

THE EXPERIENCE OF LIVING WITH STROKE IN LOW URBAN AND RURAL SOCIOECONOMIC AREAS OF SOUTH AFRICA

ABSTRACT: *The effects of stroke on stroke survivors are profound and affect their quality of life. The aim of this study was to establish the experience of people living with stroke in low socioeconomic urban and rural areas of South Africa.*

A qualitative study using semi-structured interviews was used to collect data. Participants were identified from stroke registers and recruited from PHC clinics in Soweto, Gauteng and Limpopo provinces. Participants had to have had a stroke, be above the age of 18 and had lived in the community six months to a year following their stroke. The researcher or research assistant conducted the interviews of participants who had had strokes as well as their caregivers in the home language of the participants. The interviews were audio taped, transcribed and translated into English. A thematic content analysis was done.

Thirty two participants were interviewed, 13 from Soweto, Gauteng, and 19 from rural Limpopo provinces. The results suggest that the sudden, overwhelming transformation as a result of a stroke forms a background for loss of community mobility, social isolation, role reversal within the family and community, loss of role within the family and community, loss of meaningful activities of daily living, loss of hope and threat to livelihood amongst stroke survivors living in low socioeconomic areas of South Africa.

An overwhelming picture of despondency was found, with few positive stories told in both settings. The themes identified from the interviews reflected the experience and issues that a patient with stroke has to deal with in low socioeconomic areas of South Africa.

KEY WORDS: *LIVING WITH STROKE, EXPERIENCE, LOW SOCIOECONOMIC STATUS.*

INTRODUCTION

Stroke is one of the major causes of long-term disability and is among the top ten leading causes of disability worldwide (Feigin et al, 2003; Lopez 2006). The prevalence of disabling stroke in South Africa (SA) is thought to be as high as it is in high income countries (Connor et al, 2004). This prevalence includes that of black people in South Africa (SA) (Disler et al, 1986). Although stroke has been recognized for many years as an important cause of death and disability in high-income countries, its importance in low-income countries has only recently been emphasized. Cardiovascular diseases were thought to be diseases of a "western" style of life but more recently, they have become recognised as significant diseases in low socioeconomic societies (Connor et al, 2004). However, little is known about the burden and nature of stroke in low-income countries, particularly in sub-Saharan Africa (Connor et al, 2004; Feigin et al, 2003).

In SA, the average length of stay in a tertiary hospital for patients with stroke is six days (Mudzi, 2009). A study by Mamabolo et al, (2009) concluded that patients with stroke have limited functional independence on discharge from hospital (Mamabolo et al., 2009), thus these patients are sent home where community based rehabilitation services are not adequate and accessible. In SA the community-based rehabilitation services are poorly developed and inadequate (Hale and Wallner, 1996; Rhoda and Henry, 2006; Mudzi., 2009). Therefore, many patients with stroke remain limited in their participation in family and community activities, and have a poor quality of life post stroke, even after satisfactory levels of independence in daily living activities and mobility have been achieved following minimal rehabilitation in the hospitals (Midwest Nursing Research Society, 2001). Therefore, this study aimed to establish the experiences of living with

stroke in low socioeconomic rural and urban areas of South Africa.

METHOD

Study design

A qualitative study using semi-structured interviews was used to collect data.

Study Setting

This study was performed in Gauteng and Limpopo provinces of South Africa. These two provinces were purposively sampled due to their diverse rural and urban composition (Statistic South

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Africa, 2001). Eighty nine percent of Gauteng province can be considered urbanized and has low socioeconomic areas such as Soweto, which is a high population density, multilingual, multicultural urban community predominately comprising illiterate black people. Limpopo province on the other hand is more rural with only 11% of the province urbanised. The villages in this province are also described as low socioeconomic areas, comprised mainly of illiterate black residents and these areas are different to Soweto in that they have low population density, monolingual, monoculture rural communities (Statistic South Africa, 2001; Aitchison & Harley, 2004).

Study population and sample

The participants were included in the study if they had sustained a stroke and were aged 18 years and over. In the case of participants with expressive or receptive aphasia only the caregiver was interviewed with the permission of both the participant and caregiver. Participants had to be members of the community in which they had lived pre-stroke and had been back living in their community for six to twelve months since their stroke. Participants were identified from the stroke registers. Patients were approached and recruited from primary health care (PHC) clinics in Soweto, Gauteng and Limpopo province by the physiotherapists and occupational therapists working in these provinces.

