

Perceived Needs of Caregivers of Stroke Patients' Receiving Out-Patient Physiotherapy Treatment in Lusaka, Zambia

ABSTRACT: Caregivers of stroke patients have needs that should be addressed. The aim of this study was to gain information regarding the expressed needs of informal caregivers of stroke patients who are receiving out-patient physiotherapy treatment at the University Teaching Hospital in Lusaka, Zambia. A qualitative study, using in-depth interviews, was carried out to collect data regarding the needs of these caregivers. Ten caregivers formed the study sample. The interviews were audiotaped, transcribed and analysed into themes that emerged from the data. Five themes relating to the needs of the caregivers emerged following the analysis of the data. These included: the lack of information regarding stroke; the need for skills training to enable the caregiver to assist the patient at home; the need for financial support; a need for home-based therapy and the need for physical assistance when caring for patients at home. The caregivers of patients need more information regarding strokes as well as a community-based rather than an institution-based approach to rehabilitation. Rehabilitation professionals in Zambia could use the information gained from this study to implement rehabilitation programmes, which would address the needs of caregivers in that country.

**Khondowe O,
MSc Physiotherapy UWC¹,
Rhoda A, MSc Medical
Sciences (Rehabilitation)²,
Mpopfu R, PhD UWC³**

¹ Department of Physiotherapy, University of the Western Cape, Bellville.

² Lecturer, Department of Physiotherapy, Faculty of Community and Health Sciences, University of the Western Cape, Bellville.

³ Dean, Faculty of Community and Health Sciences, University of the Western Cape, Bellville.

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INTRODUCTION

Stroke is a serious health problem in both developing and developed countries (Giacaman 2001, Dowswel et al 2002). More than half of stroke survivors are left with residual disabilities that require assistance with activities of daily living, such as eating, bathing and dressing (Dorsey and Vaca 1998). Stroke patients who are left post-stroke with a resultant disability often need the assistance of someone in the community to assist them with their function (Anderson et al 1995). After initial hospitalisation, 80% of stroke survivors return to the community, relying on their family members' emotional, informational and instrumental support for daily living (Anderson et al 1995). In the

majority of cases, caregivers are family members, with spouses being the most likely caregiver, followed by the client's own children (Teel et al 2001). They are therefore referred to as informal caregivers. These caregivers frequently accept or are expected to assume the caregiver role without regard for the possible emotional, physical and financial consequences (Kasuya et al 2000). Despite the high prevalence of stroke and the potentially high burden on caregivers of stroke survivors worldwide, few studies have systematically addressed the consequences of stroke on family members and other informal caregivers (Periad and Ames 1993).

Due to the nature of the illness, taking care of a patient who has suffered a stroke can be immensely complex and demanding. Caregivers of stroke patients could have needs that should be addressed as they are at risk of their own health deteriorating, thereby becoming patients themselves. The needs of these caregivers include the need for information relating to the stroke, emotional and spiritual needs, need for financial

support, respite care as well as the need for support (Pound, et al 1993, Zwygart-Stauffacher et al 2000, Van der Smagt-Duijnsteet et al 2001). Although this is the case, stroke rehabilitation at present mainly addresses the needs of the patient and little attention is given to the needs of the caregivers of these patients (Eaves 2002).

The burden of caregiving is greater in developing countries, such as Zambia. This is due to limited rehabilitation resources. Patients receive very little in-patient rehabilitation, and are discharged at an acute stage. Caregivers can therefore be expected to care for these patients almost immediately post stroke. Information relating to the needs of these caregivers is therefore important so that rehabilitation professionals can address these needs as part of out-patient rehabilitation programmes. The aim of the present study was, therefore, to gain information regarding the expressed needs of informal caregivers of stroke patients receiving out-patient physiotherapy at the University Teaching Hospital in Lusaka, Zambia.

CORRESPONDENCE TO:

Anthea Rhoda
Department of Physiotherapy,
University of the Western Cape
Private Bag X17 Bellville 7580
Tel: (021) 959-2542 (w)
(021) 904-6288 (h)

METHOD

Ethical clearance

Ethical clearance for this study was obtained from the ethics committee of the University of Zambia, the head of the physiotherapy department at the University Teaching hospital as well as the ethics committee at the University of the Western Cape. Informed consent was obtained from the caregivers who agreed to participate in the study. They were assured of confidentiality and anonymity.

Design

A cross sectional study design was used to collect data in this study. Although a quantitative as well as a qualitative approach was used for the study, the present article will only be reporting on the qualitative results relating to the needs expressed by the caregivers. The purposively selected sample consisted of 10 caregivers of stroke patients receiving out-patient physiotherapy at the University Teaching Hospital in Lusaka, Zambia. Caregivers were selected on characteristics relating to age, gender, employment status, living arrangements and relationship with the patient.

