is disabled.

There is a great need for more research on the caregiver burden in order to provide social workers with greater insight into the phenomenon and enable them to render more efficient services. This study aims to investigate the burdens experienced by family caregivers of persons with physical disabilities.

PROBLEM STATEMENT AND FOCUS

In the past many research studies have investigated the challenges of persons with disabilities, but not many placed much emphasis on the family members who care for them. This research study will focus on the caregiver burden caused by some of the challenges facing the family caregivers of persons with physical disabilities. The NEXUS research database (Nexus, 2016) lists fewer than ten research studies done in the past 10 years with a similar focus on the challenges facing family caregivers of persons with physical disabilities.

Because of the lack of relevant previous studies, it is evident that there is a gap in the research field. A study of this nature is therefore beneficial in enabling the social work profession to gain a better understanding of the experiences of family caregivers of persons with physical disabilities. Families often continue to take care of the person with the disability throughout their lifetime. Parents, professionals as well as academic researchers have claimed that families of children with disabilities face unique burdens because of their children's disabilities (Leiter, 2004:6).

Blanes *et al.* (2007:401) found that caregivers of persons with paraplegia included the spouses (26,6%), but also sisters (23,4%) and mothers (18,3%). For this study the focus will be on adult family members (whether a parent or another family member) who take care of the person with the physical disability. The person with the disability could thus be a child, adult child, spouse or sibling. By understanding the challenges, and essentially the caregiver burden, of families caring for a person with a disability, service providers can identify areas for improvement in the delivery of disability services and the development of new strategies to support caregivers in their required roles (Murphy, Christian, Caplin & Young, 2007:184). The research question of this study is: "What are the caregiver burdens portrayed by family caregivers caring for persons with physical disabilities?"

CAREGIVER BURDENS EXPERIENCED BY FAMILY CAREGIVERS CARING FOR PERSONS WITH PHYSICAL DISABILITIES

Most parents eagerly anticipate the birth of a healthy child. Because of this expectation, an initial diagnosis of disability is seen as the shattering of an ideal. Parents and other family members may experience a range of feelings once confronted with the significant change stemming from someone close to them having a disability (Ross & Deverell, 2010:36).

Family caregivers operate as extensions of health-care systems (performing complex medical and therapeutic tasks as well as ensuring adherence to therapeutic programmes). However, they usually do not receive adequate training, preparation or ongoing support from these systems. The responsibilities of caregiving, as well as the lack of preparation, guidance and support, erode their physical and emotional health as well as their financial resources (Elliott & Pezent, 2008:2).

Informal care is usually seen as an efficient and cost-effective way of caring for people with disabilities. However, exclusive reliance on informal support can have significant consequences for caregivers, including compromised health-related quality of life such as post-traumatic stress disorder, emotional distress, caregiver burden, depression and anxiety (Elliott & Pezent, 2008:2; Kress & Herridge, 2012:341).

Reichman, Corman and Noonan (2008:680) conducted a study that focused on the impact of child disability in general on the family. A child with a disability often requires caregiving throughout life and thus also in adulthood. Although the type and the severity of the disability would have a specific impact on the family, the researchers noted some general experiences found to be true in most cases that concern a child or adult with a disability.

Financial burden on family caregivers

According to Reichman *et al.* (2008:680), one impact of having a child with a disability in the family concerns the financial effects on the family. Families may experience difficulties in finding appropriate and affordable child care, the out-of-pocket costs of medical care and other services may be substantial, and they might have to rely on public support. As indicated before, caring for a child with a disability is often a life-long commitment, obviously having huge financial implications.

Negative emotional experiences

Families may experience guilt, blame or reduced self-esteem (Reichman *et al.*, 2008:680). Other emotions include ambivalence, anger, denial, depression, embarrassment, fear of stigma, grief, shock and even withdrawal. These feelings can emerge with the sudden realisation that the anticipated 'normal child' they had expected for nine months is quite "different". Because of their child's

disability, parents may harbour an enduring sense of loss. However, some parents show greater tolerance of these stressors than others (Gull & Nizami, 2015:144). Family members may have negative reactions such as stress, resentment, depression, ambivalence, anger, denial, depression, embarrassment, fear of stigma, grief, guilt, shock and withdrawal (Gull & Nizami, 2015:144; Goldner & Drentea, 2009:499; Reichman *et al.*, 2008:680).