Data collection tool

The interview guide/prompt was developed from the literature (Pilkington, 1999; Trigg et al., 2000) and the questions were chosen to cover aspects of patients' lives before and after the stroke. The following were the guiding questions used in the interview:

1. Tell us about your family
2. Can you please describe a typical day? How do you fill your day?
3. Has your life changed following the stroke? Please explain the changes to me.
4. Do you think that you have settled back into your community well following the stroke? Please explain your answer.

5. What activities or things would indicate that you have settled back well into your community following the stroke?

Ethical considerations

Ethical clearance was obtained from the human research ethics committee (HREC) of the University of the Witwatersrand (M070816) and the relevant health authorities and institutions. Written informed consent from participants and their caregivers was sought and obtained prior to the interviews.

Procedure

The interviews were conducted at patients' homes and PHC clinics in both settings.

Information sheet were read to the patient and caregiver in order to get informed consent from both.

After consent was obtained, the demographic data was collected prior to the interviews and this included information such as patients' age, date of stroke etc (See Table 1).

The interviews were conducted by the researcher or trained research assistants (local physiotherapists), in local languages namely SeSotho or IsiZulu in Gauteng and TshiVhenda and Xitsonga in Limpopo.

All the interviews were audio taped.

After the interviews, participants were given an opportunity to listen to the recording and make changes.

Initial analysis of the results was done and in order to verify, enrich the existing data from these interviews, gain more insight and ensure data saturation a second round of interviews was conducted.

Analysis

The interviews were fully transcribed word for word in the language spoken in the interview and translated to English by the researcher (physiotherapist) and research assistants (physiotherapists) who spoke, IsiZulu, SeSotho, TshiVhenda and Xitsonga fluently. A thematic content analysis was done. The transcripts content were read through multiple times to establish the experiences of the participants. In order to establish themes, common

concepts were identified, reduced into categories and then into themes. Once data were coded an independent therapist (experienced in qualitative research methods) who was not involved in the research coded independently, the results were then compared, and differences were sorted.

RESULTS AND DISCUSSION

A total of 32 participants were interviewed. The average length of time for interviews was 1 hour 30 minutes. The characteristics and other data of the participants are presented in table 1.

The data analysis revealed seven themes, namely

- loss of community mobility or restriction in community mobility,
- social isolation,
- role reversal and loss of personal identity within the family and community,
- loss of role within the family and community,
- loss of meaningful activities of daily living,
- threat to livelihood (sustainable/productive livelihood),
- loss of hope.

These themes are discussed in details below.

All participants in both settings expressed concerns regarding their reduced mobility within their homes and within their communities. They expressed feelings of frustration, poor motivation and discouragement. These feelings were shared by most participants albeit to varying degrees and in different environments as some participants found it difficult to move in their own homes whilst others could move in their homes but found it difficult to move around in the community. One **rural** participant told of her distress at being confined to her home:

“Yes, I do. I am always at home, I do not go anywhere. Where could I go? I am unable to walk. When I go out with other people they say I slow them down so it is better to stay at home. I am also afraid that I will fall when I walk with my walker. The roads are also not in a good condition, they are very rocky and

