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Research Paper

Assessment of experiences of survivors of cerebro-vascular accidents and their caregivers functioning at home in the Oshana region of Namibia

Suama W Kuugongelwa [1]*, Louis F Small [1]

[1] *Institution: University of Namibia, Private Bag 13301; Windhoek; Namibia*
**Corresponding author E-mail: skuugongelwa@unam.na*

Abstract

In the wake of a cerebro-vascular accident, survivor and caregiver are often apprehensive about being on their own at home; this is particularly so for those living in low socioeconomic circumstances in the rural areas of Namibia. The situation is aggravated by the fact that there is no structured system of home visits by health workers that could assist caregivers in their daily tasks. Phenomenological interviews were therefore conducted to explore how these caregivers cope with providing home care to the survivors of such accidents. The findings that emerged were categorised into four themes, namely, survivors were unable to provide self-care and were dependent on others for help, the altered role function and performance of survivors, negative emotions because of altered self-esteem, and disrupted social interaction. These experiences together illustrate that some survivors are unable to take care of themselves at all and depend completely on their caregivers for help.

Keywords: *Caregivers; Cerebro-Vascular Accident; Functioning; Home-Care, Survivors.*

1. Introduction

A cerebro-vascular accident is one of the diseases that often lead to extensive disabilities in terms of which the afflicted person experiences varying degrees of self-care deficits. Consequently, assistance is required with the activities of daily life. In Namibia, this assistance is generally rendered by the extended family, as facilities for persons with impaired mobility and chronic diseases are not readily available and, even if they are, are not always affordable (Ministry of Health and Social Services, 2005). In the Oshana region of Namibia, the focus of this study, approximately 66 new cases of cerebro-vascular accidents were reported in the Oshakati Intermediate Hospital between April 2009 and February 2010. Of these, 23 cases were male and 43 female (Ministry of Health and Social Services, 2009–2010). All of these cases receive home-based care.

The phenomenon of home-based care is not new and, for the survivors of cerebrovascular accidents (referred to from now on only as survivors), is becoming an increasingly common practice, with these patients spending a significant portion of their recovery at home. As a result, informal caregivers, who are generally individuals with no formal health education, provide more complex care for longer periods than ever before (McCann & Christiansen, 2004; Smit, Forster, & Young, 2004; Rodgers, Bond & Curless, 2005). This situation also prevails in Namibia.

Today's health care environment has high expectations of the caregiver, particularly when they are a family member. For many survivors of cerebro-vascular accidents, it can happen that the only caregiver available is a fragile spouse or elderly family member who is overwhelmed by health problems of their own (Fjaertoft, Indredavik, Johnsen, & Lydersen, 2004). Therefore, caring for a person with a cerebro-vascular accident can have a detrimental effect on the caregiver's health, possibly leading to the health service having to respond to their needs as well (Low, Roderick, & Payne, 2004; Ritcher & Peu, 2004). In Namibia, culture dictates that the care of the ill is a responsibility that is anticipated by family members.

2. Purpose

The purpose of the study was to explore and describe the experiences of survivors of cerebrovascular accidents and their caregivers at home in order to develop a home-based programme to facilitate optimal functioning.

3. Study design and methods

A qualitative, explorative, descriptive and contextual study was conducted. The population consisted of two groups: the survivors, who had been receiving home-based care for at least six months, and the caregivers, who could be a spouse, a parent, a child or other relative.

A sample of eight cases comprising a survivor and a caregiver in a home setting was purposefully selected. The sampling criteria used for this study were the participants' context and the language of communication, which was the participants' mother tongue. This was important in order for participants to be able to express and discuss their experiences relating to functioning effectively at home. The survivors of cerebrovascular accidents who had been discharged from hospital and had been at home for six months or longer and their caregivers were chosen because they had had

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more exposure to the challenges of optimal functioning at home. For the purposes of data collection, it was decided to select this population in order to verify the assumption that they were supposed to have adjusted their daily routines despite the difficult transitions they had experienced.

The survivors' details were obtained from the patient records after discharge. From the records it was possible to obtain information on the survivor's name, home address or village, region, and the date on which he or she had been discharged. The identified survivors and their caregivers were visited and the whole study process was explained.

