

Being a stroke patient: a review of the literature

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Being a stroke patient: a review of the literature

The purpose of this paper is to review the research literature on the patient's experience of stroke. Four qualitative studies on how patients experience stroke were identified. The findings of these studies show that the stroke patient often has clear goals for himself in relation to functional abilities, against which he measures all success and forward progress in his rehabilitation. Even though the stroke patient accepts a lower level of functional ability, he is not willing to accept the rehabilitation professionals' prediction of his ultimate functional level if it is lower than his own goal. Furthermore, stroke patients see recovery as a return to the existence they had lived before the stroke, which is different from the health care providers' view. To the health care provider, recovery is measured in terms of isolated and discrete return of movement, whereas in the eyes of the patients, recovery is a return to previously valued activities. Further, studies on psychosocial function after stroke were reviewed. Recent studies show that the psychological impact of the stroke experience is immense and that stroke patients experience stress on a variety of levels. Also, depression exists in a large portion of the stroke population. The impact of stroke also influences the patient's social existence, as studies have shown that stroke patients do manifest diminished social function. However, the reviewed studies are not without limitations. Further studies, with a qualitative design, are needed to throw light on the patient's experience of being ill with stroke, and the process of his recovery.

Keywords: stroke, recovery, patients' experiences, satisfaction, depression, psycho social function

INTRODUCTION

Strokes are the third leading cause of death, and a major cause of disability in the western world today (Dickstein 1989). In The Netherlands the annual overall incidence is

1.74 per 1000 per year (Herman *et al.* 1982) and the prevalence is 6.48 per 1000 (Schulte & Gijn 1989). In the United Kingdom the incidence has been reported to be about 2–2.5 per 1000 per year, with a prevalence of about 6 per 1000 per year (Wade 1989). Most people with stroke are older adults and one-third die within a month. Of the survivors, two-thirds have some degree of permanent disability (Bronstein 1991). Because of their sequelae, strokes are categorized as a sudden-onset, constant course chronic illness (Wright *et al.* 1987).

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During hospitalization, the stroke survivor experiences stress on a variety of levels. In addition to the insult, which leaves the patient experiencing loss of movement, he is submitted to complex nursing and medical interventions. Also, there is a network of health care personnel to assist the patient, most of whom he does not know. Activities happen in close proximity to him, in a strange and unknown environment. It can be assumed that this may put an enormous psychological strain on the individual.

Recovery process

In most of the research literature, the overriding perspective is that recovery is analogous to the improvement of physical functioning (Lehman 1975, Garraway 1980, Andrews *et al.* 1982, Hamrin & Wholin 1982, Logigian *et al.* 1983, Wade *et al.* 1985, Lewis 1986, Mulder *et al.* 1986, Basmaian *et al.* 1987, Wagenaar *et al.* 1990, Salter *et al.* 1991). However, during the last years there is an increased awareness among health care professionals that recovery after stroke can not be measured purely by one's functional abilities. Researchers are incorporating standard psychological and social indices with activities of daily living (ADL) measurements in an effort to capture the realistic lifestyle stroke patients actually lead. However, these studies mainly evaluate patients at intervals of 3 months, 6 months and 12 months after the initial insult. Therefore, thorough description of the recovery process is lacking.

Little attention has been paid to research on the experience of stroke from the patient's point of view. Account of the patient's experiences during the recovery process is badly needed. The stroke patient's descriptions of his experiences during hospitalization and his responses to the experiences will help researchers to identify the potential process of the stroke recovery, and may also help nurses to individualize nursing care to meet the stroke patient's physical and psychosocial needs. Furthermore, the findings may assist nurses in altering the environment to improve the stroke patient's recovery and in helping them to adapt to their deficit.

