An Interpretative Phenomenological Study of the Experiences of Stroke Patients’ and their Careers’ During One Year of Rehabilitation

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Abstract

Stroke is the third leading cause of death and one of the leading causes of disability in the United States. The transition from hospital to home has been described as a distinct rehabilitation period for individuals with stroke. As most research to date has quantitatively assessed the outcomes among patients of stroke diagnoses, less is known about the experiences of stroke patients and their caregivers. The current study has been designed to examine the experiences of stroke patients’ and their carers’ during the one year of rehabilitation. Qualitative interviews with 10 stroke patients, age range 42-61 years (8 persons with cerebrovascular accident and 2 with subarachnoidal hemorrhage) and their caregivers over the course of a year (i.e., 1, 3, 6, 9 and 12 months) were analyzed using interpretative phenomenological approach through semi-structured interviews. Reading and re-reading of each interview transcript several times led to identification of several themes and sub-themes. Three major themes emerged, namely: The concept of Reality adjustment; The grown self; and The limited support for carers. All interviews led to unraveling of these three major clusters under each of which several themes were identified, some common to multiple cases and some unique to individual cases. These themes highlight the significance of the transition phase in the process of adjustment and that transition is characterized by adapting to a new normality. Research has highlighted the significant adjustment for individuals with stroke and their carers’ particularly in relation to identity change, appraisal and coping.

Keywords: Stroke, Interpretative phenomenological approach, Reality adjustment, Grown self, Burden.

INTRODUCTION:

Stroke is third leading cause of death and one of the leading cause of disability (Agency for health care policy and Research, 1995). Stroke leads to significant impairments in physical, cognitive and psychological functions among patients. Limitations in the functional abilities are experienced among stroke patients. In the first three months rapid neurological and functional recovery occurs among the stroke patients. Stroke leads to disruption in the activities of daily living like dressing, bathing, feeding, toileting, grooming, and transfers, e.g., bed to chair and in and out of the bath. The transition of the patients from the hospital setting to the home setting leads to increased stress, long-term social, emotional consequences, feelings of uncertainty and perceived burden of care (Wyller, 2003). Thus, the experience of stroke poses a significant challenge to both stroke survivors and their caregivers.

Psychosocial transitions also occur when a major life change requires an individual to restructure ways of looking at the world and to develop new and adaptive ways of living in it (Parkes, 1971). Parkes (1971) found that in the initial first 10 weeks after hospital discharge depression decreased among the primary caregivers of stroke patients but family dysfunction increased during this time period (Parkes, 1971). Studies have shown that the transition process from hospital to home is initially chaotic with changes in family relationships and caregivers’ struggle to cope with physical and emotional exhaustion (Bull, 1992; Fraser, 1993) which is followed by a phase of reorganization (Fraser, 1993). There is a paucity of research on how persons with stroke and their caregivers experience their interactions in daily situations in the home and how social interaction changes over time. Studies have also shown the evidence of a positive outcome when families are
involved in the rehabilitation process of the stroke patients (Smith, Forster & Young, 2009; Turner, Fleming, Ownsworth & Cornwell, 2008). This knowledge can serve as a basis for the development of effective rehabilitation programs for both the person with stroke and their caregivers. The aim of the study was to examine the experiences of patients’ of stroke and the carers’ during the first year of rehabilitation.

METHOD:

A qualitative research method with an interpretative phenomenological approach was used. A semi structured interview guide was developed to allow for open-ended questions, asking the patients and their carers to describe their experiences freely and openly. This approach allows exploration of the experiences of individuals with stroke and their carers and recognizes that individuals construct their own meanings of the world and life experiences.

Participants

A total of 10 participants and their carers were chosen for the study. The inclusion criteria for participation were: first stroke less than one month ago, ability to understand and respond to interview questions, limitations in the performance of daily activities and ability to recall daily experiences. All participants received information about the study and gave their informed consent to participate. The study was approved by the hospital ethics committee. The demographic details of the interviewees are presented in Table I.