The data were collected using in-depth interviews until saturation point was reached (Streubert-Speziale & Carpenter, 2007). The interviews were conducted in a quiet place in the individual homes where no interruptions could take place. The best time for these interviews was arranged with the participants prior to the interview so that the family's daily activities were not disturbed. Participants were thus given the opportunity to make arrangements in advance. One central question was posed to the survivors and one to the caregivers. The survivors were asked how they experienced the disability (cerebrovascular accident), and the caregivers were asked how they experienced caring for the survivors.

The analysis of the data was done according to Tesch's method of qualitative data analysis (Creswell, 2008). This method comprises the transcribing of all transcripts, whilst focusing on the lived experiences of the survivors and their caregivers at home. The data collected were first analysed in the vernacular language used by the participants. The data were coded and organised until applicable themes emerged (Guba & Lincoln, 1990). During the process of data analysis the researcher also used a co-coder to assist with the analysis of the narrative experiences, that is, the stories of the survivors of cerebro-vascular accident and their caregivers at home. The co-coder in this study was an advanced medical-surgical nursing practitioner with additional knowledge in the field of qualitative research.

3.1. Ethical considerations

Approval for conducting the research was obtained from both the research committee of the Ministry of Health and Social Services and the Oshana Health and Regional Council offices.

The survivors' and their caregivers' informed consent was obtained, and these participants were given a statement of the research purpose. They were also informed about the benefits of the study. Aspects of anonymity, privacy and confidentiality were explained. Detailed contact information was provided for this purpose. They were also given the option to discontinue participation at any time.

4. The results

The findings of the study revealed negative experiences among both the survivors and the caregivers. Four themes emerged from the data. The first theme relates to the physical challenges experienced by the survivors. These physical challenges are characterised as an inability to self-care after a cerebro-vascular accident and the resulting disability and the dependency on others for help. The second theme is also related to the survivors only and is concerned with the experiences of their altered role function and performance. The third theme refers to both the survivors and the caregivers and relates to experiences of disrupted social interaction because of disability. The fourth theme is also related to the survivors only and pertains to the negative emotions experienced because of altered self-esteem.

5. The discussion of the results involved

Theme 1: *The survivors of cerebro-vascular accidents experience an inability to self-care and dependency on others.*

As the literature shows, a cerebro-vascular accident is a devastating experience; those who survive the initial incident suffer from a variety of physical disabilities. This type of affliction creates a condition whereby an adult becomes incapable of or limited in the provision of continuous effective self-care (McLean, Roper-Hall, Mayer, & Main, 2006). Accordingly, the survivors talked about their difficulties in carrying out of the activities of daily living, such as dressing, bathing, feeding, toileting, grooming and transfers from bed to chair and in and out of the bath. This is evidenced by the following response by one the participants.

"I don't have much of a life right now. I sit here in this chair waiting till I get well enough to get out and start doing something. Right now it is my wife who is bathing me, dressing me, feeding me, getting me in and out of bed, and also transferring me from the bed to this wheelchair".

The study also found that some survivors are unable to take care of themselves at all and depend completely on their caregivers for help. The observational data collected on the survivors also indicate that they struggle to establish routines in their day, not only for mobility but also for other self-care functions that a person must be able to perform in order to be independent. In concurrence with claims made by previous studies, the inability to self-care experienced by the survivors in this study is accompanied by perceptions of loss of independence, in that survivors have to ask others for help (Rittman, Haircloth, Boylstein, Gubrium, William, Van Puymbroek, & Ellis, 2004; Doolittle, 2003; Becker, 2004; McLaughlin, 2002; Van Excel, Scholte, Brouwer, Van der Berg, Koopmanschap, & Van den Bos, 2004).

Not being able to practise the activities that individuals personally initiate and perform on their own behalf in maintaining life, health and wellbeing, the survivors of cerebro-vascular accidents feel dependent on others, which consequently compels them to request help from others. Therefore, Charmaz (2005) maintain that informal caregivers provide health services in the home in order to promote restore and maintain a person's maximal level of comfort, function and health. In addition, the caregivers in this study indicated that survivors become incapable of or limited in the provision of continuous effective self-care, as evidenced by the following statement:

"We cannot leave her alone at home. I am doing almost everything for her. I am always at her side because she is being helped out with bathing, eating and toileting and of course she needs someone to give her company".

