

EXPERIENCES OF CAREGIVERS OF STROKE PATIENTS IN LUSAKA, ZAMBIA

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Abstract

Introduction: Stroke is a major cause of death and most survivors are left with residual disability and are dependent on others for essential care.

Objectives: The objective of the present study was to determine the experiences of informal caregivers of stroke patients receiving out-patient physiotherapy treatment at the University Teaching hospital in Lusaka, Zambia.

Methods: Both quantitative and qualitative approaches were used to collect data in the present study.

Participants: A convenient sample of 70 caregivers was selected for the quantitative part of the study while 10 caregivers were purposively selected for the in-depth qualitative interviews.

Setting: Out-patients at the University Teaching Hospital (UTH) in Lusaka, Zambia

Intervention: The Caregiver Strain Index was used to collect quantitative data and in-depth interviews provided the qualitative data.

Results: The mean age of the participants was 37.6 years. The study sample consisted of more females (70%) than males (30%). Financial constraints, family adjustments and being overwhelmed by their care-giving role were the experiences mostly highlighted by the caregivers in this study

Conclusion: Caregivers are important role players in the rehabilitation of stroke patients. It is therefore important that rehabilitation professionals are aware of the experiences of these caregivers so that their needs could also be addressed when managing the stroke patient

Keywords: Experiences, caregivers, stroke, Zambia

Introduction

Stroke is a leading cause of death and a major cause of disability in most societies (Bakas, Austin, Okonkwo, Lewis & Chadwick, 2002). It is a serious health problem in both developing and developed countries (Dowswell, Dowswell, Lawler, Green & Young, 2002; Giacaman, 2001). More than 50% of stroke survivors are left with residual disabilities that require assistance with activities of daily living (Dorsey & Vaca, 1998; AHA, 1995; Wade, 1994). Their need for assistance could result in the affected individuals being dependent on others for essential care (Vanetzian & Corrigan, 1995). Those who provide the assistance with the activities of daily living for the disabled person on a voluntary basis are referred to as informal caregivers (Anderson, Linto & Stewart-Wynne, 1995). These informal caregivers often include family members, such as children and spouses (Pollock-Hoeman, 1992).

As stroke is a sudden event, caregivers of stroke patients are therefore forced to accept a large amount of unforeseen responsibilities in the absence of preparation. In addition to this, the care giving role has various other implications for the caregiver. Future plans are shattered, income-generating activities are abandoned, leisure time is decreased and they are susceptible to a deteriorating health status (Dowswell, Lawler, Dowswell, Young, Forster & Hearn, 2000; WHO Technical Report, 2000; Fritz, 1997). In the process of care giving, the abilities of the caregivers to provide for their own emotional, personal, physical, social and financial needs are seriously compromised (WHO Technical Report, 2000; Fritz, 1997). The lives of the caregivers are also interrupted in various areas such as, family

responsibilities, education, social activities, leisure time and work.

Despite the high prevalence of stroke and the potentially high burden on caregivers of the stroke survivors worldwide, few studies have systematically addressed the consequences of stroke on family members and other informal caregivers (Wolfe, Rudd & Beech, 1996; Periad & Ames, 1993). Studies regarding the needs and experiences of caregivers for stroke patients have been done mostly in developed countries. To date there is no documented information regarding the experiences of informal caregivers of stroke patients in Zambia. Due to limited rehabilitation resources the burden of care giving is greater in developing countries such as Zambia. This study therefore aimed to identify the experiences of informal caregivers of stroke patients who attended physiotherapy sessions as out-patients at the University Teaching Hospital (UTH) in Lusaka, Zambia.

Method

A cross-sectional descriptive study design was used to collect data in the present study. Both quantitative and qualitative approaches were used. A survey method was used to collect quantitative data while in-depth interviews were used to collect qualitative data. The shared application of both qualitative and quantitative research perspectives, within a single study provides a richer and deeper understanding of the area under investigation than would otherwise be possible and increases validity (Corner, 1991).

