

# LIMITATIONS IN ACTIVITY AND PARTICIPATION EXPERIENCED BY STROKE PATIENTS: A QUALITATIVE INQUIRY

**ABSTRACT:** *Stroke affects individuals in a number of ways. The International Classification of Functioning, Disability and Health can be used to conceptualize disability post stroke. This framework not only identifies the factors as it relates to disability but also highlights the conceptual factors which impacts on the individual's ability to function. Within the framework of the ICF, the aim of the study was therefore to explore the activity limitations and participation restrictions experienced by patients with a stroke. A qualitative approach was used to interview a convenient sample of 8 participants who were living in the community. A semi-structured interview was conducted to obtain the data. The findings reveal that the participants had impairments of body functions of both the upper and lower limb. They experienced limitations in activities such as caring for themselves and mobility and were restricted in their ability to fulfill roles such work and caring for family. The factors which influenced the above were personal factors such as impairments and environmental factors such as family and therapy. This study provides valuable qualitative information that could be used by health care professionals when providing rehabilitation services to people with stroke aimed at reintegration back into the community.*

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**KEY WORDS:** STROKE, ACTIVITY LIMITATIONS, PARTICIPATION RESTRICTIONS.

## INTRODUCTION

Disability post stroke can be conceptualized within the framework of the International Classification of Functioning, Disability and Health (ICF) (WHO 2001). Within this framework disability is a term that encompasses impairments, activity limitations and participation restrictions. Impairments are the problems experienced with body structures and functions, activity limitations refers to the difficulties in performing tasks or actions and participation restrictions as the challenges individuals would have "in involvement in life situations" (WHO, 2001:12). The ICF also identifies the contextual factors that influences either functioning or disability. These contextual factors refer

to the internal and external factors that influence the ability of the individual to function as before. The internal influences refer to the personal factors such as gender and age and while the external influences are the environmental factors which include the physical and attitudinal environment (ICF 2001).

In patients with stroke, a number of common impairments have been identified. These include impaired motor function, abnormal muscle tone, speech problems, cognitive impairments, sensory impairments, urinary incontinence and dysphasia (Lawrence et al 2001). In addition, the most common activity limitations identified were, limitations with walking and the ability to independently perform activities of daily living (Rhoda et al 2011; Hartman-Maier et al 2007; Mayo et al 1999) whereas the participation restrictions experienced by these patients, relates to the inability to return to work, caring for one's family and education as well as a decrease in the participation in leisure activities (Daniel et al, 2009). These common impairments, activity limitations and participation restrictions as highlighted above have

also been compiled in the ICF Core Set for Stroke (Glåseel et al 2010).

The components of disability post stroke have mainly been identified using standardized outcome measures (Salter et al 2005). These measures are instruments that could either measure the impairments, activity limitations or participation restrictions (Finch et al 2002). Standardized measures provide quantitative data that is often used to categorize the level of disability using closed ended questions (Hacke et al 2008).

This means that there is no opportunity for the respondents to give a personalized experience of the situation. These standardized measures are structured in a manner that it does not capture the personal complexities that could be experienced differently by individuals recovering from a stroke. In addition outcome measures do not allow for additional information that is not covered by questions or tests addressed in the measure.

As a disabling condition such as a stroke is often unique, a more detailed personalized account of the challenges experienced by the individual would be useful when planning interventions.

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To obtain this type of data a qualitative enquiry has been suggested (Clarke 2009). Qualitative research provides the ability to understand phenomenon (disability post stroke) in the respondents natural setting (Creswell 2000). It further emphasizes the respondents' experiences and meanings they give to things as well as their individual views (Creswell 2000). A qualitative enquiry would therefore provide information relating to how the individual views his or her disability. This information is obtained via rich data provided by participants rather than responses to standardized questions (Creswell, 2000). As qualitative research is exploratory, it provides an opportunity to obtain information about why certain things have occurred or is a challenge.