Another issue, as illustrated in the above statement cited by one of the caregivers, centres on the constancy of care: on the one hand the caregivers were concerned about the survivors' inability to take care of themselves and, on the other, they demonstrated their dedication by being available to meet the survivors' needs, which subsequently led to a disturbance in the sleeping patterns of both the survivors and caregivers. Additionally, this study revealed that the caregivers stay awake during the night because of concerns about what will happen to the survivors and also to be available as the survivors may need them, thus caregivers are present all the times.

In this regard, the literature cautions that the impact of caregiving on the caregiver is most notable during the night (Baumgarten, Battista, Infante-Rivard, Hanley, Becker, & Gauthier, 2006). In addition to increased fatigue, caregivers are challenged with fears and concerns that may in turn lead to sleep disturbances. Besides the physical effects, Brosseau, Raman, Fourn, Coutu-Walkulzyk, Tremblay, & Pham, (2007) maintain that the psychological effects of sleep deprivation may result in exhaustion, incoherence and disorientation. The following statements are the evidence of this:

"I have to be there almost every time even at night time, not because I am saying she expects it from me, I just worry about her. Yes, it has affected my sleeping pattern".

"I wake up all the time during the night, just in case he may need help".

It is therefore obvious that the caregiver may develop fatigue which can hinder the care-giving role.

Theme 2: *The survivors' experience of altered role function and performance related to their disabilities after a cerebro-vascular accident*

Analogous studies have found that cerebro-vascular accidents contribute directly to changes in family relationships; this often results in feelings of powerlessness. In addition, role reversal commonly occurs, with the spouse and children taking on many of the survivor's previous roles and tasks. At the same time, survivors take on a more dependent role within the family (Duncan, Zorowitz, Bates, Choi, Glasberg, Graham, & Reker 2005; Doswell, Lawler, Forster, & Hearn 2005).

Additionally, the ability to function as a marital partner and parent usually diminishes and sometimes ceases after a cerebro-vascular accident. Chronically ill individuals grieve over multiple losses; the purpose of grief is to deal with these losses and to preserve a sense of personal integrity and dignity (Miller, 2003; Thompson & Pitts, 2005). There is evidence from this study to show that the survivors were overwhelmingly concerned that their old roles as partners or parents had either diminished or disappeared or were being carried out by a spouse or children. The following quote, among many, bears testimony to this:

"I feel kind of useless … I can't do things for any of my kids, my wife or neighbour, or anything else".

Similarly, caregivers of survivors have also reported that several types of roles and performance have vanished as a result of the survivor's disability, as evidenced by one of the caregiver's responses:

"My husband was a good supporter and a helping hand to me and the kids. He also took part in activities in our neighbourhood. It is very sad because his disability has limited his usual performance".

In addition to the survivor's inability to function as a partner and parent, they also stated that they are often unable to function in the work situation as they did before the incident. Time is often lost from work because they live with the chronic disabilities resulting from the accident that require long-term care. The survivors expressed their fear of losing their jobs owing to the inability to function in such circumstances. The following statement is evidence of this:

"I was a cook at a restaurant, now I am unable to use my hands to do my regular work. I am not sure what type of job I will be doing once I get better".

In line with comparable studies, Glass & Maddox (2006) maintain that most survivors are challenged by the tasks of daily life. Greveson & James (2004) concur on this point, stating that the survivors of cerebro-vascular accidents judge their functional ability on the way they can accomplish the tasks of daily living and engage in activities that are important to them.

Furthermore, and in line with the literature, the survivors fear that their inability to function in the workplace and/or their permanent disabilities may prevent them from being reinstated in their previous job. Their fear, combined with a feeling that their job performance has decreased, causes much anxiety about their job security. Hence, they are afraid that they may be losing their creativity as well as their job.