Feelings of guilt

Research conducted by Trollope (2013:9) focused on raising a child with a mental disability. That study found that parents could struggle with feelings of guilt. One or both parents blamed themselves for the child's disability either as a result of genetics, alcohol use, stress, accidents or other logical or illogical reasons. Such feelings of guilt can affect the parents' emotional health, if they are not properly dealt with. Furthermore, some parents may struggle to find reasons for the disability ("why?") and experience a spiritual crisis or even blame each other. Lastly, parents may also experience severe disappointment in view of any aspirations they might have had for their child.

Stress

Reichman *et al.* (2008:680) suggest that having a disabled child and having to provide lifelong care may increase stress and take a toll on the mental and physical health of parents. The demands of caring for a person with a disability often result in stress for families, particularly for women, who tend to be responsible for domestic chores, which would then have to be balanced with caretaking (Hartley *et al.*, 2011:142). Modifying factors of caregiver stress include the characteristics of the caregiver (e.g. age, marital status, coping ability), characteristics of the recipient (e.g. the degree of disability), the shared history (relationship) between the caregiver and the person being cared for, social factors (e.g. access to social networks and social support), economic factors (e.g. socio-economic status, ability to access formal care, employment), and cultural context (Parminder, O'Donnell, Rosenbaum, Brehaut, Bin & Wood, 2005:627).

These factors suggest that stress occurs across a broader context than merely caring for a child with a physical disability (Parminder *et al.*, 2005:627). Primary caregivers – usually the parents – are under continuous stress to maintain their child's health and wellbeing. This poses an increased risk and may exacerbate feelings of uncertainty over child health outcomes, daily difficulties associated with medical regimens, social isolation, role restrictions and financial strains. Caregivers also described the need to repeatedly advocate for their child with a disability as another major source of stress (Shanbhag and Krishanmurthy, 2012:36; Murphy *et al.*, 2007:184).

Experiencing burn-out

Murphy *et al.* (2007:184) observed that many caregivers occasionally experience burn-out, which has been described as overwhelming feelings of despair with no end in sight. They stated that many caregivers felt they lacked control over their daily activities. Caregivers reported that they had too little time to complete daily tasks and were worried that they were not meeting the needs of other family members. In general, caregivers indicated high levels of stress. There is also evidence to show that most caregivers are ill-prepared for their role and provide care with little or no support, which could also lead to burn-out (Dawson, Balloch & Moore, 2011:115).

Feelings of depression

Caregivers who experience problems with depression and too heavy a burden may be more likely to institutionalise dependent family members. Depressed caregivers may display potentially harmful and abusive behaviours toward care recipients (Elliott & Pezent, 2008:2). Caregivers perceive in-home support services negatively because of feelings of inadequacy and loss of environmental control. Family members often experience depressive symptomatology in caring for stroke survivors (who may have a physical disability as a result of the stroke), with rates ranging from 34% to 52% or even higher in the first three months after return to the community (Grant, Elliott, Weaver, Glandon, Raper & Giger, 2006:343).

Caregivers' health issues

Caregivers often place a low priority on their own health compared to that of their children with disabilities and their other family members. Cantwell, Muldoon and Gallagher (2014:2220) pointed out that previous research had linked the stress of caring for children with developmental disabilities with parental mental health outcomes. They contended that parents' physical health would also be influenced by factors such as poor sleep, greater risk of hypertension, arthritis, increased headaches and higher rates of infection.

Murphy *et al.* (2007:184) found that the caregivers who participated in their study tended to rank their own health needs as the lowest priority and indicated that most of their time and effort was vested in caring for other family members. Almost all the participants in their study had experienced chronic fatigue and sleep deprivation. Most caregivers described one or more chronic physical ailments that they attributed directly to the long-term effects of caregiving.

In general, participants in the study by Murphy *et al.* (2007:184) observed that their physical challenges were more demanding when their child was young, but that their own health suffered more when the child got older. Approximately 60% of the caregivers reported difficulty in performing daily work because of their own poor physical health, whilst slightly more than 50% had experienced moderate to severe physical pain within the preceding four weeks. Several older caregivers reported that they had developed osteo-arthritis because of years of caregiving.

