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The meaning of participation to stroke survivors: a qualitative study

Research article

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Abstract

Background/aims: The effect of stroke can be all encompassing, and have an impact on significant roles in life. Assessing someone's level of participation is seen as essential to understanding the social impact of a disability on a person's life, and tailoring support accordingly. This study aimed to examine the meaning of participation to stroke survivors, in order to provide insight into the meaning of participation in the context of a stroke.

Methods: A qualitative approach drawing on methods of phenomenology was used, with data collected via semi-structured interviews and a follow-up focus group. Analysis was undertaken using techniques of Interpretative Phenomenological Analysis.

Findings: Six stroke survivors and six carers were interviewed, and four stroke survivors attended a focus group. Three main themes in relation to the meaning of participation were identified in the data: 'being actively involved'; 'making meaningful choices'; and 'being me'.

Conclusions: The work confirms the findings of previous studies on participation, and adds to current understandings by developing the meaning of "involvement" beyond a social concept. It highlights that "involvement" can include active engagement in life through being alone. It also identifies a specific link between stroke survivor sense of self, and participation.

Keywords: stroke; participation; identity; qualitative research; stroke survivors

Introduction

Approximately half of all people who have had a stroke may be left with a long-term disability, which can include physical, cognitive and communication changes. All of these affect the capacity to manage everyday life (The Stroke Association 2008). Survivors of stroke may view recovery as a return to all aspects of their former existence (Thompson & Ryan 2009). However, it has been found that the impact of stroke on a person's social roles and activities remain, even when physical abilities have been restored (Hoffmann et al. 2010).

The process of recovery from stroke is generally seen in two phases: firstly, that of the acute phase immediately after the incident where the patient is likely to be hospitalised; and secondly, a period of rehabilitation which may be spent in hospital, in a special rehabilitation centre, or at home. The level of disability may make a return to work too difficult, and the

individual can be left with limited opportunities for, and reduced participation in social roles including household management and recreation (Hinckley 2002).

The International Classification of Functioning, Disability and Health (ICF), defines participation as “involvement in a life situation” (World Health Organisation, 2001). In this classification it replaced the previously used term “handicap”, which came to be seen as a negative descriptor. The inclusion of the term “participation”, in the ICF (2001) represents a shift in healthcare and research, to a more holistic view of rehabilitation and recovery. This takes into account the impact of personal and environmental factors in how a person’s disability affects their life (Brown et al 2006).

Assessing someone’s level of participation is seen as essential to understanding the social impact of a disability on a person’s life, and tailoring support accordingly (Cardol et al. 2000). However, while there have been attempts to define the term “participation”, there is no universal agreement as to exactly what it means. The definition of participation and participation restriction found in the ICF has been described as “intuitively satisfying” but “difficult to measure” (Scherer, 2006). Many measurements of participation are based on the former concept of handicap, or use a specific list of activities. There is a need for a deeper knowledge of the patients’ own perceptions of what participation is (Lund et al., 2005).

A small yet growing body of qualitative research has emerged, which aims to view the experiences of participation in the light of the participants’ own understanding of the concept. While there have been few studies exploring participation for stroke survivors, several studies have attempted to define participation in other groups. Mars et al. (2008) for example explored the concept of participation for older adults with a chronic physical illness. They identified four domains of social participation: social contacts and social activities; work and informal support; cultural activities and public events; and politics and media. Hammel and Magasi (2008) aimed to establish the meaning of participation for disabled people from an “insider perspective”. They presented the results as a cluster of values which defined participation encompassing: meaningful engagement/being part of; personal and societal responsibilities; having an impact and supporting others; social connection, inclusion and membership; access and opportunity; choice and control. The participants described the need to define and pursue participation in their own terms, rather than meeting pre-determined societal norms.

The aim of the current study was to build on this work in other groups, to investigate the experiences of stroke survivors, and to identify elements that capture the essence of the meaning of participation to stroke survivors.

Methods

The study used a qualitative approach drawing on methods of phenomenology. Phenomenology aims to examine the person as whole, and explore their relationship with their physical and social environment (Carel, 2011). The approach is valuable for examining a person's experience of illness, in order to illuminate this experience and enable healthcare providers to enhance their understanding of it (Carel, 2011).