To date components of disability post stroke have mainly been identified using quantitative studies which have lately used the ICF as a contextual framework (Alguren et al 2012.) A quantitative study has been conducted to determine the outcomes of stroke patients attending Community Health Centers in South Africa (Rhoda et al 2011). This study was conducted within the framework of the ICF (WHO 2001). The results of the quantitative study revealed that the participants were more independent in their ability to perform basic activities of daily living as measured by the Barthel Index. They were however less able to perform instrumental activities of daily living and had participation restrictions related to return to work, caring for others and participating in leisure activities. These individuals therefore had limited community reintegration (Resnick et al 2012). A limitation of the quantitative study was that it could not provide the reasons for the challenges the participants experienced with activity limitations and participation restrictions. It was therefore not clear if the limitations and restrictions were related to personal factors or environmental factors. A follow-up qualitative study was therefore conducted to explore the stroke patients' difficulties experienced with common activities and participation restrictions. It further aimed to explore the contextual factors that influenced functioning of these individuals. In addition the study aimed to add to the limited qualitative

data currently available with regards to outcomes of patients with stroke.

## **METHODS**

Semi-structured interviews were used to explore the experiences of stroke patients within the ICF context of activity limitations and participation restrictions. Creswell has described qualitative research as an approach that studies concepts within their natural settings. Phenomenon such as social or human problems is explored according to experiences of the individuals (Creswell 2000). The semi-structured interview process which assists the researcher in obtaining a detailed account of the participants' perceptions of a particular experience which in the current study was their experiences of activity limitations and participation restrictions post stroke (De Vos et al 2002).

## **Participants**

A total of 8 participants were conveniently selected to participate in the study. The sample of convenience was used as participants invited to take part in the study were those who could be accessed by the researcher (Carter et al 2011). The sample was accessed from those who had been part of the initial quantitative study. A number of the participants who were part of the quantitative study had died, moved or were not contactable due to changed telephone numbers. Based on findings of the quantitative study (Rhoda et al 2011), participants were also only considered for inclusion in the follow-up qualitative study if they were living in the community for at least one year post stroke and if they were not fully independent in all basic or instrumental activities of daily living at their last follow-up assessment as measured by the Barthel Index or Extended Activities of Daily Living Index respectively. As the participants had to give a personal account of their experiences those who had cognitive and or speech impairments were excluded.

## **Data collection instrument**

The interview guide was developed based on the components ICF (2001). The questions were also based on the difficulties participants had indicated

were a problem during the quantitative study (Hartman-Maeir et al 2007). Demographic information such as age, gender, and level of functioning was collected from the records of the quantitative study (Rhoda et al 2011).

## **Data collection procedure**

Before the study commenced the necessary ethical clearance and permission was obtained. Data was collected by research assistants who had experience in conducting qualitative interviews and were fluent in both English and Afrikaans one of the local languages used in the research setting. The selected participants were invited telephonically to take part. If they agreed a time and place which suited the participants were arranged for the interviews. At the time of the arranged appointment, the aim of the study was explained to the participants and written informed consent was obtained. All the interviews which were tape-recorded were conducted in the patients' homes and lasted from 45 minutes to 60 minutes. At the end of the interviews the participants were given an opportunity to expand on the information provided. This ensured saturation of the data collected during these interviews. Trustworthiness which assures rigor of qualitative research was ensured by explicitly presenting the methodology, peer review of the transcriptions as well as coding and recoding of the transcripts (Dowswell et al 2000).

## **Data Analysis**

The data was analyzed inductively using thematic analysis. All the interviews were conducted in Afrikaans. The transcripts were therefore translated into English. The translated interviews were transcribed verbatim. The transcriptions were read and re-read several times by the researcher. Transcripts were coded according to words and phrases. The coding process was repeated at a later stage. Phrases and words were grouped into categories within the predetermined themes. To ensure trustworthiness of the data collected an independent person who was also a physiotherapist independently reviewed the transcripts and verified the inclusion of data into the pre-determined themes and categories.

## Ethical Considerations

Ethical clearance to conduct the study was obtained from senate research committee at the University of the Western Cape. Written Informed consent was obtained from the participants. In addition the participants provided permission for the interviews to be audio-taped. The participants were ensured confidentiality of the information they provided. Confidentiality was maintained by using pseudonyms (P1-P8) instead of the participants own names. Additionally the tape recordings and transcripts were only available to the researcher and the research assistant who transcribed the data. Participants were ensured that they could withdraw from the study at any time during the interviews without any consequences.