REVIEW OF RESEARCH LITERATURE

The aim of this paper is to review the research literature on the patient's experiences of stroke. The reviewed papers revealed only one literature review (Doolittle 1988) and four nursing studies on the experience of stroke (Mumma 1986, Doolittle 1991, Folden 1994, Häggström *et al.* 1994). In addition, studies in relation to psychological changes (Robinson & Szetela 1981, Robinson & Price 1982, Robinson *et al.* 1985a, 1985b, House 1987a, 1987b, House *et al.* 1991, Whitney 1987, Thompson 1989, Bronstein 1991, Herrmann & Wallesch 1993, Whitney *et al.* 1994)

and social changes (Gresham *et al.* 1975, Evans & Northwood 1982, Stroker 1983, Parikh *et al.* 1987, Evans *et al.* 1992, Baker 1993, Rosenthal 1993) were reviewed.

The findings from the literature are organized into the following four sections: being a stroke patient; the experience of physical changes following stroke; the experience of psychological changes following stroke and the experience of social changes following stroke.

Being a stroke patient

In her longitudinal, descriptive, ethnographic study on the patient's experience of recovery following lacunar stroke, Doolittle (1992) conducted 120 interviews with 13 individuals over a period of 6 months. Lacunar stroke has been defined as: 'brain lesion of presumed ischemic origin having a maximum diameter of 1.5 cm' (Garcia *et al.* 1992 p. 135). In this study participants were interviewed within 72 hours of the infarct and also frequently during both the acute and rehabilitation phase of recovery. Each participant was followed-up after discharge either to their home or to an extended care facility for 6 months. The analysis of the interviews revealed the following seven themes: stroke as a bodily experience; stroke in evolution; meaning of hospitalization; living with uncertainty; differing medical and personal views; facing the night, and discharge home.

In relation to implications, four themes are described: plateau periods; experimentation; contextual preparation for return home; and personal experience as priority. The benefits of this study are, among others, that many interviews were conducted with each participant at various time points during the recovery phase. Thereby, it describes the stages of the first months of recovery from the patient's point of view thoroughly. Patients who have had a lacunar stroke commonly experience the recovery as having a sequential focus, with plateau periods and experimentation.

Because the study sample was limited to patients with lacunar stroke, the findings are only applicable to that patient group. However, lacunar strokes are only one type of stroke. A similar study, conducted with other types of stroke, for example haemorrhagic stroke, which might be followed-up over a longer period (up to 1 year after the stroke event) may be of much importance.

Patients' and spouses' perception of losses following stroke was the focus of an exploratory, cross-sectional study conducted by Mumma (1986). By using a combination of structured scales and open-ended questions, the researcher interviewed 60 middle-aged and older couples in which one person had suffered a stroke at least 3 months prior to participation in the study. The data were analysed using a combined qualitative and quantitative method. Content analysis of the responses yielded three major categories of loss: activities, abilities and independence. The

loss most often described by patients was mobility and travelling was most frequently described by spouses. In all phases after the stroke onset, independence was identified as a prominently mentioned loss for most groups.

In this study the range of time after the stroke at which the interviews were carried out was very wide, and varied from 3 months after the stroke up to 72 months or 6 years after the stroke. This influences the comparability and hence analysis of the data. The research, therefore, does not describe adequate strategies to deal with the differences due to time-frame. The validity of the data also suffers from the reconstruction of memories taking place, when a long time has elapsed between the event (the stroke) and the interview.

The author describes the data collection method used as semistructured interviews, when in fact a combination of structured scales and open-ended questions were used. In using structured scales and open-ended questions, the researcher chooses the questions to be asked from his/her own perspective, which may not be relevant for the patient in his illness situation. Therefore, the patient's point of view may not be fully ascertained.

Management of functional deficits

Folden (1994) conducted a qualitative study with a grounded theory design, the aim of which was to identify the process stroke survivors used to manage the multiple functional deficits produced by a stroke event during the first months after the stroke. Twenty participants, between the ages of 65–78 years, were interviewed for the first time in the rehabilitation facility within 2 weeks of the stroke event, and for the second time 3–4 weeks following discharge from inpatient rehabilitation. The process described by the participants ensured forward progress, which included accepting that life would be forever different, maintaining hope, preserving energy and increasing personal control over recovery.