Recruitment

Convenience sampling was used to recruit stroke survivors and their family carer due to the time and geographical restrictions of the study. A notice inviting participation was put on a popular and well-used local information and web forum. Other participants were recruited via word of mouth, a women's health group for Asian women, and via colleagues working with stroke survivors.

Data collection

Semi-structured interviews were used to enable in-depth description of participation. Participants were interviewed either at their home, at the University, or in a public place according to their preference. Interviews consisted of open ended questions around the topic of participants' perceptions and perceived importance of "participation" (see Appendix for interview topic guide). A focus group was also carried out later in the study to further explore themes identified during the interviews.

One third of people will have communication difficulties following a stroke (Department of Health 2007). Including people with communication and cognitive difficulties in research is challenging, and people with communication difficulties are often excluded. This study enabled stroke survivors with limited communication to be included by using a total communication approach (Lawson et al. 2001). In this method any form of communication is encouraged (such as gesture or writing) so creating flexibility in means of communication.

Setting and timescales

Interviews and the focus group took place in the local area, between January and May 2010.

Data analysis

The interviews and focus group were recorded and later transcribed, and notes were also taken. Analysis of the data was carried out in parallel to data collection, drawing on techniques of interpretative phenomenological analysis (IPA). This method compares individual data from individuals or “cases” to build a picture of the “essence” of a phenomenon and develop an understanding of how people make sense of their major life experiences (Jonathon et al., 2009). Although there is no single prescribed method of data analysis for IPA, the steps suggested by Smith et al. (2009) were used to guide the analysis. This involves: familiarising themselves with an interview by listening and reading a transcript many times, before making initial notes of the transcript of a descriptive, linguistic and contextual nature. Emergent themes are developed from these initial notes, and these are then organised in relation to each other. These steps are repeated for each interview, with the additional task of looking for patterns across cases with the researcher moving back and forth between steps as understanding of the findings develops. While the results of an IPA analysis may be similar to that of a thematic analysis, there are significant differences in the process. Thematic analysis focuses mainly on patterns of meaning across participants, while IPA has a dual focus, looking at both the unique characteristics of the individual, and also the patterns of meaning across individuals. Within IPA coding starts with one data item (e.g. interview) and themes are developed for this data item before progressing to the next, unlike thematic analysis where themes are developed over the entire data set. A sample of the data and analysis were reviewed by a fellow researcher.

Ethical considerations

The study received ethical approval from the university department ethical approval panel. Potential participants were informed about the research with the aid of an information sheet and asked to sign a consent form prior to the interview/focus group. These documents were designed to be accessible for people with aphasia, using simple sentences, and picture prompts. All participants were screened prior to giving consent with the Six Item Cognitive Impairment Test (Callahan et al. 2002). This screening was used in order to assess the participants’ ability to give informed consent rather than acting as an exclusion criterion. The information gained helped to identify modifications that should be made to the interview/focus group process. The interview data were transcribed and anonymised. Study

forms and interview transcripts was protected by being in a locked filing cabinet or stored on a password-protected computer.

Findings

Six stroke survivors and six carers were interviewed. Four of the six stroke survivors also attended the focus group. Of the four who attended, three had some degree of aphasia which limited their communication ability. See Table 1 for characteristics of the participants.

Insert Table 1 here.

Analysis of the data provides insights into the meaning of participation within the context of stroke. Three main themes in relation to the meaning of participation were identified in the data: “being actively involved”; “making meaningful choices”; and “being me”. These themes are outlined below and relationships between the themes are illustrated in Figure 1.

Insert Figure 1 here

Being actively involved

Words that people used to describe participation had common elements which suggested an active involvement and related to the subthemes of “taking part” and “being needed, wanted and useful”. This suggested that for individuals in the study participation means not only being present, but also having an active role, for example:

“It means taking part, being one of the team...a cog within a wheel”

The stroke survivors described how participation meant being part of something, which involved working in co-operation with others. While this could be experience of work, study, or involvement in community activities, others used partaking in the research as an example of taking part. Merely being present at an activity did not necessarily constitute participation. Physical and communication problems meant that even if they could be physically present in a situation, stroke survivors were often not fully included in it, and communication was particularly important in this regard:

“The communication is between them. I mean I’m still in it but I’m much less”.