Data collection

Demographic and qualitative data were captured. In-depth interviews were used to gain information relating to the needs and experiences of the caregivers. An interview guide which included information relating to the caregivers' needs was used to gather the data. The interview guide had sufficient flexibility to allow the researcher to probe statements as well as to repeat questions for clarification. The caregivers were interviewed in their own homes or when they brought the patients to the hospital for physiotherapy appointments if this suited them. The rooms where the interviews were conducted were assessed prior to commencing the interviews to ensure good quality recordings and least possible interruptions and distractions. The caregivers were given the option of the language in which the interviews could be conducted. Five interviews were conducted in Nyanja, one in Bemba and the remaining four in English. A translator

was used to assist the researcher in conducting the Bemba interview, as the researcher is not fluent in this language. The interview lasted between one hour to one and a half hours. The interviews were recorded on audiotape and the researcher also made field notes.

Data analysis

Data from the transcribed (and in some instances, translated) interviews and field notes made by the researcher during the interviews were analysed. The interviews that were not conducted in English were transcribed in the original language and then translated into English. Each transcript was read several times and common concepts were coded as suggested by Huberman and Miles (1994). The coded data were reduced to categories. This allowed for comparisons between the different interviews. Associations between the categories were established and the following themes relating to the caregivers needs were established: need for information; need for training in caring for a patient at home; need for financial assistance; need for home-based therapy; need for assistance in caring for a patient at home. In addition two physiotherapists independently reviewed the data for appropriateness of the categories and themes identified.

RESULTS

Socio-demographic status

The mean age of the caregivers was 34.1 (SD 22, range 16 – 86 years). There were six female and four male caregivers. The majority (80% n = 8) lived with the patient. Only two of the caregivers, a husband and a brother, were employed.

Data from in-depth interviews

Five main themes emerged from an analysis of the results. These were the need for:

- information
- training in caring for a patient at home
- financial assistance
- home-based therapy
- assistance in caring for a patient at home.

Need for information

The need for information related to two specific issues. The caregivers firstly expressed the need for information regarding the stroke itself. *"I don't think I have enough information about stroke ... very little. The doctors have tried to give me whatever they think is adequate but some information is still lacking"* (daughter). *"I don't know how stroke begins"* (son). There was secondly a misconception about what could be the cause of a stroke as expressed by one caregiver *"At the village the traditional healer was attending to the patient as we thought he was bewitched"* (daughter). Although it appeared that the caregivers had been given no information regarding stroke, some information (e.g. risk factors) must have been available, as mentioned by one caregiver *"I don't know where this stroke is coming from as my child has no hypertension or diabetes"* (mother).

Need for training in caring for a patient at home

In addition to their lack of information regarding stroke the caregivers expressed the need to gain information and training regarding the ability to care for a patient at home. *"At discharge not enough information was given to me about what I was going to do with the stroke patient at home"* (wife). *"I need information to help in rehabilitation of the patient on how to deal with his moods at home"* (wife).

Need for financial assistance

Financial assistance was another need expressed by the caregivers. *"It's difficult to cope with financial needs especially that I have children to take to school and the health cost to take care of"* (husband) *"It's financially a problem to bring the patient to the hospital"* (sister). From the above quotations it is clear that caring for a person who has had a stroke places an increased financial strain on the families. In addition to this, one caregiver was concerned about the amount of time needed to care for the patient and how this could influence his job, *"I spend too much money for him, about five million kwacha a month ... I have a job and need much time"* (son).

Need for home-based therapy

Taking the patient to the hospital for physiotherapy sessions appeared to be a problem to the caregivers as they clearly expressed that it would be better for them if the physiotherapist or other health workers could come and treat the patient at home.

"If physiotherapist could come to our homes it would be better" (daughter). A reason for this was once again linked to finances as expressed by one of the caregivers *"We need community health workers to do visits in our homes than us coming here, because it is very costly"* (son). There was therefore a need expressed by the caregivers for home-based care or home visits by therapists

Need for assistance in caring for the patient at home.

In addition to the need for assistance at home the caregivers also expressed the need for physical support and/or assistance while caring for the stroke patient. *"I need a person to help me so that I am not alone helping the sick person"* (brother). This physical assistance is needed to assist with activities of daily living, *"The other help I need is for someone to help dressing her, bathing her ... it is a very big task to bath her and it takes all my time"* (husband). It was also necessary to allow the caregiver time to fulfil other duties, *"I need someone to help in caring. Sometimes I need to do some other things but can't because if I do then no one will remain with the patient"* (wife).