In this study, Folden (1994) does not differentiate between what kind of stroke the patients had (nor the size nor site of the stroke). It is however, not unlikely that different types of strokes, with differences in onset, symptoms and sequelae, lead to differences in experience.

The stroke survivors' experience of living with stroke and their future expectations was explored by Häggström *et al.* (1994). Twenty-nine people, 60–91 years old, narrated stories about two different photographs, showing a person of the same age and gender as themselves, being fed or eating independently. The stories were analysed and interpreted by the phenomenological hermeneutical method. Four themes were found: uncertainty; sadness and mourning; gratefulness, hope, and satisfaction; and isolation. The stories were then condensed into four core stories. The emotional content of each core story was expressed by a metaphor.

In the study conducted by Häggström *et al.* (1994), 60 patients had non-embolic infarction, and only five patients had other diagnoses. Thus, most of the patients had cerebral infarcts. To what extent the information can be generalized to other types of stroke patients is questionable.

PATIENTS' EXPERIENCES OF PHYSICAL CHANGES FOLLOWING STROKE

During the days immediately following the stroke, especially if the stroke was still evolving, the uncertainty for the individuals was enormous. They described being completely awake and alert while the involved arm and leg became weak, frequently ending in complete paralysis of one entire side of the body. They further describe the lack of control over their bodies, not knowing when or where progression of the weakness would stop (Doolittle 1991). As previously described, the most frequently reported losses perceived by stroke patients are 'loss of physical activity' and 'loss of mobility' (Mumma 1986). When stroke patients identify themselves as having a stroke, they follow two distinct patterns. The first is self-diagnosis, in which some participants readily identified their symptoms as indicative of a stroke. These participants sought medical care immediately or consciously made a decision to delay treatment. The second pattern was diagnosis by others, whereby participants experienced vague symptoms and were diagnosed by emergency personnel or a physician (Folden 1994). Patients who had had a lacunar stroke described how difficult it was for them to understand how they could possibly worsen after they had been hospitalized and could still worsen following medical and nursing intervention (Doolittle 1991).

Having been diagnosed with stroke, the patients immediately set out on a path to recovery. The end of this path, getting well, was the accomplishment of personal goals (Folden 1994). In the study by Folden (1994) the patients' goals were related to improving functional abilities and returning to some of their former activities. Goals were set with the realization that returning to complete prestroke functional abilities was not a possibility. Even though the participants accepted lower levels of functional ability, they were not willing to accept the rehabilitation professionals' prediction of their ultimate functional level if it was lower than their own goal. However, in the study by Doolittle (1991), for participants recovery was seen as return to the existence they had lived before the stroke, or prestroke life. This was also different from the health care providers' view.

Views of care provider

To the health care provider, recovery was measured in terms of task performance, improved mobility and independence in self-care. Improvement was considered

in terms of isolated and discrete return of movement, whereas in the eyes of the patients recovery was a return to previously valued activities (Doolittle 1991). The process to recovery used and described by the participants ensured forward process, which included preserving energy, increasing control over recovery and maintaining hope. The most prevailing obstacle to getting better was the overwhelming feeling of fatigue, which made participants want to protect their time. They attributed their tiredness to sleeplessness and too much medication. Participants describe how they attempt to save energy for valued therapies which were necessary for goal achievement (Folden 1994). In the study by Doolittle (1991) participants described feelings of plateau in performance or 'going downhill', which were difficult times when individuals experienced declines in the return of strength and motor activity. These plateau periods occurred as early as 2–3 weeks following the stroke.

No participant was prepared for plateau periods, or informed of them by their caregivers, which caused frustrations. Doolittle (1991) suggests that these 'plateau periods' may be seen as periods of stabilization. During these periods patients need extra guidance and support.