Participation had an element of being needed and wanted, and people gave examples of times they had been asked to do things, such as helping with arrangements. Stroke survivors often

felt less needed as other people in their life had taken over certain responsibilities that they could no longer manage, for example:

“I was the dad, dad had to sort some things out, d’y’know what I mean, if there were some problems, but now the lads talk to my wife.”

Making meaningful choices

It was evident that participation involved an element of choice, and this manifested in three main ways, “personal meaning of participation”, “the power to choose”, and “independence”.

It was clear from the wide range of examples given for “participation”, that participation is a subjective concept, and whether activities are seen as participation depends on their meaning to the individual. Family was a big factor for all participants, and work was for those who had been working prior to having a stroke. Some respondents specifically mentioned friends and social life, whereas other talked more about a community level participation. Ultimately it was the meaning that the activity had for the individual, rather than the activity itself, which defined it as participation. The distinction between activity and participation was discussed in the focus group, where one participant suggested that personal choice was central to the distinction, participation being:

“Something that you like doing and you want to be doing it”

Whereas activity was:

“Something that you’ve got to do.”

For stroke survivors, a degree of choice may be removed if they are not able to participate in the way that they would wish to. One participant was reliant upon carers coming into her home, and so was not even able to choose when to eat or drink, or use the toilet. For another, being outdoors and doing outdoor activities was one of the main ways he participated however since his stroke he was not physically able to do many of the things he used to do, and even simply going for a walk outside seemed daunting:

“Even though I love being outside I’ve got no confidence to do it anymore.”

Participation was often seen as something done with others, involving interaction, however it could also be perceived as an individual activity:

“It’s being involved with other people and doing things with others and individually as well.”

Being able to do favourite activities alone which had always been done alone, was described as a form of participation. The need to have someone with them for such activities post-stroke was described as a key change to life. It was not only important to be able to do loved activities alone, but to have time alone to contemplate life was seen as a way of participating in ones’ own life.

Being me

It was apparent that participation had a profound meaning for stroke survivors, that of defining who they are. “Doing” and “being” were often mentioned simultaneously, suggesting that they are intertwined. Stroke, which had an impact on what the participant could do, ultimately had an impact on their sense of self:

“I want to be that person that I was...I’ve lost so much of the Mary that I used to know, sometimes I look back and I’m not exactly sure how much of it I am anymore.”

The impact of stroke on participation meant that stroke survivor’s roles often changed. This was most notable in the younger participants, however the role change seemed to be experienced by all participants to some degree, and they all felt the loss of useful activity in their life:

“People don’t tend to come and see you as much as they used to, cos you’re of no use to them really. Can’t take the kids out any more y’know, can’t pick the kids up”.

It was acknowledged by participants that the stroke had an impact on their identity, but many referred to feeling that they were the same person inside. How people saw themselves had an impact on their attitude to rehabilitation following the stroke.

“I couldn’t walk for the first couple of months, so my son bought me a wheelchair. I had longer hair and my son said I looked like Father Ted, y’know cos my hair’s grey, so I threw the wheelchair and forced myself to get a walking stick and walk up and down, so y’know you have to push yourself.”

Self-image seemed to have an impact on confidence which in turn affected participation:

“I don’t think there’s ever been a time up until this thing, where I would ever walk away from something...that side of me has totally gone”.

It was not easy to distinguish between the participants’ awareness of how they saw themselves, and how others saw them. Other people’s reactions often brought home to stroke survivors how they appeared following their stroke:

“I couldn’t work out why everybody looked as sad as they did, I don’t want to see that on people’s faces. So I think a lot of that was I was worried what other people perceived me as.”

Some participants were concerned that they appeared drunk or stupid, because people did not know what was wrong with them:

“I must look like I’m drunk. I’m not steady either.”

One participant mentioned that he sometimes needed to ignore his family’s concern for him in order to continue to participate in the way that he wished:

“They don’t want me to do any participation, active participation in the politics, because I don’t feel well health-wise and they are worried for me. But sometimes I listen to them and sometimes I don’t listen to them.”

“How others see me” was part of a two-way relationship between ‘being me’ and participation. Participating helped people to feel like themselves, while ‘being me’ also gave people the confidence to participate. “Being me” appeared to be an important aspect in the meaning of participation, and to be profoundly affected by people’s experience of participation following stroke.