The study was carried out at the University Teaching Hospital (UTH) in Lusaka Zambia. All the primary caregivers of stroke patients dependent in

at least one Activity of Daily Living and attending the out-patient physiotherapy department at UTH during the period that data collection took place were identified and recruited to participate in the study. The study sample for quantitative interviews consisted of 70 caregivers. Ten of these caregivers were purposively selected for the in-depth interviews. The ten caregivers represented the diverse characteristics, namely, age, gender, employment status and relationship to the patient, of the total sample of caregivers. The Caregiver Strain Index was used to capture quantitative data relating to the care giving experiences of the participants (Scherbring, 2002; Montgomery; Borgatta & Borgatta, 2000). The Caregiver Strain is a 13-item scale. Each item is answered with either a "yes" or "no" response. The highest score that can be obtained is 13 with higher scores indicating a greater amount of strain being experienced by the caregiver. A score of 7 or above indicates a high level of stress (Scherbring, 2002). Questions included in the scale relate to domains such as; employment, family life, finances and emotions. The internal consistency reliability of this scale is high ($\alpha = 0.89$) while the construct validity is supported by correlations with the physical and emotional health of the caregiver as well as with subjective views of the care giving situation (Sullivan, 2002). A separate questionnaire was also developed by the researcher to collect demographic information of the patients and their caregivers. The English questionnaires were translated into Nyanja, the local language by a local transcriber. A second independent translator translated the Nyanja version back to English in order to verify that it was a true translation. A consensus meeting between the researcher and both translators addressed the differences in the original English version and the back translated version.

The sample was obtained through physiotherapists attending to the stroke patients needing assistance with Activities of Daily Living. Carers were identified and referred to the researcher, after informing them about the nature of the study. Those willing to participate were requested to sign a written consent form and informed that they were free to withdraw from participating in the study at any point, and they were assured of confidentiality. The questionnaires were administered to the caregivers when they brought the patients for out-patient treatment at the department of physiotherapy. The in-depth interviews were conducted at a place and time, which suited the participants. Interviews therefore took place at the UTH or in the carers home. Descriptive and inferential statistics were employed in analyzing data from the closed-ended questionnaire. The Word Excel computer programme was used to code and capture data and the Statistical Package for Social Sciences (SPSS) was used to obtain frequencies, cross tabulations and correlations. The audio-taped qualitative in-depth interviews were transcribed verbatim. Each interview was read several times and coded. The data was reduced into categories and the categories into themes. The researcher obtained ethical clearance from the ethics committee of the University of Zambia, the head of the physiotherapy department at the University Teaching hospital as well as the Higher Degrees Committee at the University of the Western Cape.

Results

The mean age of the study population was 37.6 years, with ages ranging from 16 years to 85 years and a standard deviation of 16.5 years. There were more females (70%) than males (30%). The majority of the caregivers were less than 45 years (73%), lived in the same household as the person they

were caring for (89%), had a low education level (60%) and were unemployed (77%) (Table 1). Among the caregivers, 57.2% reported that the

person they were caring for was dependant in at least more than 2 activities of daily living.

Table 1. Biographical data

| Age Group Interval | Male N=21 | | Female N=49 | |
|---------------------------|------------------|------------|--------------------|------------|
| | n | (%) | n | (%) |
| 15-30 | 10 | (14.3) | 20 | (28.6) |
| 31-45 | 8 | (11.5) | 13 | (18.6) |
| 46-60 | 1 | (1.4) | 13 | (18.6) |
| 61-75 | 2 | (2.8) | 1 | (1.4) |
| 76-90 | 0 | (0) | 2 | (2.8) |
| | Yes | | No | |
| | n | % | n | (%) |
| Live in same household | 62 | (89) | 8 | (11) |
| Low education | 42 | (60) | 28 | (40) |
| Unemployed | 54 | (77) | 16 | (23) |

Caregiver Strain Index (CSI)

The majority of the caregivers (68.6%) scored above 7 on the CSI. The mean score was 8.2. Table 2 illustrates the number and percentage of participants who answered "yes" to the individual items on the scale. The majority (90%) of the participants indicated that caring for the person who had had a stroke resulted in a financial strain for them. They also felt that they had to adjust the family and were overwhelmed with the responsibility. Many of the caregivers felt that they had to make changes in their personal plans and that they now had more demands on their own time. Only half of the care givers felt that disturbed sleep,

emotional adjustments and inconveniences put strain on them. Only 40% of the participants reported that work adjustments were needed, but this was to be expected as 77% of the care givers reported that they were unemployed. In Zambia people that are young, female, uneducated, unemployed and poor are more prone to assume

care giving roles. There were no statistically significant difference found between CSI and socio-demographic factors. Caregivers who were living with the person they were caring for had a higher CSI scores than those who were not.