Caregivers run a great risk of becoming ill themselves. High rates of insomnia and depression, serious illness and lack of preventive health measures have been detected in caregivers. Caregivers with compromised health, such as evident in their own physical or psychological limitations, may find it more difficult to complete caregiving tasks (Collins, Swartz, College & Jefferson, 2011:1309-1317). Murphy *et al.* (2007:184) found that caregivers identified several barriers to promoting their own health. These included lack of time, not enough respite hours, a dearth of qualified alternative care providers for the patient, and low prioritisation of their own needs, all contributing to poor health.

RESEARCH METHODOLOGY

The goal of this study was to explore and describe the caregiver burden experienced by family caregivers caring for persons with physical disabilities. A qualitative study was conducted to achieve this goal. The qualitative approach provided the research study with comprehensive information from participants about their experiences and challenges (Drisko, 2013:1). According to De Vos, Strydom, Fouché and Delpont (2011:95-96), the aim of an exploratory research design is to gain insight into a phenomenon, situation, community or individual. In this study the challenges that family caregivers experienced were explained by conducting a literature review and collecting data from participants who met the criteria for inclusion. A descriptive research design can be described as a more intensive analysis of phenomena to build up a more comprehensive description (Rubin & Babbie, 2005:125). This study offers a clear description of the characteristics of the caregiver burden as conveyed by the participants.

The sample consisted of 20 participants, with whom interviews were conducted. The method of sampling was purposive sampling, which necessitated a clear definition of the population and the intended sample (Given & Munhall, 2008:799). One of the participants was identified through snowball sampling, which is usually used when there is limited access to appropriate participants (De Vos *et al.*, 2011:233). The method of sample selection entailed first obtaining permission from an organisation that delivers services to persons with disabilities and their families, and asking them to identify possible participants. For this study the sample universe included all the family members of persons with disabilities. The population consisted of family caregivers of persons with a disability, as identified by an organisation in the Cape Town area.

The criteria for inclusion for the sample were the following: every participant had to be

- a family caregiver of a person with a physical disability (who could be a child or an adult);
- caring for a person with a physical disability not as a result of old age;
- living in the Cape Town area;
- able to understand and speak either Afrikaans or English.

The data collection was done by means of a semi-structured interview schedule. This instrument, according to De Vos *et al.* (2011:352), is mainly used to gain a sense of the participant's perception of the research topic at hand. A voice recorder was used to tape the interviews after consent from participants was obtained. These interviews were then transcribed. Field notes were also made during interviews to assist the researcher with the analysis of interviews. This research study made use of the denaturalistic method of transcribing, where unique elements of speech such as pauses and non-verbal factors were removed (Oliver, Serovich & Mason, 2005:1273).

The study ensured that data collected were verified as described by De Vos *et al.* (2011:419), who stated that credibility and authenticity, transferability, dependability and conformability must be taken into account when establishing the integrity of the qualitative research that was done in this study.

Babbie (2007:378) describes qualitative data analysis as a non-numerical analysis and interpretation of observations to discover underlying meanings and patterns of relationships. This study collected the information from the different interviews and identified the main discussion points (themes) as well as the differences and connections between the different participants' answers. The data were categorised into themes and sub-themes.

DISCUSSION OF FINDINGS

The contents of the interviews were analysed and seven themes emerged relevant to the caregiver burden as experienced by the caregivers taking care of a person with a physical disability.

Theme 1: Physical health issues

Reichman *et al.* (2008:680) state that having a disabled child and having to be responsible for lifelong caregiving may increase stress and take a toll on the mental and physical health of parents (and other family caregivers). Some of the participants echoed this view:

"I'm worried about myself because really I've been warned about all these things. This thing is working on me, but the only thing that the counsellor said ... the last thing they don't want is for me to get a stroke because if I get a stroke, who's going to take care of us." Participant 4

"From the time he was born I have been up every single night. Sometimes two to three times an hour." Participant 20

"When she got bigger, I mean obviously, you know, she was gaining weight, it is heavy on our backs." Participant 15

Murphy *et al.* (2007:184) found that caregivers tend to rank their own health needs very low as they focus on caring for the person with the disability. Caregivers in this study reported chronic fatigue, sleep deprivation, chronic physical ailments, shoulder pain and lower back pain. This is in line with some of the experiences of the participants with regard to their own physical health, including back problems, insomnia and general difficulty with regard to the physical strain of taking care of an (adult) family member with a disability. Most of the participants were taking care of an adult family member with a physical disability.