The disclosures of this study indicate that the changes that survivors experience in their work roles and the resulting financial concerns contribute to feelings of powerlessness. The survivors expressed concerns about no longer being able to work and support their family the way they are supposed to. According to Erikson (2005) and Chance (2009), a cerebro-vascular accident is a disabling disease. These authors state that the psychological impact of a cerebro-vascular accident is great because of feelings of fear, uncertainty and loss of body control. The loss of body control is an obstacle in managing daily living, thus the survivors' inability to function becomes a hindrance in the work situation. For the same reason, caregivers become aware of altered performance related to survivors' disability after a cerebro-vascular accident.

As can be inferred from the survivors' plight with regard to financial challenges, and supported by parallel studies, the caregivers also experience financial difficulties stemming directly from the survivor's disabilities, which have resulted in prolonged periods of home care. Consequently, the caregivers experience challenges in meeting daily household expenses since the survivors' income is either reduced or has disappeared altogether.

Theme 3: *The survivors and caregivers experience disrupted social interaction*

As both the literature and this study show, the survivors of cerebro-vascular accidents and their caregivers are challenged by the survivors' physical limitations, which prevent them from participating in social activities (Boswell & Wingrove, 2009). Such limitations disrupt social interaction, since survivors are unable to fulfil their previous social roles and, in addition, sometimes the family and friends do not provide the social support needed. The following statements are evidence of this:

"To be honest, none of the day is the best part because I get bored quickly. I used to be active and I get upset when I can't find anything to do or I can't go anywhere, you know".

"The only thing to do is to watch television. So, I am just waiting on time. I just sit around and waiting on time. I know it takes time".

"I lost contact with friends".

It would appear that survivors may become withdrawn because of depleted energy reserves or a poor self-concept, feeling unworthy of previous social contacts, or simply being physically unable to participate in former social events. Moreover, the literature also shows that disabilities prevent the survivors of cerebro-vascular accidents from resuming their previous social roles. Many of their social contacts and support are negatively affected, and only the most loyal friends may persist in being supportive during this repetitive pattern of interaction (Kim & Keshian, 2007; Levine, 2004; Peu, 2008).

Additionally, caregivers experience feelings of being isolated from society. Accordingly, they spoke about the way that the survivor's disabilities make it difficult for both of them to take part in shared activities (in case of spouses) or spend time with someone else or elsewhere.

The caregivers' negative experiences entailed the following:

"We do not attend the church service together as usual, he is still recovering".

"We do not go out as usual; it is not easy".

"I feel as if everyone has forgotten about me. Perhaps it is because I am always at home looking after my son".

Obviously, if the family and friends of the survivors or caregivers do not visit them, as indicated in this study, feelings of neglect, loneliness and being isolated from society will be experienced by both survivors and caregivers. Moreover, the findings of this study revealed that social isolation occurs because of a restricted social network, little energy to share leisure activities and increasing amounts of time spent on illness management.

The study also found that survivors and caregivers experience a lack of follow-up from health professionals. Although the literature maintains that as more care is being given in homes, survivors and their caregivers require increased follow-up in their homes from health professionals, as the survivor may experience pain or other problems which the caregiver may be unable to manage (McLean, Roper-Hall, Mayer, & Main 2006), the findings of this study show that nurses do not visit them at home. The following statements are evidence of this:

"The only time I come into contact with nurses, is when I go back to hospital to receive my tablets".

"We want the nurses to visit us at home and observe how we are trying to cope at home".

"It could be helpful and encouraging if nurses could follow up patients after sending them back home".

Besides the lack of follow-up from health professionals, the hospital where the survivors of cerebro-vascular accidents who participated in this study are treated on a regular follow-up basis has only one clinic for patients suffering from high blood pressure. This clinic appears to be very busy and there are always many

clients waiting to be attended to by nurses and doctors. Hence, the survivors and caregivers experience long, exhausting delays when attending their follow-up appointments. The survivors and caregivers verbalised their experiences of this as follows:
"I get tired at the hospital because the waiting line is at most times very long due to the fact that patients are always in a higher number".
"The date of the follow-up is very tiring; disabled and nondisabled people are being treated in the same room by the same nurses and doctors. I don't know why they cannot attend to the disabled in a separate place, so that they go back home early".
"There is only one clinic and it is always full. I think something must be done".
As the literature has shown, there is an increase in the number of patients with chronic conditions, including cerebro-vascular accidents; consequently hospitals are overcrowded and their resources are overstretched. This has a negative impact on the capacity of hospitals to manage patients, making hospitals unsuitable environments for patients with terminal or long-term diseases. Consequently, there is a growing need for care at home (Perry, Brooks, & Hamilton, 2004; Widen Holmqvist, Von Koch, & De-Pedro Cuesta, 2006).