PATIENTS' EXPERIENCES OF PSYCHOLOGICAL CHANGES FOLLOWING STROKE

During the initial evolution of the stroke, participants describe extreme shock and fear when they feel their arm and leg becoming increasingly weak. The suddenness of the stroke, the loss of body control associated with evolving weakness and the uncertainty set the scene for a shocked immobile self, and dismantled the person's life-world (Doolittle 1992). Throughout the process of acute rehabilitation the feeling of not having control continues (Folden 1994). The participants described having many sleepless nights and nightmares during this time. Insomnia was aggravated by the fact that they could not turn and had difficulties with moving their bodies (Doolittle 1992). These periods are described by participants as lonely and humiliating, especially when they needed assistance with toileting. The fear of not receiving such assistance was expressed by all participants. These descriptions show how shocking and frightening the initial evolution of stroke is to patients.

Rehabilitation process

As the participants progressed towards their goals, they perceived themselves as seizing control of their recovery. They felt confident in their ability to manage during rehabilitation as long as they were moving forward. Maintaining hope was essential, due to the slow process of getting better.

Their descriptions of the rehabilitation process were overwhelmingly directed towards the future. Hope was necessary to ensure their forward progress. The fear of setbacks, such as a fall or another stroke event, was forever present (Folden 1994). In the study conducted by Mumma (1986), patients with seemingly mild aphasia mentioned communication as a significant loss. Some participants could be extremely frustrated at being unable to communicate 'normally'. Also, losing the ability to move and having to rely on others for basic needs caused participants frustrations.

Depression in stroke

When caring for stroke patients, nurses and other health care professionals often encounter people who have depression. Sometimes the symptoms are subtle, but sometimes they encompass every activity that the patient does. Often the patient makes statements such as: 'Why bother to teach me how to dress? I can't do it anyway'. In earlier literature on stroke patients, authors described depressive feelings as an understandable emotional reaction to the patient's disability.

Robinson and colleagues have systematically studied depression in stroke patients (Robinson & Szetela 1981, Robinson & Price 1982, Robinson *et al.* 1985, Shinar *et al.* 1986, Parikh *et al.* 1987, Morris *et al.* 1992, Downhill & Robinson 1994). Their theory of post-stroke depression is explained as the behavioural manifestation of neurophysiological or neurochemical responses to brain injury (Robinson *et al.* 1983). That is, injury to specific brain structures produces pathological mechanisms that lead to the clinical syndrome of major depressive disorder (Robinson *et al.* 1990). Thereby, these researchers, among others, suggest that post-stroke depression may represent more than a simple reaction to functional impairment. Some of these studies, however, have been criticized for their methodological limitations, such as small number of subjects and the use of ill-defined selection criteria, among others (House *et al.* 1991).

Other researchers maintain that there is no conclusive evidence that depression found in stroke survivors differs from that found in patients with other physical illness (House 1987a, 1987b, House *et al.* 1991). Within this latter explanation, the authors maintain that depression does in fact occur as a result of the stroke, the patient's struggle to adjust to his losses and the whole experience of stroke (Mumma 1986).

Untreated depression

Interestingly, according to some studies, stroke patients were not being treated for their depression (Feibel & Springer 1982, Robinson & Price 1982). Recently, Bennett (1996) conducted a study on how nurses in a stroke rehabilitation unit attempt to meet the psychological needs

of patients who become depressed following a stroke. She interviewed 14 nurses on the subject. She found that the nurses were able to identify patients who were becoming depressed and tried to help them, to the best of their abilities. They felt constrained, however, mainly by the lack of appropriate training. The nurses wanted to be able to meet the needs of the depressed patients and thought that this could be achieved through better staff education and access to other health professionals experienced in providing psychological care.