The need for assistance in caring for the patient is further illustrated by the fact that some of the families had implemented methods to allow the caregivers time to continue with other duties should the need arise, *"My husband and I have decided to continue with our normal activities. What we have done is to delegate duties to everyone at home"* (sister). *"I have someone who does come to be with the patient when I need to go out like shopping and sometimes I have to go to see my sick mother. I do pay her. In fact my sister-in-law helps me to pay the girl"* (wife).

DISCUSSION

The aim of the present study was to

determine the perceived needs of a selected group of informal caregivers of stroke patients living in Zambia. The perceived needs as expressed by the caregivers were related to a lack of information and the need for support and assistance.

Lack of information

The lack of information regarding strokes was a definite need expressed by the caregivers in this study. This has been expressed by caregivers of stroke patients in other studies as well (Garwick et al 1995, Denman 1998, Van der Smagt-Duinsteet et al 2001). Issues of concern relate to the type of information, amount of information, and the manner in which the information is conveyed. Patients and caregivers are anxious for knowledge in the following areas: cause of stroke, risk of recurrence, prognosis, rate of recovery and services available (Anderson et al 1995, Denman 1998). Caregivers' first questions are usually "will the patient get better" and "how long will it take for them to get better". They are also anxious about whether the patient could have another stroke and how they could avoid this from happening. In addition to this caregivers often perceive that information is being withheld from them; they therefore appreciate professionals who keep them informed about the condition of the patients (Thorne 1993), and that serious issues be discussed privately in a separate room (Garwick et al., 1995). When providing information to caregivers it should be kept simple and understandable (Yoon and Byles 2002).

Need for financial assistance

Caring for a patient who has suffered a stroke places an increased financial strain on these families. Finances are mainly needed to transport the patient to and from the hospital for physiotherapy. Managing finances, adapting to a special diet, insufficient government funding and transporting the patient were identified in other studies as attributes to the need for additional finances as expressed by caregivers (Low et al 1999, Bakas et al 2002). No financial aid is available in Zambia, neither in the form of a caregiver grant nor a disability grant

for the patient. Families therefore have to cope with the additional financial burden on an already limited budget.

Need for assistance and training when caring for the patient at home.

The caregivers also expressed a need for assistance when caring for the patient. The need for someone to assist them while they tended to the patient's daily needs was mentioned. Caring for a physically disabled individual can be physically and emotionally stressful (Anderson et al., 1995). Caregivers, therefore, need to be physically healthy to be able to perform this task. The need for good health becomes critical when dealing with patients whose functional levels are decreased (Grant et al 2000). Informal caregivers have to take up responsibilities that were not anticipated (Dowswell et al 2000).

Caregivers often feel abandoned and isolated after the patient has been discharged from hospital as expectations of continued support have not been met. Many of them are often left to learn for themselves about how to care for the patient (Simon and Kumar 2002). To decrease the helplessness and anxieties experienced by caregivers when having to care for the patients at home, they should be appropriately trained in basic skills. Ensured follow-up support should also be provided. A failure to involve the caregivers in rehabilitation services contributes to services that are inadequate, inappropriate and poorly tailored to individuals needs (Brereton and Nolan 2002, Richardson et al 1996).

Need for home-based therapy

There are different strategies for rehabilitation: institution-based, outreach and community-based. Stroke rehabilitation may be provided in an acute setting such as a stroke unit, or a sub-acute setting such as a nursing home or sub-acute rehabilitation hospital, out-patient department and/or within the home environment (Flick 1999, WHO 1989). The caregivers stated that it would be beneficial if the physiotherapist could come and treat the patient at his/her home. The reasons for this could include the amount of time it took them to get to and from the hospital as well

as the financial burden of transportation. Community-based rehabilitation was introduced in certain developing countries as large groups of people with disabilities did not have access to rehabilitation services (Helander 1999). In this rehabilitation strategy community-based workers are trained to provide basic rehabilitation to disabled people in their homes. A community-based rather than an institution-based approach to rehabilitation could address the needs of the caregivers interviewed in this study.

As has been previously indicated by Pound et al (1993) the present study also revealed that there are shortcomings of stroke services in meeting the needs of caregivers of stroke patients. As the comprehensive management of stroke patients depends largely on the cooperation of the caregiver and his or her ability to provide care, it is important that the caregivers' needs are considered.

CONCLUSION

It can be concluded from this qualitative study that the caregivers of stroke patients receiving treatment at the University Teaching Hospital in Lusaka, Zambia have similar needs to those mentioned in the literature (Pound et al 1993, Zwygart-Stauffacher et al 2000, Van der Smagt-Duijnsteet et al 2001). These needs related specifically to a lack of information about stroke and support to assist the caregivers to cope with the patient at home. A community-based approach as opposed to an institution-based approach could assist with supporting the caregivers while caring for the patients in their homes. Rehabilitation of stroke patients should include addressing the needs of the caregivers as well as the patients. The needs of these caregivers living in a developing country with limited rehabilitation resources could be greater than those caregivers living in developed countries, as the patients are at home in the acute stage post-stroke when their functional limitations are greater. If health professionals are serious about providing rehabilitation programmes that acknowledge patients and their caregivers, they need to adapt these programmes so that they address the needs of the caregivers as well.

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REFERENCES

- Anderson C, Linto J, Stewart-Wynne L 1995 A population-based assessment of the impact and burden of care giving for long-term stroke survivors. *Stroke* 26: 843-849
- Bakas T, Austin J, Okonkwo K Lewis R, Chadwick L 2002 Needs, concerns, strategies and advice of stroke caregivers the first six months after discharge. *Journal of Neuroscience Nursing* 34: 242-249
- Bereton L, Nolan M 2002 "Seeking": A key activity for new family carers of stroke survivors. *Journal of Clinical Nursing* 11: 22-31.
- Denman A 1998 Determining the needs of spouses caring for aphasic partners. *Disability and Rehabilitation* 20: 411-423
- Dorsey M, Vaca K 1998 The stroke patient and assessment of caregiver needs. *Journal of Vascular Nursing* 16: 62-67
- Dowswell G, Dowswell T, Lawler J, Green J, Young J 2002 Patients' and caregivers' expectations and experiences of a physiotherapy intervention 1 year following stroke: A qualitative study. *Journal of Evaluation in Clinical Practice*, 8: 361-370
- Dowswell G, Lawler J, Dowswell T, Young J, Forster A, Hearn J, 2000 Investigating recovery from stroke: A qualitative study. *Journal of clinical nursing*. 94: 507-515
- Eaves Y 2002 What happened to me? Rural African elders' experiences of stroke. *Journal of Neuroscience Nursing* 32: 37-46
- Flick C. 1999 Stroke Rehabilitation 4. Stroke Outcome and Psychosocial Consequences. *Archives of Physical Medicine and Rehabilitation* 80: S-21 to S-26
- Garwick A, Patterson F, Blum R 1995 Breaking the news: how families first hear about their child's condition. *Archives of Physical Paediatrics and Adolescent Medicine* 149: 991-1001
- Giacaman R. 2001 Comments on community based rehabilitation programmes in Palestine. *Journal of Palestine studies* 31: 142-152
- Grant J, Elliot T, Giger J, Bartolucci A 2000. Social demographic, physical and psychosocial characteristics of depressed and non-depressed family care-givers of stroke survivors. *Brain Injury* 14: 1089-1100
- Helander E. 1999. An introduction to community-based rehabilitation: Prejudice and dignity: http://dag.virtualave.net/p_d.htm
- Huberman A, Miles M 1994 *Qualitative Data Analysis. A source book of new methods.* Sage, Newbury Park CA
- Low J, Payne S, Roderick P 1999 The impact of stroke on informal carers: A literature review. *Social Science & Medicine* 49: 711-725
- Kasuya R, Polgar-Bailey P, Takeuchi R 2000 Caregiver burden & burnout: A guide for primary care physicians. *Postgraduate Medicine* 108(7): 119-123
- Periad M, Ames B, 1993 Lifestyle changes and coping patterns among caregivers of stroke survivors. *Public Nursing Health* 10: 250-256
- Pound P, Gompertz P, Ebrahim S. 1993 Development and results of a questionnaire to measure carer satisfaction after stroke. *Journal of Epidemiology and Community Health* 47:500-505
- Richardson E, Wartburn F, Wolfe C, Rudd A. 1996 Family support services for stroke patients. *Professional Nurse* 17: 92-99
- Simon C, Kumar S 2002 Stroke patients' carers' views of formal community support. *British Journal of Community Nursing* 7: 158-163
- Teel C, Duncan P Lai S. Caregiving Experiences After Stroke. *Nursing Research* 2001 50:53-60
- Thorne S 1993 *Negotiating Health Care: The social context of chronic illness.* Sage, London
- Van der Smagt-Duijnsteet M, Hamers J, Abu-Saad H, Zuidhof A 2001 Relatives of hospitalised stroke patients: Their needs for information, counseling and accessibility. *Journal of Advanced Nursing* 33:307-315
- World Health Organisation 1989 *Stroke: Recommendations on Stroke Prevention, Diagnosis and Therapy.* Report of the WHO Task Force on Stroke and Other Cerebrovascular Disorders
- Yoon S, Byles J 2002 Perceptions of stroke in the general public and patients with stroke: a qualitative study. *British Medical Journal* 324: 1065 - 1071
- Zw ygart-Stauffacher M, Lindquist R, Savik K 2000 Development of Health Care Delivery Systems that are Sensitive to the Needs of Stroke Survivors. *Nursing Administration* 24: 33-42.