Theme 2: Personal isolation

Family caregivers who experience positive (social) interactions when raising a child (or caring for a family member) with special needs have been found to have greater parenting wellbeing, which in turn also had an effect on the person with the disability whom they were taking care of (Qayyum, Lasi &

Rafique, 2013:132). Most participants indicated that since having the added responsibility of taking care of a person with a physical disability, they were not able to “go out” as much as before, which could put them at risk of feeling complete personal isolation if they did not have other means of support:

“I can’t go out any more because I am cautious now that that my child is at home. I can’t leave him alone. I can’t stay away long ... because I’m worried about him.” Participant 2

“Well, I realised that I can’t go out as I like any longer ... uhm ... my hours are curtailed, yes ... and then I realised that I will have to depend on someone if I want to go out, to ask them just to look after him.” Participant 13

Qayyum *et al.* (2013) noted the isolation that family caregivers often experience because of a 24-hour commitment to their task. This closely relates to the next theme, namely the lack of respite services.

Theme 3: Lack of respite services

In a study by Murphy *et al.* (2007:184) parents of persons with disabilities identified several barriers to accessing resources. Obstacles included lack of time, lack of respite hours, lack of qualified alternative care providers and low prioritisation of these needs. Some parents with young children were reluctant to use respite care, because they considered it their responsibility to look after their children themselves, and were reluctant to involve other people in the caring (Mannan, O’Brien, McConkey, Finlay, Lawlor & Harrington, 2011:43). It was also common for caregivers to use respite hours to care for other family members rather than to restore themselves (Murphy *et al.*, 2007:184). Many participants in the current study felt that they did not have the time to break away from their caregiving responsibility or to have some time for themselves:

“It’s difficult. The thing is you don’t have your time. I don’t have ‘my time’ ... I can never just go out and have coffee somewhere. Even if I go somewhere, I must be rushed ... I must always make sure that I am here. If I’m not here, if I’m at work.” Participant 4

“If someone could just relieve me maybe...” Participant 17

Dingana (2012:115-122) reported that caregivers of people with physical disabilities needed more time for themselves. Some caregivers in this study expressed a wish for extra help to relieve the strain of caregiving. They wished to have day-care centres, where they could take their grown-up children, which could afford them some time to do what they wanted to do. According to the Integrated Service Delivery Model of the Department of Welfare, community-based support services should provide sufficient support to the family caregiver(s) (Department of Social Welfare, 1997).

Theme 4: Employment of caregivers

Owing to the time-consuming responsibility of taking care of a family member with a disability, family caregivers may have to reduce or completely give up their paid employment, leading to financial challenges (Hartley *et al.*, 2011:142). About half of the participants were not employed at all. Some of them were unemployed because of their responsibilities as caregivers. They could not make any other provisions in taking care of their charge, because of the lack of assistance with long-term care, recreational activities/groups or disability-friendly employment. Some participants gave up their jobs once they took on the caregiving role:

“I had to give up my job to take care of him. It was a big sacrifice because it was an extra income that fell away.” Participant 7

“I worked but that was in the time my mum was ill ... and then after she died, I had to leave my work ... I can’t work right now because who will take care of her ... I worked at a printing company in Montague Gardens ... and now in this time there were many opportunities in employment that I had to decline ... even if I wanted to take it ... but I can’t. I don’t have a choice.” Participant 8

These findings correspond with those of Collins *et al.* (2011:1309-1317), namely that many (family) caregivers adjusted their work schedules to meet their caregiving responsibilities. This could have financial implications such as a loss of salary and benefits, loss of promotional and training opportunities, and a reduction in retirement savings, which will be discussed in the next theme.

Theme 5: Financial issues

As discussed, a lack of employment for both the caregiver and the person with a disability could put extra financial strain on the family. With caretaking, there is additional spending including acquiring assistive devices, special diets or personal care and assistance. The caregiving may also last a lifetime and money might have to be put aside in a trust fund to ensure the proper care of the person with a disability, should the family caregiver pass away (Trollope, 2013:9). Participants indicated several financial issues they faced, such as medical services and equipment expenses, school-related expenses, specialised transport expenses and just general financial struggles, especially if they were the main income provider:

“The difference is that I am struggling. I’m struggling financially...” Participant 4

“Yes, but it is a lot of money ... we did some research the other day about wheelchairs ... and we found that the one that he can ride without help ... that was almost R24 000.” Participant 2