The reported prevalence of depression after stroke varies widely, from 18% to 61% (House 1987b). In a recent prospective study, Åström *et al.* (1993) found that the prevalence of major depression was 25% at the acute stage and approximately the same at 3 months (31%), decreased to 16% at 12 months, was 19% at 2 years, and increased to 29% at 3 years. The most important predictors of immediate major depression were left anterior brain lesions, dysphasia and living alone. Consistent with this study, Whitney *et al.* (1994) reported that stroke survivors do show depression during the first 3 months of recovery. Morris *et al.* (1992) found that 38% (34 patients) had a diagnosis of major or minor depression. Also, Evans *et al.* (1988) found that, compared with community norms, stroke patients were reported to be more depressed, confused and anxious. House *et al.* (1991) found that stroke patients initially had a significantly higher incidence of depression compared with a control group of non-brain-damaged outpatients. These differences, however, had largely disappeared by 12 months. These studies show that depression does occur during stroke.

Location of lesion

In the acute post-stroke period, the single most important determinant of major depression is the location of lesion in the left anterior hemisphere (Robinson *et al.* 1985a, 1985b, Parikh *et al.* 1987, Åström *et al.* 1993, Herrmann & Wallesch 1993, Downhill & Robinson 1994). However, contrary to these findings, Feibel & Springer (1982) did not find a significant relationship between depression and the site of lesion. Studies have also shown that patients with right hemispheric damage also suffer from depression (Folstein *et al.* 1977, Whitney *et al.* 1994).

Depression has also been found to be significantly correlated with cognitive impairment for the first 6 months after the stroke (Parikh *et al.* 1987). Downhill *et al.* (1994) found that the frequency and severity of cognitive impairment was significantly greater in patients with major depression than compared with non-depressed patients during the initial hospital evaluation. The effect occurred predominantly in patients with major depression, following left hemispheric stroke. The association of depression and cognitive function was strongest during the initial evaluation but was present up to 1 year.

Patients with both depression and cognitive impairment had a greater duration of depression than depressed patients without cognitive impairment. Downhill *et al.* (1994) maintain therefore that depression with cognitive impairment appears to be a phenomenon produced by left hemispheric lesions. These authors suggest that left hemispheric stroke may produce depression through different mechanisms than lesions in other locations. However, other researchers have also reported no association between depression and cognitive impairment (Feibel & Springer 1982).

Dysphasia

Dysphasia is a frustrating condition with considerable psychological and social consequences which may contribute to depression. Stroke patients describe their inability to communicate as extremely depressing and frustrating (Mumma 1986). Robinson & Szetela (1981) reported a high depression rate in stroke patients with dysphasia. As mentioned before, dysphasia, together with left anterior brain lesion and living alone, has been found to be an important predictor of depression (Åström *et al.* 1993). However, dysphasic patients have often been excluded from studies, and therefore this association has been concealed.

One of the most important aspects of depression in stroke is the potential negative impact of depression on patient participation in the rehabilitation process and the associated rehabilitation outcome. Depressed stroke patients, in comparison to the non-depressed, have been found to evidence greater functional impairment at both admission and discharge (Sinyor *et al.* 1986). Furthermore, there was a significant correlation between depression and impairment in ADL, which peaked at 6 months and thereafter fell, but remained significant at 1 and 2 years post-stroke (Parikh *et al.* 1987). This is of special importance during the subacute phase of recovery, when rehabilitation efforts are thought to be most critical in defining outcome.

PATIENTS' EXPERIENCES OF SOCIAL CHANGES FOLLOWING STROKE

The striking impact of stroke reaches beyond the patient's physical and psychological being, as it also involves his social existence and lifestyle. During hospitalization following stroke, the patient is dependent on others and has to rely on health care personnel for his basic needs. Later on he has to rely on his next of kin for his basic and social needs. In the study conducted by Doolittle (1991) patients describe that because of the tremendous fear and uncertainty created by the stroke, they needed to regain a sense of control over their lives. In the acute stroke period, mental striving, i.e. directing the body with the mind, helped them to do this. Carefully thought-out actions gave

them a sense of control over their bodies, and through this they were dramatically involved in recovery. However, although they managed through effortful mental striving to regain a sense of bodily control, there was little opportunity to regain a sense of social control. Patients describe how bodily and social immobility facilitated dependency and powerlessness which led to lack of social control. Their lack of social control matched their lack of bodily control.