Table 2. “Yes” responses to individual items on the Caregiver Strain Index (CSI)

| Item on CSI | n | % | Item on CSI | n | % |
|---------------------------|----|----|-------------------------------|----|----|
| Financial strain | 63 | 90 | Disturbed sleep | 35 | 50 |
| Family adjustments | 56 | 80 | Emotional adjustments | 35 | 50 |
| Overwhelmed | 56 | 80 | Inconvenient | 35 | 50 |
| Changes in personal plans | 50 | 70 | Patient behaviour upsetting | 36 | 50 |
| Other demands on time | 49 | 70 | Patient changes are upsetting | 30 | 43 |
| Physical strain | 42 | 60 | Work adjustments | 28 | 40 |
| Confining | 40 | 57 | | | |

The above quantitative results were confirmed by the major themes, which emerged from the in-depth interviews. These themes related to the financial constraints experienced by the carers, changes in their usual routine and the changes, which occurred in the person who has suffered a stroke. They also found the care giving experience overwhelming.

As indicated by the results of the CSI care giving resulted in a financial strain for the carers. This was explained by one of the caregivers in the following quotation.

“The government need to assist caregivers financially. Churches should be involved with the government to assist caregivers”.

Another caregiver indicated that *“It is difficult to cope with financial needs especially that I have children to take to school and the health cost to take care of”*

The participants also noted that they found the care giving experience overwhelming as is expressed in the following quotations.

“...I don't know how to deal with it...”

“During the early days after discharge it was very difficult to cope...”

“Throughout my experiences I have come to conclude that stroke caring is a very huge task and it doesn't end quickly”

The caregivers also experienced changes in their daily routine. This is noted by the following quotations.

“I am a farmer, so I can't go and cultivate because no one can remain with him the... my work is stuck”

The following was expressed by another caregiver.

“...sometimes I need to do other things but can't, because if I do, then no one will remain with the patient”.

A serious problem noted by one of the caregivers was the change noted in the emotional state of the person they were caring for as is indicated in the excerpt below.

“She gets angry many times and insults a lot. Her temper rises so much. I wish I could make her change”

Another caregiver pointed out that the patient had become very sensitive and needed help in dealing with this change.

"When we sit somewhere and talk she accuses us of gossiping about her. If I could be taught how to handle such things that would be better"

Discussion

The study found that the mean age of caregivers was relatively lower than what was found in previous studies (Gräsel, 2002; van der Smagt-Duijnste, Hamers, Abu-Saad & Zuidhof, 2003; Anderson et al., 1995). There are strong implications for young caregivers as they are in the productive age group in society. According to Lackey & Gates (2001), parents and health-care providers need to pay attention to the effects of care giving on selected areas of young peoples' lives — particularly school and family life. They found that those who were of dating age, either did not date, or dated early to "get out of the home". Respondents expressed various areas in which the care-giving role disrupted their daily routine. Some of the areas affected were: employment, social participation, personal privacy and family functioning. According to literature, disruption of daily routine occurs in various areas such as family functioning, work, social and physical health and independence (Bakas et al., 2002; Anderson et al., 1995). The participants in this study indicated financial constraints as a major problem. This is often the case as most caregivers are unemployed and more finances are needed for transportation of the patient to the health care facility, payment for health services, medication and appliances (Mitchell, 1999). The participants also highlighted disruption in their daily routine as a challenge. The major cause of disruption of daily routine is often the caregiver's need to assist the patient in performing some activities of daily living and thus the need to be with the patient most of the time (Eaves, 2000).

Caregivers had many other commitments but couldn't attend to them as a result of the confining nature of care giving. Adjustment to the change in the family was also perceived as a difficult process, most particularly, when the patient was the breadwinner. Reversing roles, relinquishing old roles, acquiring new roles and obligations can result in serious disruption in the dynamics of the family unit (Canam & Acorns, 1999). Delaun & Brown (2001) report that new roles in care giving such as husbands having to assume traditionally female-roles.

Conclusion

The caregivers of stroke patients in the present study experienced financial strain, a need for family adjustments and a sense of being overwhelmed by their care giving role. Caregivers are important role players in the rehabilitation of stroke patients. It is therefore important that rehabilitation professionals are aware of the experiences of these caregivers so that their needs could also be addressed when managing the stroke patient.

Implications for practice

Physiotherapists and other health professionals can influence informal caregivers' experiences by including them in the rehabilitation process. Assessments and reassessments should include caregivers and they should be referred to other services they may need. It is imperative that health care professionals assess caregivers' adaptation to their roles in order to provide needed education and develop more comprehensive discharge planning for stroke patients and their caregivers. These interventions may assist families to prepare for responsibilities that occur after discharge, ease hospital-to-home transitions, and facilitate more effective role adjustment. Health professionals

should support informal caregivers and identify sources and means of allocating resources and support services with the involvement of the government health system, non-governmental organizations and other stake holders. Necessary measures should be put in place to ensure that care givers do not incur major social setbacks, such as job loss, as a consequence of care giving. There should be establishment of sufficient respite care services and facilities to relieve caregivers temporally when they become overburdened.

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