Discussion

This study used a qualitative methodology to investigate in depth the multiplicity of the experiences of stroke survivors and to identify elements that capture the essence of the meaning of participation to stroke survivors. Three main themes in relation to the meaning of participation were identified in the data: “being actively involved”; “making meaningful choices”; and “being me”.

Many of the findings of the present study are congruent with the results of other studies seeking to explore participation. The sub-theme of “active involvement” for example has

similarities to the value “being part of”, found in the Hammel and Magasis, (2008) study. It would also encompass concepts described by other authors such as “doing things for others” (Haggstrom & Lund 2008), “being engaged” (Hjelle & Vik 2011), and “contributing and receiving resources from society” (Mars et al. 2008). The study also confirms other work (Barclay-Goddard et al. 2012; Hammel & Magasi 2008) in illustrating the multiplicity of activities which may be considered participation to an individual, and highlighting that it is the meaning of the activity, rather than the activity itself, which distinguishes it as participation.

The theme ‘being me’, reflects findings within the previous literature around illness/stroke and the self. Clarke (2003), while not specifically mentioning participation, touches upon many relevant issues in her discussion of how role and activities impact upon identity, and Robison et al. (2009) make a link between resuming valued activities post-stroke, and sense of self. A review of the literature by Salter et al., (2008), emphasised the way in which the stroke challenged the stroke survivors sense of self, and Lamb et al. (2008) found from their review of studies concerning the psychosocial spiritual aspects of stroke, the idea of ‘connectedness’, an important aspect of recovery which involved partaking in previously valued spiritual and religious activities. These can be seen as activities central to the stroke survivor’s sense of self.

The area in which the results of this work differ from other studies, is that of expanding the concept of “involvement” beyond a social concept to include active engagement in life through being alone, either by doing loved activities alone or engaging in contemplation of life. Also, the specific link between stroke survivor sense of self and their perception of participation, has been little explored in previous literature. Murray and Harrison (2004) for example describe “disrupted embodiment and the loss of self” among stroke survivors although do not explore how this might impact on participation. In the present study, the meaning of participation to stroke survivors goes further than just “doing”, to them it was about “being”. What they did defined who they were, so when they lost the ability to participate in certain activities, this affected their self-identity.

Clinical implications

The study highlights that each stroke survivor has a unique experience of participation, and what is considered to be participation for one stroke survivor may be different for another. Therefore, it highlights the benefits of individualised approaches to rehabilitation as best

assisting stroke survivors to participate in a way appropriate to their own needs and preferences.

The National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2012) recommend that rehabilitation goals should be meaningful and relevant, suggesting that the importance of participation is already becoming recognised in evidence based practice. The emphasis on the importance of the personal meaning of participation adds to the argument of some researchers (Hammel & Magasi, 2008), that standardised measures of participation may not capture the full meaning of participation. The present study identified features of the essence of participation, which underlie the subjective meaning it has for the individual. This suggests the potential for using the concept of participation in a way which may be beneficial for people working with stroke survivors. A more appropriate approach would be to address skills and deficits, emotional and social needs, and create joint goals between the stroke survivor and the person working with the stroke survivor.

Areas for future research

The finding of this study that the concept of “involvement” is more than a social phenomenon and should include active engagement in life through being alone, is important for the conceptualising of participation, and is an area of interest for future research.

Future research should also further explore the link between participation and self-identity in stroke survivors, as while both participation and self-identity are already discussed in relation to stroke within the literature, the link between participation and self-identity in relation to stroke has not yet been fully explored. Some authors have argued that a weakness within the ICF (World Health Organisation, 2001) is that activities and participation are not clearly distinguished (Mars et al., 2008). It is generally recognised that for the successful application of the ICF a distinction between these components needs to be made. The current research may provide insight into how the two components can be differentiated, particularly that choice and meaning may be central to the distinction.

Limitations

Qualitative analysis gives a central role to the researcher, and an inherent feature of IPA is the double hermeneutic - meaning that events are interpreted firstly by the participant and then by the researcher. Therefore, the presented interpretation of the data must be seen as only one possible interpretation. A small sample size is advantageous in qualitative research

in order to achieve the depth of analysis required, but makes it difficult to generalise the findings of this research to all stroke survivors. However, the study provides important insights into the concept of "participation" among our participants which may be applicable to the wider population.