Theme 4: *The survivors experience negative emotions because of altered self-esteem.*

The revelations of this study indicate that survivors experience some changes in their mood, such as anger, worry and guilt feeling. Survivors may feel very depressed because they have been ill, are unable to work and have difficulties with their day-to-day activities. Their disabilities have led to them living a restricted lifestyle which prevents them from doing the things they value and enjoy.
According to Gagarina (2005) and Gibson, Swartz, and Sandenberg (2002), survivors will express anger about the loss. This study found that survivors experience anger because they are disabled and they have lost their physical abilities. This means that their various needs are no longer being met, as evidenced by the following survivors' responses:
"Sometimes, I am angry at myself, because of my disability, since I am not able to do the tasks I usually did".
"I have no words to describe this condition. I feel like a baby. This is too hard for me. Why me?"
"My family may have noticed it (his anger). At times I would easily become annoyed by them even when not necessary".
In addition to being angry about the loss, survivors are also worried about their ability to function. The survivors expressed worry about the fact that they are uncertain about their recovery and also the type of functions they are able to perform at present. And a result they regard themselves as worthless.
Moreover, the findings have shown that some of caregivers are also worried about the survivors' progressive inability to function. The following quotes, among many, bear testimony to this:
"We do not know what is going to happen, and we do not know if this is it (referring to the condition), or if there is more, because the attack can happen again. You get very frustrating when you do not know".
"It is worrisome when your mom is just sitting in the chair the whole day. It is very difficult".
As supported by parallel studies, it would seem that survivors' delayed recovery can have negative consequences that may discourage caregivers from acting as carers (Gibson et al., 2002).
Furthermore the findings revealed that survivors feel guilty and express regret and sorrow about what has happened to them. They blame themselves and are in denial about their disabled condition, as evidenced by the following statements:
"Sometimes I blame myself because of what I have become. Life is never easy for me and I simply do not understand why this has to happen to me".
"Why me? I am still asking myself why this has to happen to me. I never felt guilty before like the way I am feeling about this condition".
"I was not sick, not at all. I was not supposed to be like this".
It has been shown that survivors feel guilty because they have become emotionally attached to an event that they feel in some way responsible for, either because they feel that they did wrong or because they feel that they should have done something. All of these feelings stem from an apparent lack on their part (Tangney, Miller, Flicker, & Barlow, 2006).
In this study it became clear that the way of life of survivors and their caregivers has changed, with inability being one of the major challenges that face them. The way in which challenges are experienced depends on how they are perceived and appraised by the person involved. A given challenge may be perceived differently by different people; thus it is perceptions that determine the behaviours for coping and health outcomes (Glanz, Rimer, & Viswanath, 2008).

6. Conclusion

The findings of this study provide evidence of the challenges experienced by the survivors of cerebro-vascular accidents and their caregivers. These challenges were identified as the inability to self-care, altered role function and performance, disrupted social interaction and negative emotions, and are strongly supported by the literature. By implication, optimal functioning at home is challenged by the disability on its own, but in addition it is an ongoing process that requires professional intervention in the form of care to help survivors and caregivers cope at home. As a result of the findings of this study, a home-based healthcare programme to support survivors and caregivers to function optimally at home was conceptualised. This programme will be discussed in a follow-up article.

6.1. Limitation

One limitation of the study relates to the fact that the interviews were conducted in Oshiwambo and then translated in English, which might have resulted in the meanings being lost in the translation.

6.2. Recommendation

The research discussed in this article found that both survivors and caregivers need support. Consequently, the survivors require emotional and physical support while the caregivers are in need of a wider social and community support intervention. The original study, of which this article formed the first phase, recommended that a short programme be developed. This programme still has to be submitted for publication.

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