Recognition that depression was frequently found in stroke patients has led to questioning of its impact on the stroke survivor's social function. In the Framingham study, Gresham *et al.* (1975) reported that of the 119 stroke patients evaluated, 84% were living at home, 80% were independent in mobility and 69% were independent in ADL. However, only 29% were engaged in gainful employment, and 62% showed decrease in social activity. Social dysfunction has been found to be significantly related to depression only at 6 months (Parikh *et al.* 1987).

Social activities

Depression has also correlated significantly with failure to resume premorbid social activities, as depressed patients reported 67% decrease in social activities, while non-depressed patients reported 43% decrease in social activities (Feibel & Springer 1982). However, these authors point out that the association between lost activities and depression does not imply a causal relationship. They maintain that more studies of psychosocial adaptation to stroke are needed to define the temporal relationship of these variables. Evans & Northwood (1982) found that perception of social needs being met by the stroke patient was correlated with positive adjustment to physical limitations resulting from a stroke. They further indicate that social support appeared to be fostered by communication skills.

The literature identifies the importance of family involvement to the success of rehabilitation efforts of the stroke patient. Studies have shown effective family involvement to be related to functional improvement in stroke patients (DeJong & Branch 1982, Lind 1982, Brandstater & Basmajian 1987). Consistent with these findings, Baker (1993) found that stroke patients who completed a rehabilitation programme achieved a higher level of adaptation if they had a spouse present.

Rosenthal *et al.* (1993) studied which needs the wives of hospitalized stroke patients perceived as important, and the degree to which those needs were met by the members of the nursing staff. Of the 27 needs identified, the following four were perceived as the most important: (a) a wife's need to know what she could do to assist with her husband's care, (b) a need to be included in discharge planning for her husband, (c) a need to know that nursing personnel cared about her husband, and (d) a need to know what kind of activities her husband was able and/or would be

able to do. Interestingly, the wives perceived that 18 (66%) of the 27 needs were not well met by the nursing staff. These studies show the importance of involving the family member(s) in the nursing care plan for the stroke patient.

IMPLICATIONS FOR NURSING PRACTICE

The findings of the literature reveal various aspects in relation to the patient's experience of stroke and rehabilitation. Even though the focus of successful rehabilitation has been the restoration of lost function, this can not be the only focus, because as the patients themselves have described, subjectively recovery is marked by what matters to the person. The impact of the stroke causes physical, psychological and social changes for the patient, which lead to enormous frustrations and fears both for him and the members of his family.

The findings of the studies show that the stroke patient often has clear goals for himself in relation to functional abilities, against which he measures all success and forward progress in his rehabilitation. Those goals may be a return to full prestroke functional abilities, or to the existence he/she had lived before the stroke. The importance of respecting the patient's own goals in relation to his functional abilities should not be underestimated. Nurses may improve their patient's care by learning to know the patient's goals and by respecting those goals. Thereby, they respect the patient's own view about his progress and increase his own control of his own recovery. Protecting the patient from fatigue and preserving his energy by teaching him energy-conserving measures and limiting his mobility to certain times is emphasized in the literature. Further, informing the patient about 'plateau periods' and giving him support through those periods are equally important.

The psychological impact of stroke on the patient is great, because of the feelings of fear, uncertainty and loss of body control. These feelings continue from the onset of stroke and throughout the recovery phase. However, as the patient progresses towards his goals, he gradually gains control over his recovery. It is of vital importance for the nurse to provide information and emotional support for the patient and to foster hope during the whole process.