Conclusions

Participation has become a concept of growing importance in stroke rehabilitation literature, but is currently ill defined. This research provides an examination of participation from the perspective of stroke survivors themselves, and suggests a link between participation and the impact of stroke of self and identity, which would benefit from further examination in future research. It emphasises the importance of individualised approaches to rehabilitation, as best enabling stroke survivors to participate in a way appropriate to their own needs and preferences.

The authors declare no conflicts of interest.

Key points

- Assessing someone's level of participation is seen as essential to understanding the social impact of a disability on a person's life and tailoring support accordingly, but while there have been attempts to define the term "participation", there is no universal agreement as to exactly what it means.
- The findings identified features of the essence of participation, which underlie the subjective meaning it has for the individual. It emphasises the importance of individualised approaches to rehabilitation.
- The findings suggest a link between participation and the impact of stroke of self and identity.

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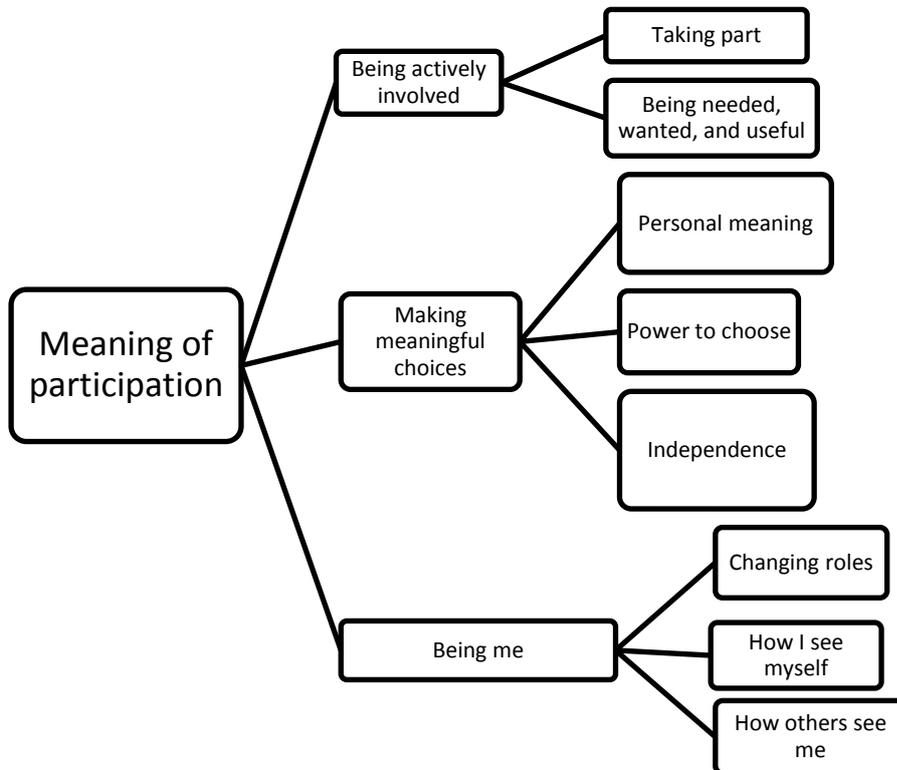
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Table 1. Participant characteristics

Stroke Survivors	Age	Ethnicity	Language	Aphasia
1	66	Pakistani	Punjabi/English	Yes
2	68	White German	German/English	Yes
3	56	White British	English	Yes
4	48	White British	English	Yes
5	54	White British	English	Yes
6	60	White British	English	No
Carers				
1	68	White British	English	
2	47	White British	English	
3	55	White British	English	
4	41	British Pakistani	English/Punjabi	
5	58	Pakistani	Punjabi	
6	16	White British	English	

Figure 1. Themes and subthemes in the data



Appendix Interview topic guide

Can you tell me what happened around the time you had your stroke?

Can you tell me what life is like now?

What does the word participation mean to you?

Is participation important to you?

Does anything prevent you from participating in the way that you would like to?

What helps you to participate (personal, social, environmental factors)