Table I. Participant’s characteristics.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age (years)</th>
<th>Diagnosis</th>
<th>Marital Status</th>
<th>Carer</th>
<th>FIM(motor/cognitive)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>61</td>
<td>LCVA</td>
<td>Married</td>
<td>Spouse</td>
<td>89/28</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>51</td>
<td>LCVA</td>
<td>Married</td>
<td>Spouse</td>
<td>90/5</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>48</td>
<td>SAH</td>
<td>Married</td>
<td>Spouse</td>
<td>69/5</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>55</td>
<td>LCVA</td>
<td>Married</td>
<td>Spouse</td>
<td>89/35</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>42</td>
<td>RCVA</td>
<td>Married</td>
<td>Spouse</td>
<td>67/14</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>54</td>
<td>SAH</td>
<td>Married</td>
<td>Spouse</td>
<td>90/27</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>57</td>
<td>RCVA</td>
<td>Married</td>
<td>Spouse</td>
<td>65/23</td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>48</td>
<td>RCVA</td>
<td>Married</td>
<td>Spouse</td>
<td>56/22</td>
</tr>
<tr>
<td>9</td>
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<td>45</td>
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<td>Married</td>
<td>Spouse</td>
<td>69/5</td>
</tr>
<tr>
<td>10</td>
<td>M</td>
<td>52</td>
<td>LCVA</td>
<td>Married</td>
<td>Spouse</td>
<td>6714</td>
</tr>
</tbody>
</table>

M: male; F: female; LCVA: left cerebrovascular accident; RCVA: right cerebrovascular accident; SAH: subarachnoidal hemorrhage; FIM: Functional Independence Measure (motor maximum score 91, minimum score 13; cognitive maximum score 35, minimum score 5).

Data collection

The longitudinal interview data collection was done at months 1, 3, 6 and 12 post-stroke in locations convenient to the participants. At 1 month post-stroke the participants were contacted as inpatients at a rehabilitation hospital. At 3 months and during the rest of the year, the participants were outpatients at the rehabilitation department. The interviews were conducted by the author. During the interview, patients of stroke and their caregivers were asked to express their thoughts on: (a) Experiences of returning home after stroke; (b) Training, and information provided to support the stroke patient; (c) Changes in physical and psychological well-being; (d) Participation in activities of daily living and social activities; (e) Changes in the temporal order of daily routines and activities; and (f) Disruptions
in sense of self and the experience of time. Following each interview session, comprehensive field notes were written, which chiefly included word-for-word transcriptions of the tape-recorded interview as well as the author’s feelings and reflections.

Data Analysis

Data analysis began after all the interviews had been completed. Data analysis was done by the interpretative phenomenological approach (IPA). IPA draws on three theoretical underpinnings: phenomenology, hermeneutics and idiography. The guidelines IPA recommended in data analysis consists of six steps which need not necessarily be linear and need not be strictly adhered to: repeated reading of the transcripts; writing exploratory notes; development of emergent themes; searching for connections across the themes; move from case-by-case to multiple cases; and search for patterns across cases. No data analysis software was used at any stage; the entire process was carried out manually using Microsoft Word for collation and presentation.

RESULTS AND DISCUSSION:

Reading and re-reading of each interview transcript several times led to identification of several themes and sub-themes. Case by case analysis was first completed where repetitive themes were then dropped. After the case by case theme identification, the cases were compared and clusters of themes were identified. Three major themes emerged, namely: The concept of Reality adjustment; the grown self; and the limited support for the carers.

The concept of Reality adjustment

An important cluster of theme that emerged from the participants’ experiences during the rehabilitation was the concept of reality adjustment through acting with others. The participants got to know about their psychological and physical well being post stroke through interactions with others in the process of rehabilitation. In the current study, developing one’s own way of being and acting was the most significant and repetitive theme in the cluster of reality adjustment. Through others reactions participants were developing their own way of being and acting in their “new world” after stroke. Through daily activity situations together with significant others they gained reflections that led to reality adjustment. For instance, Participant No.8 emotionally described how, at the end of the year, his children were sad when they experienced him as another person “They are actually getting very sad, because I’m not the same father as before. I forget things and I have turned out to be different” (12 months). Stroke leads to initial concerns on patient’s survival during the acute phase of treatment followed by the loss of independence (Bury, 1982). The transition from hospital to home involving changes in identities, roles, and behaviors (Schumacher & Meleis, 1994). From the participants’ responses increased sense of belongingness surfaced as an important sub-theme under reality adjustment cluster and may be comprehended as an extension or consequence of the previous theme of interpretation of each other. Yet, new forms of connection also emerged through doing these daily activities together with significant others they gained reflections that led to reality adjustment. For instance, Participant No.8 shared that “My wife understands what I mean even before I say something” (3 months). Thus, a sense of belongingness is also fostered among stroke patients (Hammell, 2004). The results of this study, then, support future proposals to study subjective experiences of the stroke patients and their caregivers and also supports the contention that observations or external measures alone do not capture the complexity of ‘lived experiences of people’ (Haggstrom & Lund, 2008).