It is evident that depression often occurs in relation to stroke. What causes depression and failure to regain social function is, however, not clear. Change in body image and loss of body function, which also may cause social stigma, may cause grief to the stroke survivor. It is necessary for nurses to assess the patient as soon as possible, so that effective treatment measures can be taken. Several scales have been developed to measure depression in the stroke community. Detecting depression early in the recovery process, and evaluating depression regularly, is of great importance, particularly because depression has been found to have a negative impact on the patient's participation in the rehabilitation. It is important for nurses to

provide emotional support to the patient, to be present for the patient and to give him the opportunity to talk about his/her feelings.

As dysphasia in stroke patients has been found to contribute to depression, it is of the utmost importance for the nurse to use helpful communication methods and teach the patient effective communication techniques, so that he may be able to communicate his own thoughts. It has been recommended that nurses have access to educational programmes and training in psychological care and counselling skills when caring for the stroke patient (Bennett 1996).

There is not only need for theoretical knowledge but the need for a body of supportive practical nursing skills and behaviours which can be used with patients in distress. Furthermore, it is important that nurses have access to expert personnel, both as a source of referral for patients and as a resource for support and guidance to staff.

Effect on family

The striking impact of stroke also involves the patient's social function. The social changes, among others, include that the patient has to be dependent on others for his basic, personal and social needs. Suddenly his social life is reduced to a small circle of close family members and health care personnel. It is common that stroke victims fail to resume social activities, even though they have regained most of their lost physical function. This may be due to psychological changes or depression because of the stroke.

However, the question remains as to why stroke survivors do not regain their previous social function, even though they have regained their physical function. One reason may be the visibility of the disability and problems with body image. Another reason may be interruption in thought processes and perception caused by the stroke. Reduced activities, loneliness and perceived loss of health may interact to lower morale with depression and isolation. Loss of transportation, which frequently follows stroke, influences feelings of isolation.

The effects of stroke also have a profound impact on the spouse and family members. The nurse should assess the family's emotional state before planning interventions, because the psychological status of family members often influences their interpretation of how the patient is progressing. Spouses could be incorporated into the care planning, developed by the nurse, and assess the needs of the spouse in addition to developing nursing interventions to meet those needs. Also, educational sessions for spouses and extended visiting hours may increase the support provided by the spouse.

Limitations on studies

Only a few studies have been conducted on the experiences of stroke from the patient's point of view. The

reviewed qualitative studies on the experiences of stroke are promising. However, they are not without limitations, such as: the wide time range at which the interviews were carried out (Mumma 1986); unclear selection criteria used (Folden 1994, Häggström *et al.* 1994); unclear description of data collection method used (Mumma 1986). In relation to the time range at which the interviews were carried out, all these qualitative studies are retrospective.

There are problems with retrospective studies. It is important to differentiate between the various time points at which the interviews are taken. There is a difference between how the patients describe their experiences when they are interviewed shortly after the event in comparison to when they are interviewed some time after the event, when the patient is reflecting on the event. Selection criteria need to be defined clearly. Patients suffer various types of strokes, and therefore their experiences may be equally various. The experiences of patients suffering lacunar infarcts may be very different from patients suffering haemorrhagic strokes. These limitations need to be addressed in future studies of the patient's experiences of stroke.

Qualitative data collection, where the above-described limitations are overcome, will provide richer data and give a more total impression of the experiences of the patients as they recovered and adjusted to the effects of stroke. There is a great need to conduct longitudinal research with larger samples, studying individuals over time, through the entire recovery process, to better understand the unique concerns of this population. Account of the stroke patient's experiences will help researchers to identify the potential passage of the stroke recovery process.

CONCLUSION

Nurses are essential participants in the ongoing assessment of both functional and psychosocial goal achievement. Knowledge of the stroke patient's experiences throughout the recovery process and his own descriptions of which interventions he experiences as helpful and which are not will also help nurses in evaluating, planning and providing the nursing care during the recovery. Intimate involvement with both the stroke patient and the family in teaching and discharge planning enables nurses to recognize the initial signs of dysfunction early and initiate appropriate intervention.

This is especially important because nurses participate in all aspects of the stroke patient's recovery phase for 24 hours a day, from acute care to re-entry into the community.

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