Table 1: Demographic Characteristics of Participants

Characteristics	Urban (n=13)	Rural (n=19)
1. Number of interviews conducted:	13 interviews conducted	19 interviews conducted
2. Age mean (range) years:	56 (27-78)	60 (35-79)
3. Gender:	Males: 11 and Females: 2	Males: 5 and Females: 14
4. Marital status:	Married: 10 Single: 2 were Widower: 1	Widows: 4 Married: 12 Divorced: 1 Single: 1 Living separately from spouse: 1
5. Date of stroke: The interviews for the study took place from January to November 2008.	Ranged from 1995 to 2008	Ranged from 2002 to 2008
6. Level of formal education obtained: School ends at year 12 (Grade 0-12)	Range: Grade 0-tertiary	Range: Grade 0-12
7. Side of the hemiplegia:	Left: 8 and Right: 5	Left: 10 and Right: 9
8. Location of interview:	In a PHC clinic: 13	Patients' home: 15 In a PHC clinic: 4
9. Who was interviewed:	Patients: 10 and caregiver: 3	Patients: 14 and caregiver: 5
10. Employment and previous employment status	Unemployed: 12 The previous occupations of the 12 unemployed urban participants included housemaid, self employed, driver, gardener, motor mechanic, accounts clerk, upholsterer, sales representative in insurance industry, university student and sales assistant in the clothing industry. Pensioner: 1	Unemployed: 8 The eight who were unemployed, their previous occupations prior to their stroke included housemaid, housewife, farm labourer, professional nurse, teacher, security guard, self employed and production line manager. Pensioners: 11
11. Period living in the community following stroke	The period (in years) of patients having lived in the community pre-morbidly ranged from over a year to their entire lives.	The period (in years) of patients having lived in the community pre-morbidly ranged from over a year to their entire lives.
12. Access to a caregiver: In SA when patients are discharged from a hospital they are taken care of their family at home not a paid carer.	All participants had access to caregivers and all caregivers were members of the family, including a child, a wife or a husband. None had medical training.	All participants had access to caregivers and all caregivers were members of the family, including a child, a wife or a husband. None had medical training.

uneven, not tarred. So I stay home all the time”

For some participants it was difficult to move around in their small homes, as expressed by one **urban** participant:

“It is hard to move around the house, the house is small and lots of furniture is in the way, so I find it hard to move in the

house. I prefer this corner all the time”

For other participants, constraints within the environment, limited community ambulation as this participant in the **urban** cohort explained:

“Yes, I am unable to walk properly when going down the slope or hilly areas when I come to the clinic”

Some participants were very aware of their disability and because of that, they did not want to be seen in public as expressed by one **urban** participant:

“I can't and I don't want to be seen like this (pointing at her body) in public”

Walking is an important human activity which enables us to be productive

and participative members of a community (Ada et al., 2009). The reduction in the ability to walk results in major limitations in community participation. Hill et al., (1997) found that many individuals after a stroke could not walk fast enough to do their shopping. The consequence of poor walking ability is widespread and affects the entire family. The impression gained from participants were that in conjunction with it being difficult to walk they were afraid to walk because of falling, slopes, rough terrain, slowing others up and difficulty in negotiating furniture. They were embarrassed to be in public due to the way they walked especially those who used walking aids. Poor walking ability has been found to reduce the quality of life with a reduction in participation in activities outside the home and therefore social isolation (Ada et al., 2009).

Social isolation emerged as a prominent theme again for participants in both settings. Participants expressed a sense of being cut off from the world as a result of their stroke and that their social relationships had deteriorated, as illustrated by the two participants below:

"I am really on my own; my children leave me here at home all the time"

"I cannot get up, my whole left side is not working, I find it difficult to do anything for myself, I really feel trapped in this body. I cannot go anywhere, visit family, neighbours, friends; I am forever locked in this room until my daughter comes back from work. I really feel all alone. I can't remember when last did I get out of this place"

Social isolation is defined through self report of knowing fewer people well enough to visit in their homes (Boden-Albala et al, 2005). Most people with stroke in this study stated that their restriction in mobility was the major cause of their social isolation. Social relationships are critical to survival for patients after stroke and become of critical importance for their quality of life (Lynch et al, 2008). Glass et al., (1993) state that high levels of social support are associated with faster and more extensive recovery of functional status after stroke and thus social support may be an important prognostic factor in recovery from stroke (Glass et al., 1993). It may

be that patients should be encouraged to socialize more so as to improve their recovery rate, to improve social relations and interactions with other people.

Due to the feeling of isolation and not being able to move around, participants felt that their role in the family and community had changed or taken over as expressed by the next theme. Most participants in both settings felt that their roles had been taken over, because the activities they used to do were now done by a member of the family or someone else in the community. The many changed roles (or taken over) are illustrated by the following quotes from a caregiver of an old man from the **rural** cohort and a man from the **urban** cohort respectively:

"He was part of the community leaders, tribesman, they would not have a meeting (Imbizo) without him. He was an advisor at the chief's kraal (Khoru). He was very good in meetings, he participated well. If there was anything that the community needed from the chief they would send him, things like funerals. He was headman, yes, he was a messenger; when people wanted or needed something or to get a message to the chief, they would send him, now this is done by someone else"

"...I am no longer a breadwinner in my house and that affect the decision I can or cannot make within the family. My wife now is the head of the family"

This loss of role in the family, and community seemed to reduce the significance and importance of the person with a stroke. The striking impact of a stroke is the change in the patient's role and social function. The participants stated that their roles changed because they had to depend on others for his/her basic personal and social needs. This dependence on others hugely changes the role of a person with a stroke within his/her family and community (Hafsteinsdottir and Grypdonck, 1997). As a result of participants loss of role, they were no longer able to carry out meaningful activities of daily living as expressed by the following theme.