“She was in a school but only for two months ... financially we could not keep it up.” Participant 8

“His hearing aid has been broken for a while now ... and his hearing aid is R50 000. I do not have R50 000 to get him another hearing aid.” Participant 14

For most of the participants in this study the lack of finances was a definite barrier in caretaking, especially for those who were not employed. The financial struggles created a secondary issue, namely an inability to access certain services. Parents might not be able to pay for private (special) education, would need to make use of public medical facilities and public transport, and would most probably not be able to put money away in a trust fund for the child (Trollope, 2013:9). There are also several obstacles within the public school, health and transport system for persons with physical disabilities.

Theme 6: Emotional health issues

Emotional health issues might emerge as an initial response to the realisation that a new role of caregiving has started. Emotional health issues could also arise from the long-term effect of caring for a family member with a physical disability, also known as informal care. Informal care is usually seen as an efficient and cost-effective way of caring for people with disabilities, usually carried out by family members such as in this study. This, however, could have adverse consequences for caregivers, including compromised health-related quality of life – for example, post-traumatic stress disorder, emotional distress, caregiver burden, depression, and anxiety (Kress & Herridge, 2012:341; Elliott & Pezent, 2008:2).

A number of participants had negative experiences and/or emotions when they realised their new role in caring for a family member with a physical disability. As time went by, however, some could reflect on positive emotions as well. However, some participants struggled with their own emotional wellbeing throughout, such as dealing with depression:

“When [person with a disability] went to [school’s name], I actually had like a uhm ... depression. I actually had a breakdown. And for the first time in my life I had to go onto tranquilisers. And I am not one of those people.” Participant 20

Ross and Deverell (2010:36) found that parents’ initial reactions to their child’s disability were likely to be negative, and similar to those related to grief. Grief is the process whereby one can separate oneself from someone or something that has been lost. Ross and Deverell state that there are nine phases of

grief when parents find out their child (or other family member) has a disability. These nine phases were adapted from Kübler-Ross's (1972) original five stages of grief (Clifton, 2014; Ross & Deverell, 2010).

Theme 7: Giving up on one's own aspirations (caregiver)

Gull and Nizami (2015:144) point out that parents usually have high aspirations and dreams for their children and, upon discovering that there are some anomalies with their child, this vision may be suppressed and different emotions may be experienced. The participants in this study did not focus much on this aspect as they seemed to have accepted their child's condition after the initial shock was over. Some participants (mostly sibling caregivers) spoke about how their caregiving role meant that they had to give up on their own dreams and aspirations and that they still struggled to come to terms with the situation:

"It hurts a lot ... because ... I'm still very young. I am only 26 years old and there are still many things I wanted to achieve but at this point I cannot achieve them." Participant 8

"It put a responsibility on my shoulders for the rest of my life. I ... will never do what I really want to do." Participant 18

Having to give up their own dreams and aspirations could lead to family caregivers feeling "an anger turned inward", which in turn could lead to their feelings of depression about their circumstances (Ross & Deverell, 2010:37).

IMPLICATIONS AND CONCLUSIONS

Participants in this study seemed to experience various degrees of the caregiver burden. Throughout the interviews with participants, it became evident that most participants struggled with physical, emotional, financial and social issues. The lack of long-term care for their family member with a physical disability formed part of their caregiver burden. Although there were specialised schools that could be accessed by the participants' family members, the main challenge was encountered when the family member was older than school-going age. The lack of help with long-term care led to other issues such as worrying about the future of the person with a disability, limiting the family caregiver in finding employment opportunities, which in turn could lead to greater financial strain, as well as affecting the family caregiver's health.

The small sample for this study is a limitation, although rich data were obtained. The small houses of some of the participants, where the interviews took place, and the lack of privacy were also a challenge as some participants could not share their experiences openly. Despite this, rich data could still be obtained as is evident in the seven themes.

RECOMMENDATIONS FOR FUTURE STUDIES

- A pilot study should be conducted for future studies to identify possible pitfalls in the study before the bulk of the interviews are done.
- Owing to the lack of previous research on the caregiver burden, it is recommended that more similar studies be conducted.
- Although studies on general feelings of negativity in family caregivers would be useful, it is recommended that a specific focus be placed on addressing the stages of grief and the relation each stage has to the feelings experienced by family caregivers.

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