Participants also shared how their family members were “interpreting each other” in daily activity situations and were finding ways of doing things together in the post stroke situation. An important theme that surfaced under reality adjustment was interpretation of each other by the family members during the rehabilitation. For example, one of the participants Participant No.10 described the
automaticity in doing, helping him when dressing, that had developed between him and his wife:
“There are many things that are functioning automatically. When I’m putting my shoes on, my wife automatically comes and ties them” (3 months). Thus, a better knowledge of the patient’s life context may assist in designing meaningful and effective rehabilitation programs for them (Liu, Chan & Chan, 2005; Blickem & Priyadharshini, 2007).

Grown self

Grown self emerged as a significant cluster of theme from the responses shared by the stroke patients during the process of rehabilitation. In the current study, comparison with other patients was the most significant and repetitive theme in the cluster of grown self. From time to time, patients with stroke constantly engaged in comparison with other patients having “more negative condition” and presented apparently more severe stroke symptoms. To illustrate, Participant No.1 recollected said “A lot of people are worse off than I am, I am getting better; they never will.” He occasionally soothed his feeling of grief about his loss when he saw some patients in the hospital who sustained severe stroke symptoms (6 months). Reinterpretation of life also came up as one of themes under the comparison with other patients cluster. Moreover, the participants compared themselves not only in terms of impairments accompanied by stroke but also of the positive impact of stroke on their entire lives. A typical example was found in Participant No.3 when she talked about a young friend with stroke who was 32 years old, she said ‘since I am 48 I have seen a lot of life and I feel bad for the younger people with stroke because this would have a negative impact on their whole life’ (6 months). This comparison certainly helped her to reinterpret her life as a whole. Thus, she repositioned herself by contrasting the two lives post stroke by adopting a broader outlook towards life. Motivation for future planning also emerged as a very important sub-theme. Also, the comparison with other people with stroke may allow the individual in fostering their motivation for future planning. Another male informant, Participant No.2, remembered that seeing other individuals with more severe stroke had been helpful in initiating thoughts about what he could do in future. He said, ‘I have decided to rejoin as a school counselor while wondering what I would be able to do in the future with my remaining strengths’ (12 months). For the individuals with stroke, the comparison with other people with more severe stroke symptoms may foster motivation and help in maintaining a sense of progress through the process of transformation and adaptation during the recovery process (Folden, 1994).

Another category that emerged under grown self cluster was contribution to positive characteristics. The experience of stroke had contributed certain positive characteristics to their lives. One type of this category commonly involved comparing their pre-stroke lives with their post-stroke lives. Participant No.4, for example remarked; “When I had stroke, it was kind of a balancing because it stopped my alcohol and cigarette use for a while” (1 month). Another informant, Participant No.6, also explained in detail that she was grateful to the stroke because she could stop cigarette thereafter. She admitted, “I left my cigarette after stroke” (12 months). Thus the experience of stroke brought on them new lives that they could not have been expected with their pre-stroke lives and thus they believed that they had experienced growth as a result of stroke. Understanding of oneself and others was still another theme that also came up under the contribution to positive characteristics theme. The participants also shared that the experience of stroke helped them to understand themselves and other people better. For instance, Participant No.4 said that he had discovered new strengths in himself that made him feel good about himself. He readily related; ‘Initially I thought that I am a weak person but now with time I have discovered that I am strong both mentally and physically, to face all the challenges posed by stroke. I like that feeling’ (12 months). Another participant Participant No.7 came to understand other people better by associating her stroke experience with their problems. She stated, “I think the stroke experience has contributed to my appreciation of other people’s ways of handling problems and I have made the future plan to become a rehabilitation counselor” (6 months). Thus, each of the participants presented their stroke experience as a momentum for growth and thus paved the ways for becoming better in the future. In the categories of “the grown self,” the self in time is virtually the main target in
narrating about oneself. Individuals with stroke focus on their past, present, and/or future to reorganize their life-stories. The acceptance of loss theory maintains that acceptance of physical disability often occurs with the person’s value change, such as subordination of the physique to non-physical characteristics (Dembo, Leviton & Wright, 1975). This represents reconstruction of one’s self-narrative found in the category of “grown self” that is described above. The category of “grown self,” for example, involves acquisition of a viewpoint to believe in one’s growth despite the challenges posed by the experience of stroke.