Participants in both cohorts expressed their loss of ability to undertake meaningful activities, when asked to explain their typical day or rather how they spent

their days. Almost all participants said they did nothing all day other than sit, watch television, or sleep. When asked about their previous lifestyle it became very clear that they were not participating in activities they enjoyed. Most women in both cohorts expressed their loss of meaningful activities as seen in the quote below:

"I cannot cook for my husband, clean my house, wash dishes, clothes, iron our clothes and sweep my yard. I cannot attend local funerals, church, weddings, parties and burial society or social club, it makes me feel sad"

A man in the **rural** cohort, who could not perform his community responsibility as expected by the community said:

"I am unable to go to the graveyard to assist with digging of the grave"

"I normally stay at the home of the people who are burying instead of going to the graveyard"

Many people who have had a stroke live with physical, psychological and functional limitations that have an impact on their daily activities and social roles (Dombovy et al., 1987). A number of people with stroke will not be able to resume their previous activities (Parker et al., 1997). Their participation in daily living and social roles will therefore be restricted, leading to handicap situations in various aspects of their lives (Desrosiers et al., 2006). The participants were not occupied during the day; these findings are similar to the ones found by Hale et al., (1999) on a similar cohort of patients. Meaningful activities are normally determined by the importance of the task and whether the person was doing the task prior to his/her stroke e.g. female rural participants have to collect firewood to cook, it is therefore expected of them to do this task but due to the effects of stroke this important task is lost.

Another activity that was affected by stroke was people's ability to return to work. The inability to return to work affects the person's livelihood and existence. The theme below explores this further. The inability to return to work appeared to be more of a concern for the urban than rural participants as stated by a man in the urban cohort.

"I have to go back to work because I need to pay rent for this (pointed at the room) room or else I would have to go back home in the Eastern Cape".

The concern could be due to the fact that most participants in the urban community were renting property and therefore had to pay rent at the end of the month or face eviction whereas in the rural communities most families own property so the pressure is less than that in urban communities. Although not all participants had returned to work at the time of the interview, most expressed the desire to return back to their paid occupations. Some expressed their desire to apply for government social grants (disability) since they were not able to return to their paid occupations. The inability to return to work affects both the person's livelihood and existence. Returning to work for people with stroke may contribute significantly to their life satisfaction, well being, self-worth and social identity, giving an opportunity to maintain independence as far as physically possible with the income generated through employment (Wolfenden and Grace, 2009).

In this study, the extreme case of loss of hope was expressed as wanting to die, by some participants. Participants felt that they were now going to be a burden to their spouses, children or family members as expressed below:

"I wish I could die than to be a burden to my children"

Whilst some felt that, they are not going to ever recover from the stroke to their usual level of activity as expressed by one participant below.

"I don't think there is a cure for a stroke; does it mean I am going to live like this until I die?"

However, despite these feelings most participants in both settings drew on their spirituality and faith for hope.

"I know God is there, he will heal me, and I believe in Him"

It is a common phenomenon for stroke survivors to express feelings of despair, depression and helplessness after a stroke (Pilkington, 1999).

CONCLUSION

An overwhelming picture of despondency was found, with few positive

stories told in both settings. The themes identified from the interviews reflected the negative experiences and issues that patients with a stroke have to deal with in a low socioeconomic rural or urban area of South Africa with minimal differences between the two settings.

It is therefore, recommended that in order for therapists to holistically manage and improve patient's rehabilitation, they must

- Be aware of activity limitations and participation restrictions that stroke imposes on a stroke survivor and include these issues in the rehabilitation programmes of their patients.
- Be aware of long term issues and experiences of stroke such as loss of hope as this have been proven to lead to depression and further isolation for patients with ultimate poor community reintegration including reduced rate of return to work.

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