## RESULTS

### Participant Characteristics

Eight participants were interviewed using semi-structured interviews. The mean (SD) age of the participants was 55.25 (9.22) years. The majority (5/8, 63%) of the participants were not in a formal marital relationship, single, divorced or widowed. The majority of the participants were mildly affected as determined by their Barthel Index (0-100) mean score (standard deviation) 73.7 (17.5), and moderately affected by their Nottingham Extended Activity of Daily living Scores (0-22) mean scores which were 10.5 with a standard deviation of 4.38.

### Challenges Experienced by the Participants.

The activity limitations and the participation restrictions experiences of the participants are presented within the pre-determined themes as it related to the components of the ICF and are presented in table 1. The emerging themes are presented in a narrative form below. Both the pre-determined and the emerging themes are supported by quotes.

### Pre-determined Themes

The constructs experienced by the participants will be presented within the different domains. These results are presented in the table 1.

## Emerging Themes

Three themes emerged from the results. These themes related to the participants reasons for their inability to perform the activities and participate in previous roles. Participants expressed that their inability to perform certain tasks were related to their impairments as is expressed in the excerpts below. Another two themes that arose related to the consequences of the challenges experienced by the participants was emotional factors and a dependency on others.

### *Inability to perform activities or participate in previous roles due to impairments*

Participants expressed that they had difficulties walking as a result of the impairments of their lower limb.

P3 *"Don't want to walk too much as I can't move my leg easily"*

P6 *"My walk is a bit difficult with this foot but I can walk"*

They also expressed that they struggled with caring for themselves as a result of their upper limb impairments.

P5 *"I struggle to wash with this hand"*

Impairments were also highlighted as the reason for not being able to work.

P2 *"The difficulty is that I can't work, can't grasp anything"*

Or going out socially

P1 *"To be honest I will not even consider going out again... It is my leg"*

### *Emotional factors*

The participants expressed experiencing certain emotions as a result of not being able to do the activities they could previously perform.

P2 *"...sometimes I feel so depressed I will then just stand outside and look around"*

P5 *"I don't like it when it's dirty I angry very quickly"*

### *Dependency on others*

They also became dependent on others to care for them and take them the shops and for assistance with self-care.

P2 *"I can't do it anymore and need to ask for help"*

P6 *"Now I must take someone with me that must push the chair. So I just send the child"*

P7 *"If they can push me I can go to the shop...So if I come in the shop I'll look and so, what this costs and what that costs so then I can tell the person take this or leave that this or go to something else. It is unusual like before"*

## DISCUSSION

The current study explored the activity limitations and participations restrictions experienced by patients with stroke within the framework of the ICF (WHO 2001). It further explored the reasons why participants were not able to function as before. Information that also emerged from the interviews was the consequences of not being able to function as before. The impairments, activity limitations and participation restrictions identified in the current study were similar to what is presented in the literature, in both developed and developing countries (Rhoda et al 2011; Hartman-Maier et al 2007). The participation restrictions experienced by the participants also fell within the dimensions of participation as identified by the State of the Art Working Group on Community Reintegration (Resnik et al 2012).

The challenges experienced with regards to walking related to speed, environment and distance walked. The fact that the distance walked influenced the participants meant that they would be restricted to the surroundings of their homes. The participants also clearly expressed that the activity of walking was affected by impairments of leg activity. Other studies have also documented the influence of impairments on activity and participation (Dowswell et al 2000). Patients who have severe stroke would therefore have increased limitations in the ability to perform activities such as walking, which may decrease their ability to be reintegrated into their communities.

Another domain of activities and participation restrictions was related to self-care. Participants highlighted impairments specifically related to the upper limb as a limitation in their ability to care for themselves. This inability clearly led to the participants being dependent on others as is illustrated in a theme that arose in this study. The dependency on others often results in individuals

**Table 1: The Constructs according to the ICF**

Components	Domain	1st Level Classification	2nd Level Classification where applicable	Supporting Quotations
Impairments	Body Function	Structures related to movement	Upper limb	P4 <i>"I cannot do anything with my hand"</i> P5 <i>"I struggle with this hand, I don't want to take chances with this hand...I'll hurt myself with this hand to keep something. It's alright to grip but its' difficult to leave"</i>
			Lower limb	P2 <i>"...because can't move my leg to easy".</i> P1 <i>"My leg did not recover fully"</i>
Activity limitations	Mobility	Walking and moving	Walking	P3 <i>"Can't walk normal, can't walk properly have to drag the leg"</i> P8 <i>"I walk but I walk only from here till by the gate and back again"</i>
		Moving around using transportation	Using public transportation	P6 <i>"...Going to the hospital and stuff like that and then pay for that wheelchair... You pay a person's fair"</i> P1 <i>"and to travel like I use to travel before, I had to wait for a lift"</i>
			Driving independently	P2 <i>"I can't drive anymore"</i>
	Self-care	Washing oneself		P2 <i>"I can't wash myself my wife needs to wash and dress me"</i>
		Dressing		P1 <i>"Need someone to tie the buttons of my pants"</i> P8 <i>"I can dress myself half way I can't maybe tie myself ... then they must help me"</i>
Participation Restrictions	Major life areas	Work and employment	Remunerative employment	P2 <i>"The difficulty is that I can't work, can't grasp anything"</i> P5 <i>"Yes I worked a lot Saturdays and Sundays,... now can't"</i>
	Domestic life	Caring for household objects and assisting others	Assisting others	P1 <i>"I cannot care for them [family] as before"</i>
		Acquisition of necessities	Acquisition of goods and services	P4 <i>"...I don't go to the shop or so forth"</i>
	Interpersonal interactions and relationships	Particular interpersonal relationships	Informal social relationships	P1 <i>"I lost some of my friends ...the thing is we don't see each other that often"</i>
	Community, social and civic life	Recreation and leisure		P1 <i>"I went out two months ago I went to a party. And to be honest with you it was difficult...to be honest I will not consider going out again"</i>
Environmental Factors (Facilitators)	Products and technology	Products and technology for personal indoor and outdoor mobility and transportation		P4 <i>"I can't walk far outside my house without my walking stick"</i> P7 <i>"I can't do without him (walking stick)"</i>
	Support and relationships	Immediate family		P6 <i>"Children do what they want but they're always here when I need them and then they are there for me..."</i> P7 <i>"...but I say they look really [well] after me"</i>
	Services and systems	Health services, systems and policies		P3 <i>"But with help of therapy everything got better"</i> P6 <i>"Especially by the therapy people they try to make things easier for you but they can only do so much"</i>
Environmental Factors (Barriers)	Support and relationships	Immediate family		P2 <i>"I can't touch the stuff in the house because my wife will shout at me, "leave it leave it you going to break it"</i> P6 <i>"...doesn't want me to touch things and don't do this and don't do that, but when I'm alone then I do it..."</i>

experiencing emotions such as frustration (Dowswell et al 2000). Associated with decreased upper limb function was the inability to drive as a result of decreased grip strength thus limiting independence.

Challenges with accessing transport can have far reaching consequences with regards to the inability to go out socially and even more participate in major life roles such as work. Costs were highlighted as a limitation to the use of public transport as patients had to pay additional fees for assistive devices such as wheelchairs. Within the participation domain the participants expressed restrictions with return to work, going shopping or engaging in other leisure activities and social interactions. These findings support the findings of previous studies (Hartman-Maier et al 2007; Daniel et al 2009). The lack of an ability to return to work also often results in a role change for the participants. Where individuals were providing for their families there has now been role reversal and they now became dependent on others (Resnick et al 2012).

The contextual factors that impact on the participants' ability to perform activities and participate included the support provided by the family and the provision of rehabilitation services. There is currently limited evidence available about the influence of social support in the outcome of patients with stroke. It does however seem to have a positive effect on the outcome of these individuals as was previously reported (Kahonde et al 2010). The involvement of caregivers and family members in the rehabilitation process are supported by healthcare professionals as they play an important role in the recovery of individuals with stroke. The caregivers should however be informed that they should allow the individual to do things independently where they are able to do so. Participants in the current study highlighted not being allowed to do certain things and in this case the family support becomes a barrier.

## CONCLUSION

Qualitative research is an effective method to explore concepts that is often not identified using quantitative

approaches. The results of this qualitative study indicate that researchers can explore the experiences of stroke patients within the ICF framework. Thus in the rehabilitation of stroke patients the focus should include addressing functioning and disability as well as contextual factors.

## LIMITATIONS OF THE STUDY

Qualitative studies cannot be generalized but the information provided within the context is meaningful for others. The deductive nature of the study could also have limited further exploration of the concepts. The exclusion of stroke patients with cognitive and speech impairments was also a limitations as patients with these impairments could have had a different experience relating to functioning.

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