**Limited support for carers**

The third important cluster of theme that emerged was *limited support for carers*. The themes related to the limited support for carers included the *carer strain, lack of education and training of the carers and the burden of burden*. Care givers of stroke patients experienced both physical and emotional exhaustion. For instance, carer of Participant No.3 said ‘I am totally tired and it’s very demanding to take care of her and the family since she had stroke’ (1 month). In addition, carers reported that they now have to undertake tasks which were previously the responsibility of the other partner. Carer of Participant No.6 said that ‘After she had stroke I had to do all the home chores also. Now it’s a great burden on me’. Most carers shared that the experience of stroke has led to reduction in time for leisure and social activities that, in turn, limited their opportunities for much needed social support. Carer of Participant No.8 said that ‘Since he had a stroke I’ve not really gone out to attend family functions or out of station trips’ (6 months). The carers of stroke patients not only responded to new roles and responsibilities in caring for the stroke survivor, but also adapted to a new relationship with them. Participant No.1 said ‘I think the wife comes to me more as a carer than as my wife now and she shouldn’t be’ (3 months). Recovery across time following stroke involves both patient’s and caregiver’s struggle to adapt themselves and cope with exhaustion which is followed by a reorganization, during which life becomes more predictable and less stressful (Fraser, 1999). Most of the carers pointed out the inadequacy of existing medical fraternity to provide education and training to the carers. Carers thus felt neglected by the health professionals. Carer of Participant No.9 said ‘Doctors forget about the carer who is looking after the sick patient’ (6 months). Carers also experienced difficulty in responding to stroke patients’ emotional and psychological needs. Carer of Participant No.3 said ‘I just don’t know what to do with her depression. I feel helpless’ (12 months). Most of the carers shared their inadequacy in physically supporting the patient. Carer of Participant No.3 said ‘I wasn’t informed and trained by the doctors and nurses on how to physically support him. It was all trial and error learning for me’ (1 month). Lack of knowledge in the important aspects of stroke such as its causes and prognosis, secondary preventative measures and support has been identified as a source of anxiety and worry among both the patients and their caregivers, and may contribute to patient’s failure to achieve their maximal potential (Rodgers et al, 1999).

The perception of the *burden of burden* also emerged as a significant aspect here. The participants perceived the burden of care giving on their family and described how the stress induced by the stroke disrupted their social world. For example, the participants could no longer perform the household activities which led to increased responsibility and burden for their families. As Participant No. 10 recounted: “Now she is responsible for the entire family and I actually feel that my wife needs someone to support her and help her all the time” (3 months). Another informant Participant No.5 described how the stroke had added to the burden for his wife and how exhausted she was after being with him at the hospital for three weeks. He shared that “She has been coming regularly to hospital for two weeks, and wasn’t able to be there for the children and other things.” (1 month). The participant’s experiences in the study revealed that “caregiver burden” was also experienced as a burden by the stroke patients. This finding has not much previously been described in literature that focuses on the burden for relatives. The experience of stress and uncertainty may be placed on family members after stroke that negatively affects family life (Murray, Ashworth, Forster & Young, 2003).
CONCLUSION:

In the planning of the discharge, follow-up care and rehabilitation programs for stroke patients and their carers, the themes identified on reality adjustment, grown self and limited support for carers should be integrated as important focus areas to ensure that patients and their carers can resume a well adjusted life after the intervention. The majority of carers in our study were female spouses and therefore future research should address whether the identified themes are relevant to non-spousal carers such as daughters and male carers. Future studies, incorporating quantitative measures, could assess the generalizability of the current findings. This study adopted a qualitative research method to analyze data collected from a relatively small number of informants, which may appear to be another limitation. However, the qualitative method allowed a deeper analysis of participants’ lived experiences for this study.

REFERENCES: