The psychosocial spiritual experience of elderly individuals recovering from stroke: a systematic review

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Abstract

Objectives The objective of this review was to appraise and synthesise best available evidence on the psychosocial spiritual experience of elderly individuals recovering from stroke.

Inclusion criteria This review considered qualitative studies whose participants were adults, mean age of 65 years and older, and who had experienced a minimum of one stroke. Studies were included that described the participant's own experience of recovering from stroke.

Search strategy The search strategy sought to find both published and unpublished studies and papers, not limited to the English language. An initial limited search of MEDLINE and CINAHL was undertaken followed by an analysis of text words contained in the title and abstract, and of index terms used to describe the article. A second extensive search was then undertaken using all identified key words and index terms.

Methodological quality Each paper was assessed by two independent reviewers for methodological quality prior to inclusion in the review using the Qualitative Assessment and Review Instrument (QARI) developed by the Joanna Briggs Institute. Disagreements were resolved through consultation with a third reviewer.

Data collection Information was extracted from each paper independently by two reviewers using the data extraction tool from QARI developed by the Joanna Briggs Institute. Disagreements were resolved through consultation with a third reviewer.

Data synthesis Data synthesis aimed to portray an accurate interpretation and synthesis of concepts arising from the selected population's experience during their recovery from stroke.
Results A total of 35 studies were identified and of those 27 studies were included in the review. These qualitative studies examined the perceptions of elderly individuals who had experienced a stroke. Findings were analysed using JBI-QARI. The process of meta-synthesis using this program involved categorising findings and developing synthesised topics from the categories. Four syntheses were developed related to the perceptions and experiences of stroke survivors: sudden unexpected event, connectedness, reconstruction of life and life-altering event.

Conclusion The onset and early period following a stroke is a confusing and terrifying experience. The period of recovery involves considerable psychological and physical work for elderly individuals to reconstruct their lives. For those with a spiritual tradition, connectedness to others and spiritual connection is important during recovery. The experience of stroke is a life-altering one for most elderly individuals, involving profound changes in functioning and sense of self.

Keywords psychosocial • recovery • stroke

Introduction

Stroke is a major cause of death and disability and the risk of stroke increases with age. As elderly individuals are often left with some form of permanent disability, many studies have focused on functional recovery and physical rehabilitation. Less attention has been given to the psychosocial and spiritual experience of an individual who is recovering from stroke. Based on a review of the literature, Hulsteindottir and Grypdonck recommended that ‘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.’

In this review, we focus on qualitative research about the short and long-term recovery process from the perspective of the elderly person, with the intent of assessing the evidence that would guide nursing practice. Previous research has suggested that health professionals lack understanding of how patients experience, interpret and manage recovery after stroke. A wide range of issues related to the experience of stroke from the perspective of the patient have been identified in the research literature and the assessment of the evidence is important for the nursing care of these individuals. These issues include discontinuity with a previous way of life, loss of control and fear of relapse, disruptions in sense of self and experience of time, loss and helplessness, connection/disconnection and independence/dependence, hope and hopelessness and communication. A number of authors and researchers have indicated a richer understanding of the psychosocial experience of those who have suffered a stroke would enable healthcare professionals to assist with the transitions and adaptations involved in recovery.

During the initial search of the literature, a 2003 review was found that focused on the perspective of professionals and patients with respect to clinical and social care. Our review will focus only on the perspective of patients and will update this review in terms of qualitative studies of the experience of elderly individuals recovering from stroke.

Objectives

The objective of this review was to appraise and synthesise the best available evidence on the psychosocial spiritual experience of elderly individuals recovering from stroke.
Review method

Criteria for considering studies for this review

Type of studies
This review considered interpretive studies that reported the experiences of elderly individuals with stroke including, but not limited to, designs such as phenomenology, grounded theory and ethnography.

Type of participants
This review included studies whose participants were adults, mean age 65 years and older, in any setting, who had experienced a minimum of one stroke. Experiences must have been reported by the stroke survivors themselves. Family and caregiver information was excluded.

Phenomena of interest
Studies were included if the focus of the study was a description of the participant's experience in response to a particular intervention. Studies were also included that described the participant's experience of recovering from stroke where no intervention had been introduced.

Types of outcome measures
Outcomes of interest were the participant's own experience through self-report. Reports from family and caregivers were excluded. Types of outcomes included sense of hope/hopelessness, connection/disconnection with others, disruptions in sense of self and experience of time, loss, independence/dependence, discontinuity with previous way of life, sense of control.

Search strategy
The search strategy aimed to find both published and unpublished studies (Fig. 1). The search was not limited to English language reports. A three-step search strategy was utilised in each component of this review. An initial limited search of MEDLINE and CINAHL was undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken. Third, the reference list of all identified reports and articles was searched for additional studies.
The databases that were searched included:

CINAHL
MEDLINE
PsycInfo
Web of Science
CDSR, ACP, Journal Club, DARE, CCTR
Blackwell Synergy
Embase (for the European literature)
CNRR (Crisp and National Research Register)
Reference lists of identified studies and review papers
See Appendix I for the search results.

**Assessment of methodological quality**

Research papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (QARI; Appendix II). The two main reviewers were both experienced nurses and academics, one with considerable experience as an advanced practice nurse in gerontology. Any disagreements that arose between the reviewers were resolved through discussion with a third reviewer.

QARI is the software component of the SUMARI suite that supports the synthesis of qualitative research evidence. QARI facilitates the reviewer's assessment of the congruity between philosophical
perspective and research methodology, research question and methods, data collection and methods, analysis and interpretation, participants and their voice, ethics, etc.

**Data collection**

Data were extracted from the papers included in the review using the standardised data extraction tool from the Joanna Briggs Institute QARI (Appendix III).

**Data synthesis**

Where meta-synthesis was possible, qualitative research findings were pooled using the QARI. This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their quality, and categorising these findings on the basis of similarity in meaning (Level 2 findings). These categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings (Level 3 findings) that could be used as a basis for evidence-based practice. Where textual pooling was not possible the findings were presented in narrative form.

**Results**

**Description of the studies**

Thirty-five studies were selected for retrieval for this review. Eight of these studies were then excluded based upon the assessment of the methodological quality of the research (Appendix I).

**Number of studies found and retrieved**

Number of studies found: 35  
Number selected for retrieval: 35

**Methodological quality**

Methodological quality was assessed by two reviewers using the assessment tool from the Joanna Briggs Institute QARI (Appendix II). A cut-off point of six out of the 10 questions answered as 'yes' was established. Eight studies failed to make this cut-off point and were then excluded from the review.

**Number of studies included and excluded**

Number of studies included: 27  
Number of studies excluded: 8

**Results of the meta-synthesis of qualitative research findings**

Meta-synthesis of studies included in the review generated four synthesised findings. These synthesised findings were derived from 165 study findings that were subsequently aggregated into 20 categories. The study findings are listed in Appendix IV and the results of the meta-synthesis process are listed in Appendix V. The relation of synthesis topics, categories and findings are displayed in Figure 2 and the synopsis table is in Appendix VI.
Discussion

The purpose of this systematic review was to examine the best available evidence on the psychosocial and spiritual experience of elderly individuals recovering from a stroke. The intent was to examine how these individuals perceive the recovery process, how they describe the psychosocial and spiritual aspects of the experience and how they describe their major concerns in the first 6 months and in the long term (up to 3 years) following the stroke.

To address these questions, qualitative studies using a variety of methodologies, such as phenomenology, ethnography and grounded theory were identified. Using methodologies in JBI-
QARI, 35 papers/reports were critically reviewed and 27 were retained for the subsequent process of data extraction. A total of 165 findings were extracted and these produced 20 categories (Findings, Appendix IV; Categories, Appendix V). These categories were then analysed to identify four syntheses:

1. Connectedness – elderly individuals who have experienced stroke identify the importance of connectedness in their process of recovery.
2. Reconstructing life – elderly individuals describe the recovery process as reconstructing their lives following stroke. They are engaged in the recovery.
3. Life-altering event – individuals perceive the stroke as having life-altering consequences.
4. Sudden unexpected event – stroke survivors perceive the stroke experience as having a sudden onset, generating shock, fear and confusion.

The sense of stroke as a sudden unexpected event was evident in the findings of studies in which elderly persons described the onset of stroke and their perceptions, thoughts and feelings during this early period. Initially, there was often uncertainty about the diagnosis and sometimes, delay in seeking treatment as they tried to understand the meaning of the symptoms. Most often, the abrupt onset and the physical and mental changes were shocking, frightening and confusing and individuals described the experience as ‘terrifying’ and themselves as ‘totally disabled’ during this time. At this time, they passively accepted care and gave up control to others. Many experienced a split of the body from the self during this period – their body was separate from themselves, unpredictable and somehow changed.

During the recovery process, connection to others, such as family and friends, spiritual connectedness and relationships with professionals were important for most individuals. The difficulties that might be encountered post-stroke with communication or social activities could lead to an absence of connectedness or a sense of isolation. Relationships with others could be challenging or consoling to elderly individuals recovering from a stroke. Although for the most part relationships with professionals are positive during the recovery process, some elderly individuals perceived a lack of respect. A respectful approach, encouragement and reassurance from health professionals were important to those who had experienced a stroke. Participants identified spirituality in terms of their upbringing in spiritual matters and formal religion. Those who grew up with a spiritual tradition found prayer to be a source of strength and that a sense of hope was strengthened by their spiritual connectedness. This spiritual connection seemed to provide a sense of confidence about the future.

A major aspect of the recovery experience for elderly individuals who have had a stroke is the considerable physical and psychological work involved in reconstructing their lives. This work involves drawing on their sense of hope and inner strength or drawing on other attitudes that assist in recovery. It also involves adapting to changes in physical functioning and to new environments and dealing with the challenges of participating in life activities despite the loss of abilities. A major change is the inability to engage in activities that formed part of former roles, for example, housekeeping activities for a woman who saw these as part of her role as a wife. Coping with physical disabilities involved taking more time to complete daily activities and frequently, the use of physical aids. Individuals had to struggle, both psychologically and physically during recovery and to develop strategies to adapt to their new life, often by re-learning and becoming active in their own care. During the period of recovery, there was often uncertainty about the extent of recovery and individuals tended to measure their progress in terms of their pre-stroke life, although they perceived that professionals measured progress differently.
Stroke survivors had positive and negative perceptions of the degree of support provided by the healthcare system. In reconstructing their lives, the stroke survivors underwent many transitions, with returning home from hospital or rehabilitation settings as a major transition. Ultimately, those who recovered from a stroke had to deal with their disabilities, which might involve accepting that they had to find new ways to do things and more frequently, accepting that they required care from others.

Stroke survivors perceive the stroke as having life-altering consequences and many perceive the event as a discontinuity in their lives, although those with comorbidities or previous strokes may view it as one event in an ongoing life. For most however, the contrast is made with their previous life and they describe the changes as profound. The changes identified range from a difference in the way they walk to their sense of self and identity.

Conclusion

The onset and early period following a stroke is a confusing and terrifying experience. The period of recovery involves considerable psychological and physical work for elderly individuals in order to reconstruct their lives. Connectedness to others and spiritual connection, for those with a spiritual tradition, is important during recovery. The experience of stroke is a life-altering one for most individuals, involving profound changes in functioning and sense of self.

Implications for practice

From the review and the syntheses, there are a number of recommendations emerged for health professionals:

- Be sensitive to and acknowledge the overwhelming sense of terror and fear experienced in the early period
- Facilitate all aspects of connection with family and friends as well as spiritual connection and be alert to signs of isolation in the recovery period
- Recognise the huge amount of work, both psychological and physical, that is involved in reconstruction of a life and consider a plan of care
- Consider ways in which the healthcare system, healthcare routines and practices support or do not support elderly persons who are recovering from a stroke
- Provide opportunities for elderly persons recovering from a stroke to discuss their perceptions of improvement/progress and how their life has changed

Implications for research

One of the perceptions of some elderly persons who have had a stroke is that of disconnection from the body or the ‘body split’ experience. Further research on this phenomenon is warranted to clarify the nature of the experience and its effect, as well as how health professionals may assist those with this experience.

This review focused on the experience of recovery from stroke as perceived and lived by elderly individuals. Further research that focuses on specific interventions designed to address the terror of the early period and the considerable work involved in reconstructing life is warranted.
Acknowledgements

Queen's Joanna Briggs Collaboration (QJBC) wishes to acknowledge the funding received from the Ontario Ministry of Health and Long Term Care (2004–2007) supporting the QJBC as a demonstration project. This review was also supported in part by the Joanna Briggs Institute. QJBC would like to acknowledge Deborah Holtom RN PhD and Sandra Melchiorre RN APN for their assistance with the data extraction process and Victoria Donaldson, B.A. for her assistance in creating the multiple charts and tables in the review report.

References

Appendix I: Search results

Included studies


**Excluded studies**

Castellucci DD. *The relationship and differences between depression and perceived enactment of autonomy scores among post-stroke elderly*. PhD. University of Maryland, Baltimore, MD. 1995.

*Reason for exclusion:* Research questions unclear and therefore lacks congruity with methods, representation and analysis.


*Reason for exclusion:* Too vague on methods and data analysis.


*Reason for exclusion:* Not enough detail to meet criteria – met only 4 of 10 criteria.

Gibbon B. Service user involvement: the impact of stroke and the meaning of rehabilitation. *J Aust Rehabil Nurs Assoc* 2004; **7**: 8–12.

*Reason for exclusion:* Only clearly meets 3 of 10 criteria.


*Reason for exclusion:* Content analysis, more of quantitative approach. Congruity between methodology and analysis unclear, representation of participants unclear.


*Reason for exclusion:* Research predominately quantitative, qualitative results less clear.


*Reason for exclusion:* Many aspects of research methodology unclear.


*Reason for exclusion:* Participants include both stroke victim and spouse, so difficult to distinguish between the two in paper.
Appendix II: QARI Appraisal Instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
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<tr>
<td>Is there congruity between the stated philosophical perspective and the research methodology?</td>
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<td>Is there congruity between the research methodology and the research question or objectives?</td>
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<td>Is there congruity between the research methodology and the methods used to collect data?</td>
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<td>Is there congruity between the research methodology and the representation and analysis of data?</td>
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<tr>
<td>Is there congruity between the research methodology and the interpretation of results?</td>
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<td>Is there a statement locating the researcher culturally or theoretically?</td>
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<td>Is the influence of the researcher on the research, and vice-versa, addressed?</td>
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<td>Are participants, and their voices, adequately represented?</td>
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<tr>
<td>Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?</td>
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<tr>
<td>Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?</td>
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Overall appraisal: Include □ Exclude □ Seek further info. □

Comments (Including reasons for exclusion)

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Appendix III – QARI Data Extraction Instrument

**Extraction Details : Extraction Name**

<table>
<thead>
<tr>
<th>Methodology:</th>
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<td>Data Analysis:</td>
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<tr>
<td>Authors Conclusion:</td>
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</tr>
<tr>
<td>Reviewers Comments:</td>
<td>[Yes] [No]</td>
</tr>
<tr>
<td>Complete</td>
<td>[Update] [Cancel]</td>
</tr>
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</table>
Appendix IV: List of study findings

Alaszewski A, Alaszewski H, Potter J. (2004). The bereavement model, stroke and rehabilitation, a critical analysis of the use of a psychological model in professional practice (for full citation see Appendix I) (U = unequivocal; C = credible)

Finding 1
Stroke as a loss for the survivor is devastating and necessitates adjustments to a changed status and identity. (U)
Absolutely, in every way. I can't imagine any way it's not really. That's the most devastating thing really, the fact that nothing is the same, you know, even a simple thing like walking up the lane, I have plan it and think about it, work out whether I am capable of doing it. (page 1072)

Finding 2
Individuals perceive life after stroke as a period of change and adjustment. (U)
Yes, my goals I set, I'd try and get myself to walk as far as the computer and as far as the toilet so I could take a wee without my wife having to change the commode for me. That's my goals. (page 1073)

Bays CL. (2001). Older adults' descriptions of hope after a stroke

Finding 1
Hope is experienced as positive anticipation regarding recovery. (U)
… that tomorrow will be better than today. (page 23)

Finding 2
Hope is related to active participation, moving the stroke survivor towards recovery. (U)
You want to do what you can do so you get better. (page 23)

Finding 3
Individuals discuss hope in terms of anticipated future possibilities. (U)
I have come a long ways since I had the stroke … I got a long ways to go … (page 23)

Finding 4
Hope is perceived by stroke survivors as an inner strength actively moving them toward achieving goals in recovery. (U)
I just have a feeling that I can. (page 23)

Finding 5
Hope is guided in part by spiritual relationships. (U)
I believe with God's help I can do these things. (page 23)

Finding 6
Some individuals maintain hope through relative comparison to previous abilities or the abilities of others. (U)
I can't do the things I used to but I can do new things. (page 23)

Finding 7
Stroke survivors view hope as life-sustaining. (U)
If there is no hope then I am probably not even going
Finding 8
Stroke survivors’ perceptions of incremental progress, supportive family and spiritual connectedness provide a sense of encouragement, support and belonging. (U)

Finding 9
Individuals discussed hope in terms of regaining previous abilities. (U)

Finding 10
Spiritual connectedness may provide stroke survivors with a sense of encouragement. (U)

Finding 11
The stroke survivors’ sense of incremental progress provides a sense of encouragement. (C)

Burton CR. (2000). Living with stroke: a phenomenological study

Finding 1
Issues in physical recovery involve a process of initial personal experience of the stroke moving them through early recovery, a slowing down and then facing new challenges. (U)

Finding 2
Issues in emotional recovery: the overwhelming nature of stroke precipitates immense uncertainty. (U)

Finding 3
Issues in social recovery: A stroke precipitates an individual’s changing roles accompanied with isolation and reflection on their previous life. (U)

<table>
<thead>
<tr>
<th>Finding</th>
<th>Illustration</th>
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<tbody>
<tr>
<td>Finding 1</td>
<td>Many (over 60%) identified physical limitations such as limited speaking ability, loss of coordination, need for a walker (inability to walk), inability to remember how to get up from a chair (the need to relearn motor functions), diminished feeling in the limbs, hair falling out or turning white, frequent falls, confusion (i.e. starting out or one part of the house and finding him/herself in another part), and loss of dexterity in the hands. (pages 79–80)</td>
</tr>
<tr>
<td>Finding 2</td>
<td>Over 20% specifically discussed the impact of short and long-term memory loss on their quality of life and functioning ability. (page 80)</td>
</tr>
<tr>
<td>Finding 3</td>
<td>People back off when they know you have had a stroke. (page 80)</td>
</tr>
<tr>
<td>Finding 4</td>
<td>Not being able to drive means being a burden or giving up on getting to church, stores, seeing friends, or just enjoying the chance to get in the car and go somewhere. (page 80)</td>
</tr>
<tr>
<td>Finding 5</td>
<td>I think my friends are being patronizing – feeling sorry for me, so I just want to withdraw from them. (page 80)</td>
</tr>
<tr>
<td>Finding 6</td>
<td>Don't do things that I'm afraid of – just let it go. (page 81).</td>
</tr>
<tr>
<td>Finding 7</td>
<td>Almost 70% of the respondents discussed their appreciation for personal care. (page 81)</td>
</tr>
<tr>
<td>Finding 8</td>
<td>I resented needing help deeply when first home; becomes almost a natural part of you after awhile; hated it, even in the hospital. (page 81)</td>
</tr>
<tr>
<td>Finding 9</td>
<td>I had to do a lot of thinking and reassuring myself that, that's what families are for and that I'd do the same for (daughter). (page 82)</td>
</tr>
</tbody>
</table>
Most participants reported satisfaction with professional care relationships. (U)

Finding 11 Illustration
Experience with professional caregivers: negative experiences. (U)

Finding 12 Illustration
Making decisions for themselves is an important part of their commitment to self-care in stroke recovery. (U)


Finding 1 Illustration
In the acute phase, the stroke was experienced as a bodily event. (U)

Finding 2 Illustration
During the acute admission period there was tremendous uncertainty for the individuals, much of which related to the diagnosis of stroke and was experienced as a loss of control. (C)

Finding 3 Illustration
The suddenness of the stroke left them shocked and stunned, with extreme fright if the stroke was still evolving. (C)

Finding 4 Illustration
The realisation that hospitalisation would not ‘cure’ the stroke further stunned the individuals. (C)

Finding 5 Illustration
Participants viewed recovery as return to prestroke life and improvement as isolated and discrete return of movement. (C)

Finding 6 Illustration
Individuals spent many sleepless nights in the hospital. (U)

The nurse said she felt she was visiting a friend and treated me like one. (page 83)

We just get acquainted and they (homemaker program) send someone else. (page 83)

Main thing is to tell yourself to get up and do it – encourage yourself to do it – self-talk. (page 85)
Finding 7
Discharge home was a major transition. (C)
Personal hygiene chores took twice as long to do as before the stroke. They talked about the frustration of morning hygiene. (page 238)

Finding 8
Some stroke survivors view their body as a passive object and their limbs as no longer under their direction. (C)
All of the participants spoke of the affected limbs in a passive, objective manner. (page 45)


Finding 1
Most individuals who have a stroke describe profound ways in which their life has been affected. (U)
I can't do anything with my hands – I can't peel a potato … (page 511)

Finding 2
Relative to the prestroke period, there was a clear deterioration in the social lives of the majority of respondents. (U)
Oh it's very hard. I cannot get to church or club or anywhere. I see nobody. I just look in window till somebody come. I'm sometimes very, very unhappy. (page 511)

Finding 3
Some participants perceived a gap between their own assessment of recovery and that of health professionals. (U)
Well at first I didn't seem to let it bother me really. I just used to talk and I slept a lot at the beginning … But as I've got further on, and I don't seem to be improving that much, then sometimes I could cry … well you just think, am I ever going to get right. The physio thinks I'm improving so, I just hang on to what she says. (page 512)

Finding 4
In measuring psychological and physical well-being, the standard used by patients was their prestroke lives. (U)
… the frustration – and I've always done these jobs and now I can't. I do get irritable sometimes, I'm too ambitious, I'd like to be my old self … (page 512)
Finding 1
Individuals are able to describe the symptoms they were experiencing when they had a stroke although they did not realise the meaning of the symptoms at the time. (U)

Illustration
See I had little signs that this was going to happen but I couldn't read 'em. I had trouble sometimes when I get up during the night or get up early in the mornings; I sit on the side of the bed (to) get myself steady. I couldn't just jump up and make a whole lot of haste coming up the hallway. (page 41)

Finding 2
Many individuals put off seeking healthcare when they had symptoms, by waiting or keeping their symptoms secret. (U)

Illustration
Yeah, I was telling her how I was feeling and she said, 'You ought to go see your doctor. I think I'll take you to the doctor.' "Well, I got a appointment Thursday morning and I'll just wait and go then.' I should have went then, but I didn't. Got up Wednesday morning feeling about the same. But, I could tell I was losing my ability to drive a car. And then I'm waiting till Thursday morning. By Thursday morning, I done got all out of whack. (page 42)

Finding 3
Stroke survivors fear that they would be dependent on their families forever and actually grieved about their loss of functioning. (U)

Illustration
I try not to run her to death, but I'm very dependent on her [wife]… And one of the most things I miss is getting in my car driving places. (page 43)

Finding 4
Stroke survivors find themselves struggling to regain their independence. (U)

Illustration
And this is the side (gesturing to the right side) which I use to depress my accelerator on the car. And put on the brakes. This also is the hand I turn the – crank the car up … But, as far as stiring [steering] the car [I can do that]– so that's one of my projects. Getting well enough so I can drive my car. (page 43–44)

Finding 5
There is a life-long adjustment to the residual impairments caused by the stroke. (U)

Illustration
Shaving is a big chore. I don't like to do that. I don't bother her (wife) to do it cause she did it for me when I couldn't do it. And so now I can. See, I have to use the wrong hand to shave with. I use this hand to shave, and that takes longer and it's awkward. Sometimes, I get impatient with myself. But, still I got to shave. Sometimes I nicks myself a little bit but I got a safety razor and most times I don't. What I keep wanting to get is a electric razor. So, that makes it tiresome, because it becomes awkward, using the wrong hand. (page 44)

Finding 6
Individuals experienced uncertainty in response to both the symptoms and their perception of health care providers and the treatment they delivered. (U)

Illustration
And the Rescue Squad came and got me [from work] and time I got to the hospital all my children were coming too. See, I have to use the wrong hand to shave with. I use this hand to shave, and that takes longer and it's awkward. Sometimes, I get impatient with myself. But, still I got to shave. Sometimes I nicks myself a little bit but I got a safety razor and most times I don't. What I keep wanting to get is a electric razor. So, that makes it tiresome, because it becomes awkward, using the wrong hand. (page 43)

Finding 7
Individuals may attempt to explain what is happening to them by grouping symptoms. (C)

Illustration
You know it was evening when it started on me, that's the only time I felt weakness in the legs. 'Cause when I went to walk, I was sitting here and when I walked cross the room I felt just as light (lightheaded). And I could hear my voice had done changed, you know, how I spoke. (page 41)

Finding 1
Fundamental life change: change that could be likened to entering a new foreign world. (U)

Illustration
It's a very severe thing to happen to anyone, it's not like getting a -- y'know -- having a broken arm or something like that which incapacitates you for a couple of months; put your arm in plaster and normally just take off and you get back to where you were before ... you lead a normal life one day and within a matter of minutes, overnight it all comes to an end. (pages 727–728)

Finding 2
The experience of self-body split: their body becomes separate, precarious, perplexing. (U)

Illustration
Cause the big, the big day I want is to be able to get up and not even think about doing it you know what I mean. I think that might happen one day you know I'll just get up like you do without thinking about walking. I've still got to get up there and stand up and get my leg just one leg out ready to take and move forward you know push my leg through all this sort of thing all these motions I've still got to think about it. (page 730)


Finding 1
Elderly stroke survivors may normalise the effects of the stroke as part and parcel of the ageing process. (U)

Illustration
I ain't deaf and the hardest part is the movement I used to have. I'm old now and I ain't as fast as I used to be. (page 249)

Finding 2
For those with comorbidities, the stroke may be viewed as one event in an ongoing life rather than a discontinuity. (U)

Illustration
Well, not that much different as it is now. Not that much at all. Stroke didn't change much. I couldn't walk before and I can't walk well now. Couldn't walk. You know, if I walked, I got tired. That's what brought me to the VA (Medical Centre) in the beginning was the aches and pains from walking. I decided I had to find out what the problem was. (page 252)

Finding 3
There is minimised biographical disruption by stroke in individuals who have a history of and pre-existing knowledge of a stroke. (U)

Illustration
No, not at all. It's not the first one I've had. The last one was a lot stronger, but what can you do? This one is just like a hiccup. Not even as bad as the other ones. Just like a hiccup. (page 255)
Folden SL. (1994). Managing the effects of a stroke: the first months

Finding 1  Illustration
Ensuring forward progress includes initial recognition of their losses and accepting that life would be forever different. (U) I took good care of myself. That was me then; what you see is the new J. I have accepted this, and I am coping. I don't like it – I hate it – but I am coping with it. But it is not the same. Everything has changed. It will never be the same. (page 82)

Finding 2  Illustration
Ensuring forward progress includes preserving energy in order to participate in therapy. (U) My friends come. They usually fix things. They ask me to go out. I just say, you go and I will be here when you get back. (page 83)

Finding 3  Illustration
Ensuring forward progress includes maintaining hope throughout the slow process. (U) I have come a long way, and I will get better. I have never given up hope. If you do, you are dead. I won't give up. The cane is not the end for me. (page 83)

Finding 4  Illustration
Ensuring forward progress includes increasing control over recovery by being more assertive and active in their own care. (U) I rang for help, no one came, so I tried to get up by myself and I sat on the floor. (page 83)


Finding 1  Illustration
Sense of control: in occupations where they felt in control, they were less debilitated by their emotional changes. (U) She also greatly enjoys tasks that involve giving to other people, including making biscuits for family and friends. (page 457)

Finding 2  Illustration
Loss of a sense of mastery: They did not want to perform the occupations which they had excelled at prior to their stroke: Their disability was not as obvious in a new occupation. (U) He describes this depression as 'I just couldn't talk to anyone and wouldn't do anything, just sit here … come and sit here all night'. (page 458)

Finding 3  Illustration
Relating to people with a disability: performing tasks that helped those they perceived as less fortunate, or providing something to others was a strong motivating force. (C) Marie describes how the lability does not occur when she undertakes a caring role at a local support group. She suggests that it may be because she has 'more control … I feel needed there as if I'm doing something worthwhile' and is working with those she describes as 'less fortunate'. (page 457)

Finding 4  Illustration
Lack of intervention and education regarding emotional changes; the lack of education regarding the physiological basis for her lability caused her to feel out of control. (C) I worry that people don't understand, I think sometimes they think I'm being a bit weak and a bit silly, and 'Oh God, mum's a bit stupid'. (page 457)
Hilton EL. (1999). The meaning of stroke in elderly women: the lived experience

Finding 1
Transformation occurs through an intellectual journey to reconstruct oneself into who one would become. (U)
Illustration
I was kind of like in another world. It was a shock and it wasn't. I had been going through this thing of losing my husband. And I was going through this thing when my body had to adjust. It was just a lot of going on and has been for the last three years of my life. My life changed so radically, I can't think of what I'm not sure of. I have so many things behind me, and I guess it has leveled off to a certain degree and probably as level as it is ever going to get. (page 62)

Finding 2
Transformation includes the process of recalling the past within the context of discovering the present. (U)
Illustration
Well as a child, my health was always good. My mother had nine of us and I was always the healthiest one to help out with the others. (page 64)

Finding 3
Subtleties of losses and helplessness are woven into daily lives and are a part of the transformation. (U)
Illustration
Looking back, I don't know. I don't know how I got thought it … my days and nights were difficult, to say the least … With everything else on my mind, I think I just drifted through it and just thought well, this is how it is going to be. (page 66)

Finding 4
Regret was expressed as grief; they mourned for a part of self that was valued in everyday life and activities. (U)
Illustration
I was happy and relaxed that afternoon; then I realized I could not see my son's face. I still can't realize that I can't see your face out of one eye. It's hard to believe, and yet, I know, I know. I was more concerned that they [the doctors] said 'its gone and its not coming back'. (page 67)

Finding 5
Uncertainty and apprehension for the future were met as the older women attempted to manipulate their environment and regain a measure of control. (U)
Illustration
Well for one thing, I worry about having another stroke. I always take my blood pressure medications, but I know I can still have another stroke. Another stroke is a big worry. (page 69)

Finding 6
Living and suffering through inexorable losses is accompanied by fear and despair. (U)
Illustration
The main thing after my stroke was that I couldn't drive my car. One day I went to the store, and I couldn't remember how to get back home. So they called my daughter, and she picked me up. Since then, she takes me everywhere I want to go. She lives with me now. (page 72)

Finding 7
Seeking self: Participants found the way in which they perceived themselves was changed by the stroke event. (U)
Illustration
Since the second stroke, I have a lot of problems dealing with crowds. Some crowds don't seem to affect me like others … some crowds make me nervous. My emotions seem to have slowed down some from the first stroke. They could [still] be better. (page 77)

Finding 8
Adapting to changes occurring from stroke can be a difficult and disheartening process. (U)
Illustration
The incontinence keeps me from getting out too much, and the blood pressure has to be watched pretty closely. I've had the problem with my urine since the stroke. My daughter keeps wanting me to get out more, but somehow, I connect getting well with being here
(retirement center). I keep thinking I won't get well if I go out too often, so I stay here most of the time. (page 79)

Finding 9

The existential re-establishment of self involves placing their condition into context and taking a hopeful outlook. (U)

I am trying to find the most good about each day and hour I am alive. (81)

Finding 10

Reconciliation and reengagement means living again having acknowledged, remembered and assimilated the experiences from the stroke. (U)

One thing I would tell you if you are a diabetic: I'd do everything in my power to keep my blood sugar under control and exercise. You are the only one that can do it for you. Until I see for myself that it is important, I will be the one to suffer if I don't do it. (page 83)

Hilton EL. (2002). The meaning of stroke in elderly women: a phenomenological investigation

Finding 1

Women believed they were in a state of transition, and were transformed by stroke. (U)

Well, I guess I accept it in a way. I still want to get better, but I just accept the fact I won't be completely well. I may be able to do some of the things that I can't do right now, and when I say that, I don't mean that I just accepts anything, because I am not. I would love to be able to do things I used to do, but just accept what you can't change, and go from there. There is no good time to have a stroke, and retirement is not a good time. It changed our plans. I can't ride. It's an hour and a half to our place on the river, and the problem I have is we have to make so many pit stops. I know that we will have to stop either coming or going, and that makes me very uncomfortable, and that, in itself, makes me tired. It's all different now. I used to be able to do what I wanted. (page 23)

Kvigne K, Kirkevold M. (2003). Living with bodily strangeness: women's experiences of their changing and unpredictable body following a stroke

Finding 1

The demanding body: The unpredictable body is demanding in different ways in everyday life: It is time consuming, limiting, dependent and conspicuous. (U)

I need a lot of time for everything. What I needed one day to do before the stroke, I now need several days to do. Nothing can be done spontaneously, which was no problem before. (Page 1300)

Finding 2

The unpredictable body: The most fundamental characteristic and experience of the body after stroke seemed to be that the body had become unpredictable. The body was experienced as non-spontaneous, vulnerable, defenceless, unreliable and betraying. (U)

She managed this walk for a few days, but suddenly one day when she stood at her mailbox, she could not move her feet and had to shout for help –"I could not trust my feet any longer'. (page 1300)

Finding 3

Illustration

Illustration

Illustration

Illustration
The extended body: Many stroke survivors needed tools or remedies, such as walking sticks, crutches, a walker, a wheelchair, large handled knives, forks, spoons, special pens and pencils, and braces. (C)

Sarah who needed a wheelchair both inside and outside, termed her wheelchair her 'feet'. (page 1303)

Kvigne K, Kirkevold M, Gjengedal E. (2004). Fighting back – struggling to continue life and preserve the self following a stroke

Finding 1
Older women described their response to stroke as fighting off disabling feelings and maintaining the will to live. (U)
Illustration
I thought that it could not be true! I felt desperate because of what had happened. I thought that it could not be true, so I tried to walk, but I couldn’t … I became very depressed and cried a lot. (page 376)

Finding 2
Striving to regain the power to accomplish necessary and valued activities met with gradual improvements and the energy and will to keep trying. (U)
Illustration
I crawl on my knees when washing the floor and I have to lie down on the sofa and rest when doing housework. (page 378)

Finding 3
Striking a balance between attending to the needs of others and addressing increased personal needs involves choices as the individual struggles to maintain a normal life. (U)
Illustration
Sometimes when someone phones and announces a visit, I want to say that I don’t want a visit. But I can’t do that. It is not fair towards my husband. Even if I feel like isolating myself, he needs to associate with other people. (page 380)

Finding 4
Attempting to maintain control of valued female roles included choices and accepting help. (U)
Illustration
I have learned that everything takes longer … and I do not accomplish everything I ought to do. You know when you have to spend all day at home as a housewife, you plan to do a lot – to bake cakes and bread. I did this for Christmas, but we did not eat it. (page 381).

Finding 5
Friendship with people who shared or understood the stroke survivor’s situation enabled relationships on equal terms. (U)
Illustration
Maybe it is strange, but I prefer to sit down and talk with the home nurses rather than with my friends. They understand me better and provide good reflections and advice about my health condition. (page 382)
Lui MHL, Mackenzie AE. (1999). Chinese elderly patients' perceptions of their rehabilitation needs following a stroke

Finding 1
Explanations about special interventions were required by patients, especially when physical restraint was carried out. (U)

Illustration
The staff tied up both of my hands ... as I woke up. I felt very uncomfortable. For an individual the most difficult time is being restrained (physically) ... They should explain to me. (page 395)

Finding 2
Patients start to seek more information about stroke recovery in the rehabilitation setting. (U)

Illustration
I really ... wanted to know what or where there are things which help my hand to be recovered. My left hand is still tired ... and I wonder if there are things like certain injections and medication which help my hand to get full recovery. (page 395–966)

Finding 3
Gaining knowledge helps as a means of controlling their feelings of powerlessness. (C)

Illustration
Frustration and feelings of anger are reported by some of the informants in this study when the staff cannot meet their informational need. (page 396)

Finding 4
Information needs remain important after discharge. Elderly patients usually have poor memory and visual problems due to normal ageing. (U)

Illustration
Major difficulties were encountered by the elderly patients in this study in retaining health information given in the hospital – I am not well educated, so I may not understand what they tell me. (page 396)

Finding 5
After discharge, some of the patients were still uncertain about stroke recovery. (U)

Illustration
The (nursing staff) simply give me little information about stroke recovery ... they told me about dietary control ... not to take fatty food ... solely talked about things like this. And I need to know more ... the way to prevent relapse. (page 396)

Finding 6
There is a need to share feelings with others during hospitalisation. (U)

Illustration
In the acute hospital ... who can I talk to? No one! ... no one. Nurses were busy ... or ... the doctor ... they just had a look on me when they came to see me ... I do need to talk to others at that time, but there wasn't anyone available to share feelings with me. (page 396)

Finding 7
Adapting to another new environment, with transfer to the rehabilitation ward, was stressful. (C)

Illustration
Informants expressed their need for a sense of security with respect to the environment in hospitals. (page 396)

Finding 8
The major psychological support valued by the informants included giving them reassurance and a sense of security, offering verbal encouragement, listening to their worries, showing a caring attitude and respecting them as individuals. (U)

Illustration
They addressed me as 'Pau Pau'. Mm ... use my name is better ... then I know who they're referring to. You know, all patients were being addressed as 'Pau Pau'. How can we know who is being addressed? (page 396)

Finding 9
In the acute phase some informants did not want to talk,

Illustration
Even though I wish to talk to others, no one was available except the
other patients … the one who was lying next to my bed in the acute ward, we talked using same dialect and I felt better after talking … we simply talked about family affairs, our life and experiences. (page 397)

Finding 10
The need for social contact gradually increased as the physical and psychological state of patients improved during their stay in the rehabilitation ward and after discharge. (U)

Finding 11
Only a minority of informants believed that their religious or spiritual belief had helped them physically, giving them a sense of psychological comfort in the acute ward. (U)

Finding 1
Trust vs. mistrust: In the early phase of stroke, individuals experienced fluctuating consciousness and confusion that threatened their security. (C)

Finding 2
Autonomy vs. shame, doubt: the balance between these poles is greatly challenged because of the individual's loss of independence and their ability to perform according to their wishes. (C)

Finding 3
Initiative vs. guilt: Individuals set and achieve desired goals but may experience guilt if they only have small signs of improvement. (U)

Finding 4
Industry vs. inferiority: the sudden loss of competence was a severe trauma for the individuals and it was hard for them to put up with their deficiencies. (C)

Finding 5
The balance between identity and identity confusion is easily disturbed after a stroke. (C)

Finding 6
... I just trusted it would straighten itself out by and by … come right gradually … it felt as if there came 'normal' life ... again but of course one pondered much over it. (page 956)

Finding 2
I have sometimes felt it embarrassing when I'm together with people who speak about things that there is no reason to laugh at … And then I begin to laugh too, you know, in a hard way … Ugh! (page 956)

Finding 3
This arm does not keep hold of anything … it is quick to release things. And yet I'm training so much ... I do as I'm told. Immediately in the morning when I wake up I have to start this training. (page 956)

Finding 4
One is bound in some way … I'm not able to drive I can't I've tried in the parking place just a little, but my foot goes off to the accelerator. No, it won't adjust … it's a disadvantage not able to do what you want to do. (page 956)

Finding 5
When I think backwards I think of the time I was capable and proficient and always pushing. (page 956)
Intimacy vs. isolation: Some stroke victims did not talk with their spouse about the disease, their struggle for improvement or their regret at not making a full recovery. (U)

Finding 7

Generativity vs. stagnation: Despite their age they were used to being productive and creative in various ways and had been so for most of their lives. It was a trying experience to realise they were no longer able to perform the work and the tasks they used to. (C)

Finding 8

Integrity vs. despair: The experience of wholeness and meaning was challenged through the losses suffered due to the stroke and there were signs of despair. (C)

Finding 9


Finding 1

The struggle to manage life despite the stroke. (C)

Finding 2

The stroke experience led to feelings of stagnancy and emptiness in life which individuals struggle to counteract. (U)

Finding 3

The struggle to manage life includes being able to grasp the severity of the new situation after stroke and still preserve hope. (U)

Finding 4

The struggle to manage involves actions to counteract the sense of helplessness and dependency that arose out of the stroke experience. (U)

Finding 5

Individuals struggled to keep up their self-image and the image of them held by other people. (U)

Finding 6

For some there was a struggle to cope in their
relationships and to communicate due to unfamiliarity with talking about emotional matters. (U)

Finding 7

Illustration

Being suddenly faced with the possibility of one's own death in some leads them to dare to confront the emerging existential issues associated with death. (U)

You have to accept that such things happen in old age ... now I'm waiting for the next stroke ... but I think ... it isn't certain to come ... (page 268)

Olofsson A, Andersson SO, Carlberg B. (2005). 'If only I manage to get home I'll get better' – Interviews with stroke victims after emergency stay in hospital on their experiences and needs

Finding 1

Illustration

The patients saw themselves as responsible and participating in what happened when they fell ill. (C)

... I was hammering in some nails ... yes then suddenly the hammer ... it didn't work ... I felt there was something wrong ... (page 352)

Finding 2

Illustration

During their stay at the hospital the patients put themselves in the charge of the staff and took a passive part. (U)

The health care staff know and decide what I need. (page 436)

Finding 3

Illustration

The patients take the blame on themselves for not getting the information that they would have liked. (U)

But the fact is that I'm not dumb usually, but suddenly I couldn't say anything ... when I ought to have asked, e.g. why did I become ill ... (page 353)

Finding 4

Illustration

Most of them had not thought about what might have been different, what they could expect, but had assumed that what had happened was the current practice in healthcare. (C)

Well, they said that, now, now ... we have ... eh, what shall I say ... now we have decided that you can go home. That was all they said. (page 436)

Finding 5

Illustration

Some patients felt that the nursing staff had such a great workload that there was no time for information during their time in care and so they had unanswered questions. (U)

No, nothing about the clinical picture and the illness itself and why I have these symptoms and why it's like this. Because they haven't time for that sort of thing, it just fell in (new patients). (page 512)

Finding 6

Illustration

The yearning to come home overshadowed everything else, and the patients saw it as an important factor for their recovery. (U)

If only I manage to get home I'll get better. (page 437)

Finding 7

Illustration

Home-coming was experienced with mixed feelings ... yes, I longed to get home, I certainly did, but at the same time I was almost...
feelings. (U)  

Finding 8  
The patients only really understood on coming home the consequences of the illness. (C)  
You see, it was just that little handicap I have, yes it's … still there. (page 437)  

Finding 9  
After coming home a gradual adaptation to the new situation began. Part of the adaptation to the new life was to try to train functions and abilities that had been affected. (U)  
Yes automatically, yes, then I do like this. Yes, to find solutions is the only way and as I am alone, … so it's like that, that's what I think, that I've always seen that I must find another way out of it … when I can't manage to do this or that, there's always another way of doing it. It'll be OK. (page 437)  

Finding 10  
The patients and their family afterwards asked for a contact with healthcare. (C)  
So I could have told them … I can do this now and so on and they could have said that I was managing fine. (page 437)  


Finding 1  
Individuals accept alternate ways to eat with their disabilities in order to maintain social relations and conceal their disability. (U)  
This is it, isn't it? It's happened so, move on. … I have to view the situation differently now, I have to set lower targets, lower goals. (page 190)  

Finding 2  
Getting back to normal, either the prestroke or a new normal, was a goal for post-stroke individuals. (U)  
I hope I can cope when I get back home. So, I know its going to be a bit difficult when I get back home. (page 189)  

Pilkington FB. (1999). A qualitative study of life after stroke  

Finding 1  
Participants express intense suffering amidst the sudden, devastating changes that accompanied the stroke. (U)  
It's a whole new lifestyle. It's like starting your life all over again, it really is, you know … It's just a nightmare! It's like lightening. When lightening strikes, you don't know what damage it's going to do, but when it does, you know it. (Page 338)  

Finding 2  
For participants, hopes for endurance mingle with dreams of new possibilities. (U)  
Life has to go on. What I had before, I have to give up. I have to find something new to be meaningful and to live again, a near normal life. (page 340)  

Finding 3  
Appreciation of the ordinary, shifts in perspective. (U)  
I think I should have learned a lot from this thing – that really, you shouldn't put too much
Lamb et al.  Psychosocial experience of elderly stroke patients©the authors 2008 page 461

perspectives for those who have experienced a stroke. (U)

Finding 4

Consoling relationships: the relationships with family, friends and caregivers are important to the participants and uplift them and their quality of life. (U)

stress on yourself. I will try and go through life with less stress and see it through a different view. (page 341)

Illustration

You can tell it in their face and their eyes, and everything. Nothing's too hard for them. It makes you feel important that they want you to live. They want you to get the best of care, and they're doing everything humanly possible to make sure it happens to you. And even the dietitians; everybody from the caretaker to a registered nurse, they all play a part. (page 342)


Finding 1

A major problem for many stroke survivors was the difficulty in leaving the house or being completely housebound. (C)

Mr Stone was unable to leave his home because the stairway from his block of flats did not have a railing. Mr Miah was trapped on the third floor of temporary bed and breakfast accommodation because he could not climb up and down the stairs. (page. 340)

Illustration

Finding 2

Inaccessible buses are often a reason for not getting out. (C)

Several people mentioned this as a reason. (page 341)

Finding 3

Stroke survivors who are confined to the house frequently have feelings of unhappiness. (U)

I've got no one to come in to talk to me or anything, got no one. I'm so fed up. I say I must know every inch of this wall, these walls, this wallpaper. (page 341)

Finding 4

A frequent cause of disadvantage to women was their inability to do housework after the stroke. (U)

Mrs Hughes was severely disabled and unable to stand without help. Her partner had taken over responsibility for the housework – a contentious area. (page 341)

Finding 5

Stroke survivors may feel disadvantaged as a result of not being able to pursue their old leisure activities. (U)

And another thing I can't – I've always been a great knitter ... So anyway, this cloak my niece wanted, I'd already knitted four for the nurses. So I said, 'Alright, I'll make that me first job, D.' And I tried, I got so wild with myself ... The thing that I like doing most, I can't do. (page 342)

Finding 6

Stroke survivors may find it difficult to adjust to walking differently or to relinquish a certain manner of walking or a particular stride. (U)

Mr Weaver missed being able to 'walk like a soldier, as I seem to have been taught. Not necessarily to have my arms swinging, but to have my right shoulder to my left leg'. (page 342)

Finding 7

Stroke survivors may experience reactions from others to the way they talk. (U)

Before the stroke my mind didn't dither. Sometimes I want to say something, I may have to stop, although I've still got in mind what I want to say. (page 343)

Finding 8
Stroke survivors may experience problems with their relationships with spouses and other family members. (U)

Finding 9  
Stroke survivors may experience poor memory and confusion. (U)

Finding 10  
Fear of another stroke may affect people's willingness to pursue all sorts of activities. (U)

Finding 11  
Many people had to try and acclimatise to bodies that seemed different. (C)

Proot IM, Crebolder HFJ, bu-Saad HH, Macor THG, Ter Meulen RHJ. (2000). Facilitating and constraining factors on autonomy: the views of stroke patients on admission into nursing homes

Finding 1  
On admission, most stroke patients experience that their autonomy has decreased in comparison with prestroke, in particular the dimension self-care because of disabilities post-stroke. (U)

Finding 2  
Individuals experienced an increase in autonomy as their self-care abilities improve. (U)

Finding 3  
Awareness of a decrease of autonomy leads patients to compare their situation with life beforehand and inevitably confronts patients with loss. (U)

Finding 4  
Patients feel insecure on admission, describe themselves as laypersons and the health professionals as experts, and find it difficult to judge the work of the health professionals. (U)
Finding 5
Most patients have a passive role in rehabilitation. On admission, waiting and seeing is often a strategy. (U)
Illustration
We are waiting patiently. It is the only thing we can do. (page 469)

Finding 6
On admission, patients feel it is difficult to have any measure of control over their own treatment because they feel like a layperson but also because of the environment. (U)
Illustration
They wake you early in the morning, and you wash and dress. Then you go to the living room. And you sit. Well, I like to take the elevator down, and sit there and smoke a cigarette. Then I take the elevator back up again. And so another half hour passes. (page 469–470)

Finding 7
Patients feel that therapy and supervised exercises in the ward facilitate regaining self-care, but they experience a lack of therapy and supervision, for example, when their therapist is ill or during weekends. (U)
Illustration
I feel that with more assistance, one could improve at a quicker rate ... I can't judge if they hire enough staff, or if they could hire more, if the budget is enough. (page 470)

Finding 8
In comparison with the hospital, patients in the nursing home experience more therapy, a hopeful atmosphere, and more opportunities for autonomy. (U)
Illustration
You have more freedom here. You can wear your street clothes ... in the hospital you wear pajamas ... Here I am allowed to make a sandwich, in the hospital you couldn't do anything. (page 471)

Finding 9
The nursing home 'seems like a hotel' which is more or less necessary because of post-stroke disabilities but offers fewer possibilities to spend time autonomously. (U)
Illustration
I did everything by myself, always. Cooking meals and everything. And now I do almost nothing by myself. Actually, I don't need to cook here, they provide the meals. (page 471)

Finding 10
The presence of fellow patients as a part of patient's context leads to waiting periods, for example, for taking showers, which constrain autonomy. (U)
Illustration
You always have to wait here. There are too many people, you can't just take a quick shower, it's just impossible. (page 471)

Finding 11
Fellow patients support each other's autonomy. (U)
Illustration
When he (fellow patient) wakes up at night and sees me lying there with my legs uncovered, or something. Also with meals, with pouring coffee. We help each other. (page 471)

Finding 12
Receiving support is of extreme importance on admission and facilitates patient autonomy. (C)
Illustration
All you had to do when you needed something was ring the bell and they would come right away. I am able to pull on my pants but only to a certain point. I still need help with that and I always get it. (page 472)

Finding 13
Sometimes, when used too pointedly, attentiveness constrains autonomy. (U)
Illustration
I feel I have to hurry up, when they watch me. Only because they are watching, I would get the job done, even if it takes a little bit more time. (page 472)
Finding 14  An attentive approach facilitates autonomy. (U)  Illustration  They make sure you won't do stupid things, starting to walk too soon, or something like that. (page 472)

Finding 15  Patients experience that paternalism is necessary, for example, when the therapist made the decision to start with ADL, which afterward appeared to be the right decision. (U)  Illustration  I must admit that when she (occupational therapist) started last week (ADL), I told her a few times, 'Girl, leave it, I don't want to learn how to manage my shirt and pants.' I really had the idea it was a lost cause. But this morning I noticed that it actually goes well. (page 472)

Finding 16  Information about treatment plans and a respectful attitude of the health professionals facilitate autonomy. The attitude is not always respectful, however. (C)  Illustration  So you go to the washroom. Says the nurse, "You have just been!" I say, 'Well I have to go again.' 'But you just went' they say then. And I find that a nuisance. (page 473)

Finding 17  Care routines lead to long waiting periods and constrain autonomy. (C)  Illustration  Sometimes in the morning, or when they bring the meals, there are a lot of them (health professionals) and then, when we have to go to the bathroom, they are gone. They are nowhere to be found, maybe they are eating. I don't know, they need to do that too. But you know, if you can't find the nurses, you have to ring the bell … And when they finally come, there are two, three, or four people who urgently have to use the bathroom. And you have to wait sometimes for half an hour. (page 473)

Finding 18  Instrumental support is a considerable facilitating factor for autonomy, for example, regarding care of premises, plants and pets, shopping, delivering mail, and laundry. (C)  Illustration  They (the children) come … My daughter does everything for me that I can't do for myself anymore. The Laundry. (page 474)


Finding 1  Illustration  For some stroke survivors, reaching toward God is a way to improve confidence after the stroke. (U)  God will help you get better or give you strength to deal with the stroke. (page 359)

Finding 2  Illustration  Prayer may be a basic part of recovery for some stroke survivors. (U)  Other participants resumed their usual patterns of praying, mostly during church services or by praying to special people such as the 'Blessed Mother,' asking her to 'show me a happier way.' (page 360)

Finding 3  Illustration  Stroke survivors often reached back to family 'Always being in church' was a major way one family coped … So that religion played
Finding 4
Participants found prayer a source of strength from God. (U)
One survivor acknowledged that prayer gave her ‘gumption and the strength to get through everything.’ (page 361)


Finding 1
Stroke survivors struggle with the loss of independence and abilities. (U)
You feel very helpless, uh, very inept, uh, paralyzed in thought, function, mind, body. (page 243)

Finding 2
Relationships helped bridge the schism in the discontinuity of their lives. Having connections with other people meant reciprocity, being with and understood by someone, and experiencing help from others. (U)
The thing that kept me going was this contact with the other person. (page 243)

Finding 3
Disruption and discontinuity in the experience of self after the stroke contrasted with the ongoing continuity of life. (U)
One day you’re working and the next day you’re an invalid. So you know, you think you’re through … you think you’ll just never be a whole person again. (page 244)

Finding 4
The experience of stroke as resulting in a bewildering and sudden loss of control, leading to the unpredictability of their bodies, memory, emotions and speech. (U)
It just hit me like lightening. (page 243)


Finding 1
Respondents generally reported a decrease in participation in daily activities. (U)
I can look after myself, I dress myself, I bath, shower, shave, toilet myself, no problems at all … I can live as I am. If my wife died tomorrow, I wouldn’t have to go into a home. (page 345)

Finding 2
Leisure activities – activities performed within the home and outside the home. (U)
My hands are a bit of it, that’s because I get stiff when I’m holding a needle. But a bit of it is because I can’t grasp the patterns. I used to knit all these lovely patterns and when I went back to knitting, I found I couldn’t do them and I lost interest. (page 346)

Finding 3
Change is experienced with regard to relationships, contact with others and
I would really like to say ‘Oh it’s a nice night let’s go out for a walk’, but I can’t. (page 436)
Finding 4
Relationships with family and friends outside the home, amount of interactions (visits to others) and appearance to others. (U)

Illustration
The thing is you feel entrapped within yourself. You know you can do so much more but you know you're so restricted and I think that makes you feel inferior. I wouldn't say it gives you a complex but you feel. And you hate meeting people you knew years before, before you were ill. You are aware that you are, I mean you go out in the road and some little old lady overtakes you and you lose your dignity. (page 347).

Finding 5
Individuals experience changes in their ability to cope with the physical environment, both at home and in the community. (U)

Illustration
I couldn't go up ... road because I think it's a bit steep. It would take ages getting up there and where do I go then? You're at the main road, all the people rushing by. One knock and I'd lose my balance and I'm down again there see. They say get out and walk but it's easy for them to say get out and walk. (page 347).

Finding 6
Changes with regard to financial circumstances post stroke, due to decreased income or increased expenditures. Change in the amount of responsibility for the management of finances. (U)

Illustration
I never have any money. Paul came round the other day and wanted 20p and I had to go to the pot and get out two coins and say 'What are they?' (page 348)


Finding 1
Patients found professionals reluctant to provide detailed information about the extent of recovery. (U)

Illustration
One thing that's absolutely clear is that they don't do any forecast because they can't tell what's going to happen and when it's going to happen and I accept that. (page 845)
Appendix V: Results of meta-synthesis of qualitative research findings

Meta-synthesis of studies included in the review generated four synthesised topics. These synthesised topics were derived from 165 study findings that were subsequently aggregated into 20 categories.

The synthesised findings are listed within category, within synthesis topic.

**Connectedness**

Comments: Elderly individuals who have experienced stroke identify the importance of connectedness in their process of recovery.

**Relation to others**

Relating to people with a disability: Performing tasks that helped those they perceived as less fortunate, or providing something to others was a strong motivating force.

Stroke survivors fear that they would be dependent on their families forever and actually grieved about their loss of functioning.

Stroke survivors’ perceptions of incremental progress, supportive family and spiritual connectedness provide a sense of encouragement, support and belonging.

Relative to the pre-stroke period, there was a clear deterioration in the social lives of the majority of respondents.

One of the impacts of a stroke is relationship changes.

Relationships helped bridge the schism in the discontinuity of their lives. Having connections with other people meant reciprocity, being with and understood by someone, and experiencing help from others.

Change is experienced with regard to relationships, contact with others and household responsibilities.

Relationships with family and friends outside the home, amount of interactions (visits to others) and appearance to others.

Friendship with people who shared or understood the stroke survivor's situation enabled relationships on equal terms.

Consoling relationships: The relationships with family, friends and caregivers are important to the participants and uplift them and their quality of life.

Fellow patients support each other's autonomy.

There is a need to share feelings with others during hospitalisation.

In the acute phase some informants did not want to talk, others got comfort from talking.

The need for social contact gradually increased as the physical and psychological state of patients improved during their stay in the rehabilitation ward and after discharge.
Stroke survivors may experience reactions from others to the way they talk.

Stroke survivors may experience problems with their relationships with spouses and other family members.

Autonomy versus shame, doubt: The balance between these poles is greatly challenged because of the individual's loss of independence and their ability to perform according to their wishes.

Individuals struggled to keep up their self-image and the image of them held by other people.

**Spiritual connectedness**

Hope is guided in part by spiritual relationships.

Spiritual connectedness may provide stroke survivors with a sense of encouragement.

For some stroke survivors, reaching toward God is a way to improve confidence after the stroke.

Prayer may be a basic part of recovery for some stroke survivors.

Stroke survivors often reached back to family spiritual life experience.

Participants found prayer a source of strength from God.

Only a minority of informants believed that their religious or spiritual belief had helped them physically, giving them a sense of psychological comfort in the acute ward.

**Isolation**

Impact of stroke on participants: Loss of abilities related to social activities.

Intimacy versus isolation: Some stroke victims did not talk with their spouse about the disease, their struggle for improvement or their regret at not making a full recovery.

For some there was a struggle to cope in their relationships and to communicate owing to unfamiliarity with talking about emotional matters.

**Relationship with professionals**

Some participants perceived a gap between their own assessment of recovery and that of health professionals.

Most participants reported satisfaction with professional care relationships.

Experience with professional caregivers: Negative experiences.

Some patients felt that the nursing staff had such a great workload that there was no time for information during their time in care and so they had unanswered questions.

Receiving support is of extreme importance on admission and facilitates patient autonomy.

Sometimes, when used too pointedly, attentiveness constrains autonomy.

An attentive approach facilitates autonomy.

Patients experience that paternalism is necessary, for example, when the therapist made the decision to start with ADL, which afterward appeared to be the right decision.
Information about treatment plans and a respectful attitude of the health professionals facilitate autonomy. The attitude is not always respectful, however.

The major psychological support valued by the informants included giving them reassurance and a sense of security, offering verbal encouragement, listening to their worries, showing a caring attitude and respecting them as individuals.

**Reconstructing life**

Comments: Elderly individuals describe the recovery process as reconstructing their lives following stroke. They are engaged in the recovery.

**Attitudes in recovery**

Loss of a sense of mastery: They did not want to perform the occupations which they had excelled at prior to their stroke: Their disability was not as obvious in a new occupation.

Hope is experienced as positive anticipation regarding recovery.

Hope is related to active participation, moving the stroke survivor towards recovery.

Hope is perceived by stroke survivors as an inner strength actively moving them toward achieving goals in recovery.

Stroke survivors view hope as life-sustaining.

The yearning to come home overshadowed everything else, and the patients saw it as an important factor for their recovery.

Integrity versus despair: The experience of wholeness and meaning was challenged through the losses suffered owing to the stroke and there were signs of despair.

The existential re-establishment of self involves placing their condition into context and taking a hopeful outlook.

Being suddenly faced with the possibility of one's own death in some leads them to dare to confront the emerging existential issues associated with death.

**Coping with physical disability**

Issues in physical recovery involve a process of initial personal experience of the stroke moving them through early recovery, a slowing down and then facing new challenges.

The demanding body: The unpredictable body is demanding in different ways in everyday life: It is time-consuming, limiting, dependent and conspicuous.

Most stroke survivors identify physical limitations incurred by stroke.

The impact of stroke on some participants: The inability to perform activities of daily living.

Individuals experience changes in their ability to cope with the physical environment, both at home and in the community.

Initiative versus guilt: Individuals set and achieve desired goals but may experience guilt if they only have small signs of improvement.
The extended body: Many stroke survivors needed tools or remedies, such as walking sticks, crutches, a walker, a wheelchair, large handled knives, forks, spoons, special pens and pencils, and braces.

**Support experiences**

Lack of intervention and education regarding emotional changes: The lack of education regarding the physiological basis for her lability caused her to feel out of control.

Care-receiving issues: Appreciation for care provided to them by their caregiver.

The patients and their family afterwards asked for a contact with healthcare.

Patients feel that therapy and supervised exercises in the ward facilitate regaining self-care, but they experience a lack of therapy and supervision, for example, when their therapist is ill or during weekends.

In comparison with the hospital, patients in the nursing home experience more therapy, a hopeful atmosphere, and more opportunities for autonomy.

The nursing home ‘seems like a hotel’ which is more or less necessary because of post-stroke disabilities but offers fewer possibilities to spend time autonomously.

The presence of fellow patients as a part of patient’s context leads to waiting periods, for example, for taking showers, which constrain autonomy.

Care routines lead to long waiting periods and constrain autonomy.

Instrumental support is a considerable facilitating factor for autonomy, for example, regarding care of premises, plants and pets, shopping, delivering mail and laundry.

Information needs remain important after discharge. Elderly patients usually have poor memory and visual problems owing to normal ageing.

**Struggle**

Stroke survivors find themselves struggling to regain their independence.

In measuring psychological and physical well-being, the standard used by patients was their pre-stroke lives.

Stroke survivors struggle with the loss of independence and abilities.

The struggle to manage life despite the stroke.

Older women described their response to stroke as fighting off disabling feelings and maintaining the will to live.

Striking a balance between attending to the needs of others and addressing increased personal needs involves choices as the individual struggles to maintain a normal life.

The stroke experience led to feelings of stagnancy and emptiness in life which individuals struggle to counteract.

Getting back to normal, either the pre-stroke or a new normal, was a goal for post-stroke individuals.
The struggle to manage life includes being able to grasp the severity of the new situation after stroke and still preserve hope.

The struggle to manage involves actions to counteract the sense of helplessness and dependency that arose out of the stroke experience.

**Living with uncertainty**

Issues in emotional recovery: The overwhelming nature of stroke precipitates immense uncertainty.

Individuals experienced uncertainty in response to both the symptoms and their perception of healthcare providers and the treatment they delivered.

Patients found professionals reluctant to provide detailed information about the extent of recovery.

Home-coming was experienced with mixed feelings.

After discharge, some of the patients were still uncertain about stroke recovery.

Uncertainty and apprehension for the future were met as the older women attempted to manipulate their environment and regain a measure of control.

**Changing/retaining roles**

Sense of control: In occupations where they felt in control, they were less debilitated by their emotional changes.

Issues in social recovery: A stroke precipitates an individual's changing roles accompanied with isolation and reflection on their previous life.

Changes with regard to financial circumstances post stroke, owing to decreased income or increased expenditures. Change in the amount of responsibility for the management of finances.

Attempting to maintain control of valued female roles included choices and accepting help.

A frequent cause of disadvantage to women was their inability to do housework after the stroke.

**Acceptance**

Individuals describe difficulty in the acceptance of care provided by others.

Individuals describe coming to terms with needing care from others.

Individuals accept alternate ways to eat with their disabilities in order to maintain social relations and conceal their disability.

**Strategies for adaptation**

Ensuring forward progress includes maintaining hope throughout the slow process.

Ensuring forward progress includes increasing control over recovery by being more assertive and active in their own care.

Making decisions for themselves is an important part of their commitment to self-care in stroke recovery.

Elderly stroke survivors may normalise the effects of the stroke as part and parcel of the aging
process.
Striving to regain the power to accomplish necessary and valued activities met with gradual improvements and the energy and will to keep trying.

Appreciation of the ordinary, shifts perspectives for those who have experienced a stroke.
After coming home a gradual adaptation to the new situation began. Part of the adaptation to the new life was to try to train functions and abilities that had been affected.
Patients start to seek more information about stroke recovery in the rehabilitation setting.
Gaining knowledge helps as a means of controlling their feelings of powerlessness.
Reconciliation and reengagement means living again having acknowledged, remembered and assimilated the experiences from the stroke.

Transitions
Women believed they were in a state of transition, and were transformed by stroke.
Individuals discuss hope in terms of anticipated future possibilities.
The stroke survivors’ sense of incremental progress provides a sense of encouragement.
For participants, hopes for endurance mingles with dreams of new possibilities.
Transformation occurs through an intellectual journey to reconstruct oneself into who one would become.
Discharge home was a major transition.
Transformation includes the process of recalling the past within the context of discovering the present.
Subtleties of losses and helplessness are woven into daily lives and are a part of the transformation.

Adjustment
Ensuring forward progress includes preserving energy in order to participate in therapy.
Individuals perceive life after stroke as a period of change and adjustment.
There is a life-long adjustment to the residual impairments caused by the stroke.
Some individuals maintain hope through relative comparison to previous abilities or the abilities of others.
The patients only really understood on coming home the consequences of the illness.
Individuals experienced an increase in autonomy as their self-care abilities improve.
Adapting to another new environment, with transfer to the rehabilitation ward, was stressful.
Adapting to changes occurring from stroke can be a difficult and disheartening process.
Participating in activities

Impact of stroke on participants: Loss of ability to drive.

Respondents generally reported a decrease in participation in daily activities.

Leisure activities – activities performed within the home and outside the home.

A major problem for many stroke survivors is the difficulty in leaving the house or being completely housebound.

Inaccessible buses are often a reason for not getting out.

Life-altering event

Comments: Individuals perceive the stroke as having life-altering consequences.

Discontinuity

Ensuring forward progress includes initial recognition of their losses and accepting that life would be forever different.

Stroke as a loss for the survivor is devastating and necessitates adjustments to a changed status and identity.

Fundamental life change: Change that could be likened to entering a new foreign world.

Individuals discussed hope in terms of regaining previous abilities.

Most individuals who have a stroke describe profound ways in which their life has been affected.

For those with co-morbidities, the stroke may be viewed as one event in an ongoing life rather than a discontinuity.

There is minimised biographical disruption by stroke in individuals who have a history of and pre-existing knowledge of a stroke.

Disruption and discontinuity in the experience of self after the stroke contrasted with the ongoing continuity of life.

Awareness of a decrease of autonomy leads patients to compare their situation with life beforehand and inevitably confronts patients with loss.

Stroke survivors who are confined to the house frequently have feelings of unhappiness.

Stroke survivors may feel disadvantaged as a result of not being able to pursue their old leisure activities.

Some stroke survivors find it difficult to adjust to walking differently or to relinquish a certain manner of walking or a particular stride.

The balance between identity and identity confusion is easily disturbed after a stroke.

Generativity versus stagnation: Despite their age they were used to being productive and creative in various ways and had been so for most of their lives. It was a trying experience to realise they were no longer able to perform the work and the tasks they used to.
Participants viewed recovery as return to pre-stroke life and improvement as isolated and discrete return of movement.

Regret was expressed as grief; they mourned for a part of self that was valued in everyday life and activities.

Living and suffering through inexorable losses is accompanied by fear and despair.

Seeking self: Participants found the way in which they perceived themselves was changed by the stroke event.

**Sudden unexpected event**

Comments: Stroke survivors perceive the stroke experience as having a sudden onset, generating shock, fear and confusion.

*Self-body split*

The experience of self-body split: Their body becomes separate, precarious, perplexing.

The unpredictable body: The most fundamental characteristic and experience of the body after stroke seemed to be that the body had become unpredictable. The body was experienced as non-spontaneous, vulnerable, defenceless, unreliable and betraying.

Many people had to try and acclimatise to bodies that seemed different.

Some stroke survivors view their body as a passive object and their limbs as no longer under their direction.

*Shock, fear and loss of control*

In the acute phase, the stroke was experienced as a bodily event.

During the acute admission period there was tremendous uncertainty for the individuals, much of which related to the diagnosis of stroke and was experienced as a loss of control.

The suddenness of the stroke left them shocked and stunned, with extreme fright if the stroke was still evolving.

The realisation that hospitalisation would not ‘cure’ the stroke further stunned the individuals.

Participants express fear related to disability.

Participants express intense suffering amidst the sudden, devastating changes that accompanied the stroke.

On admission, most stroke patients experience that their autonomy has decreased in comparison with pre-stroke, in particular the dimension self-care because of disabilities post stroke.

Explanations about special interventions were required by patients, especially when physical restraint was carried out.

Stroke survivors may experience poor memory and confusion.

Fear of another stroke may affect people's willingness to pursue all sorts of activities.
Trust versus mistrust: In the early phase of stroke, individuals experienced fluctuating consciousness and confusion that threatened their security.

Industry versus inferiority: The sudden loss of competence was a severe trauma for the individuals and it was hard for them to put up with their deficiencies.

Individuals spent many sleepless nights in the hospital.

The experience of stroke as resulting in a bewildering and sudden loss of control, leading to the unpredictability of their bodies, memory, emotions and speech.

**Uncertainty of diagnosis**

Individuals are able to describe the symptoms they were experiencing when they had a stroke although they did not realise the meaning of the symptoms at the time.

Many individuals put off seeking healthcare when they had symptoms, by waiting or keeping their symptoms secret.

Individuals may attempt to explain what is happening to them by grouping symptoms.

**Giving up control to others**

The patients saw themselves as responsible and participating in what happened when they fell ill.

During their stay at the hospital the patients put themselves in the charge of the staff and took a passive part.

The patients take the blame on themselves for not getting the information that they would have liked.

Most of them had not thought about what might have been different, what they could expect, but had assumed that what had happened was the current practice in healthcare.

Patients feel insecure on admission, describe themselves as laypersons and the health professionals as experts and find it difficult to judge the work of the health professionals.

Most patients have a passive role in rehabilitation. On admission, waiting and seeing is often a strategy.

On admission, patients feel it is difficult to have any measure of control over their own treatment because they feel like a layperson but also because of the environment.
# Appendix VI: Synthesis table

<table>
<thead>
<tr>
<th>Study</th>
<th>Title</th>
<th>Purpose</th>
<th>Methods</th>
<th>Participants</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Alaszewski et al. (2004)</td>
<td>The bereavement model, stroke and rehabilitation, a critical analysis of the use of a psychological model in professional practice</td>
<td>To explore the ways in which professionals use the bereavement model to explain and manage the rehabilitation of stroke survivors</td>
<td>Semi-structured in-depth individual and focus group interviews including: Stroke survivors and their families Professionals Self-report diaries (4)</td>
<td>31 stroke survivors At least 1 year post stroke 17 Professionals</td>
<td>Stroke survivors manage their recovery by setting goals The bereavement model is used by professionals to assist stroke survivors where their goals were unrealistic or there was a conflict over goals</td>
</tr>
<tr>
<td>2. Bays (2001)</td>
<td>Older adults' descriptions of hope after a stroke</td>
<td>To explore the phenomenon of hope and the factors associated with that hope in older adults who have experienced a stroke</td>
<td>Semi-structured interviews</td>
<td>Convenience sample of 9 stroke survivors Mean age 68.22 years All participating in a stroke support group</td>
<td>Implications for nursing practice include: The life-sustaining value of hope The benefits of stroke survivors telling their stories The importance of disseminating research findings The delicate balance between caregiver involvement and burden of care The influence of spirituality</td>
</tr>
<tr>
<td>3. Burton (2000)</td>
<td>Living with stroke: a phenomenological study</td>
<td>To identify the lived experience of stroke from the patient's perspective To describe recovery over time</td>
<td>Interviewed in hospital following admission for stroke then at monthly intervals for at least 1 year Total number of interviews was 73 A log journal was maintained throughout the duration of the study</td>
<td>6 informants (2 males, 4 females) mean age 67 years</td>
<td>Informants focused on the social context of recovery Engagement in the social world was emphasised over discrete physical function Recommended that stroke services take into account the long-term needs of stroke patients and their families in their home environments</td>
</tr>
<tr>
<td>4. Cox et al. (1998)</td>
<td>Coping with stroke: perceptions of elderly who have experienced stroke and rehabilitation interventions</td>
<td>To explore the roles, values/beliefs and behaviours of elderly stroke survivors in their recovery process</td>
<td>In-depth interviews</td>
<td>39 elderly stroke survivors Mean age 79.05 years All received rehabilitation services in a rehab hospital between 1</td>
<td>Respondents experienced significant changes in their prestroke lifestyles and abilities Stroke survivors have important observations regarding ways in which they have learned to cope with stroke-related problems</td>
</tr>
</tbody>
</table>

To capture a systematic record of the stroke experience, and to identify differences and commonalities across behaviours

Interviews were done:
- Within 72 h of the infarct
- During acute and rehabilitation phases of recovery – for a period of 6 months
- Average of 9 interviews per participant, total of 120

- 13 Thirteen stroke survivors, all with lacunar infarcts of the internal capsule of the brain
- Mean age 67 years
- Participants selected from three large urban hospitals in northern California

Stroke survivors experienced a paralysed self secondary to bodily immobility, the shock of the stroke onset and fear of not knowing what might happen next. The terrifying loss of control over bodily movements led to an experiential breakdown


To provide a more detailed description of the psychosocial difficulties associated with stroke

- Semi-structured interviews
- Stroke survivors and caregivers were interviewed separately
- Followed up at 3, 6, and 12 months post-recruitment

- 30 stroke survivors
- 13–16 months post-stroke
- Median age 73 years
- 15 caregivers

Further research and interventions must consider the diverse, complex, dynamic and highly personal character of stroke recovery. Traditional outcome measures are too simplistic to capture patients’ and caregivers’ experiences. There do not appear to be single or simple solutions to the problems of facilitating psycho-social adjustment


To examine the experiences of stroke in rural African American elders and their families

- Semi-structured interviews in survivors’ homes

- 8 stroke survivors and primary and secondary caregivers
- Mean age 67 years
- Recently discharged from a rehabilitation centre
- Within 4 months of stroke event
- Resided in a rural area

This study raises the awareness about the difficulties of adapting to the residual effects of stroke and the inherent struggle to reconstruct life following a stroke event

8. Ellis-Hill Self-body split: To explore the life

- Interviews in

- 8 stroke survivors

Stroke survivors describe a
et al. (2000) issues of identity in physical recovery following a stroke narratives of people following a single stroke to understand how they constructed the meaning of the stroke within their life story and to identify the main issues that they were facing hospital, and at 6 months and 1 year postdischarge • The Gross Motor subscale of the Rivermead Motor Assessment and the Nottingham 10 point Activities of Daily Living Scale were completed • 24 interviews in total respondents and their spouses • No previous disability, and were returning home • Mean age 67 years fundamental life change and experience a split between self and body for at least a year post stroke. Study suggests that rehabilitation professionals should consider longer-term (although not necessarily intensive) physical activity programs that address these psychological as well as neuromuscular changes

9. Faircloth et al. (2004) Sudden illness and biographical flow in narratives of stroke recovery Hypothesis: • The lives of people who have had a stroke are not inevitably disrupted • Different symbolic significance may be attached to this experience dependent upon specific biographical contingencies of the given participant • Interviews at 1, 6 and 12 months after being discharged home from hospital • Interviews conducted by native language speakers in both Spanish and English, then transcribed into English, and the English transcriptions checked against the tape-recorded interviews for accuracy by native speakers and project coordinators • 57 participants (55 male 2 female) • 23 non-Hispanic white, 16 African-American, 18 Puerto-Rican Hispanics • Mean age 66.18 years • Participants had high prevalence of comorbidities Findings suggest a biographical flow more than a biographical disruption to specific chronic illnesses once certain social indicators such as age, other health concerns and previous knowledge of the illness experience, are taken into account

10. Folden (1994) Managing the effects of a stroke: the first months To explore how stroke survivors managed the multiple deficits produced by a stroke event during the first months after the stroke event • Grounded theory • First interview in the rehab setting within 2 weeks of the stroke event • Second interview conducted at 3–4 weeks following discharge from inpatient rehab program • 20 stroke survivors participating in a comprehensive inpatient rehabilitation program. • Mean age 73.6 years • No significant cognitive deficits no aphasia • All spent at least 24 days in acute rehabilitation Stroke survivors managed the multiple functional deficits produced by a stroke event by ‘ensuring forward progress’—this included accepting that life will be forever different, maintaining hope, preserving energy, and increasing personal control over recovery

11. George Depression and To investigate the • Case study with 2 • A 70 years old There is a two-way
et al. (2001)  
Lability: the effects of occupation following stroke experience of people with lability and depression following a stroke and to understand how this impacts on engagement in occupation  
- Stroke survivors' partners were included in the interviews  
- Medical case notes from acute care, rehabilitation and outpatient treatment were reviewed  
- A 69 years old woman with emotional lability and left hemiplegia after a right hemispheric stroke 3 years earlier  

The meaning of stroke in elderly women: the lived experience  
To understand the meaning of stroke in elderly women  
- Phenomenological approach  
- In-depth interviews in participants' homes  
- 5 elderly women who had experienced stroke more than 1 year previously  
  - At least 65 years of age when the stroke occurred  

The meaning of stroke in elderly women: a phenomenological investigation.  
To discover meanings of stroke in elderly women to understand the phenomenon from the experiential perspective  
- Phenomenological approach  
- In-depth interviews in participants' homes  
- Participants were interviewed twice  
- 6 elderly women between the age of 66–80 years  
- Stroke occurred at age 65 years or older  

Living with bodily strangeness: women's experiences of their changing and unpredictable body following a stroke  
To present and discuss from a phenomenological and feminist perspective the findings from a qualitative study of how female stroke survivors experience their body and life after stroke  
- Phenomenological approach  
- Participants interviewed in-depth 3 times  
  - First interview in hospital during the first 6 weeks after the stroke  
  - Second and third interviews in participants' homes at 6 months and 1 year after they  
- 24 women suffering first time stroke  
- 3 women died before second interview  
- 1 woman died between second and third interview  
- 20 women completed all 3 interviews  
- Data from all  

The overarching theme was transformation. Women were changed or transformed by stroke and, through a process of unknowing and reknowing, were able to move forward in anticipation of the future  

Elderly women surviving stroke experience a challenging transformation from healthiness to disability. Reconstructing self was a solitary, painful journey beset with uncertainty. All of life's acquired skills were needed to enable them to reconcile losses and move forward to live the best lives possible  

Stroke survivors' experiences of their bodies were characterised by profound, disturbing and unintelligible changes during the onset and process of recovery. During the first 1.5–2 years they experienced periods of rapid improvement and slow changes. Silent but significant changes occurred as they became more familiar with their strange and unfamiliar bodies
<table>
<thead>
<tr>
<th>Study</th>
<th>Methodology</th>
<th>Participants</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. Kvigne et al. (2004)</td>
<td>Phenomenological approach</td>
<td>24 women suffering first time stroke: 3 women died before second interview, 20 women completed all 3 interviews. Data from all the women was included. Age range from 37 to 78 years.</td>
<td>The women described a lengthy struggle to continue life and preserve the self following the stroke. The struggle was closely related to their deeply rooted identity as mothers, wives, grandmothers, and housewives. The situation of women following a stroke needs particular attention because their needs may conflict with their female caring roles. Supporting them in transforming these roles may secure their sense of self and a continued meaningful life.</td>
</tr>
<tr>
<td>16. Lui and Mackenzie (1999)</td>
<td>Ethnographic approach</td>
<td>15 Elderly Chinese patients with first stroke, mentally alert, and able to communicate. Age range between 60 and 77 years.</td>
<td>Most Chinese elderly people tend to take a passive role in expressing their needs. Identification of need therefore falls on healthcare staff. Patients’ need for information was largely perceived as unmet.</td>
</tr>
<tr>
<td>17. Nilsson et al. (1997)</td>
<td>Phenomenological hermeneutic approach</td>
<td>10 participants, first time stroke, Age range 53–81 years.</td>
<td>To come through the crises successfully and experiences integrity, i.e., wholeness and meaning, the individual has to face all the essential issues emerging in the development of man. Nursing care needs to be aware of this process.</td>
</tr>
</tbody>
</table>

The women was included:
- Age range from 37 to 78 years

Returned home:
- 53 to 81 years

15. Kvigne et al. (2004) Fighting back – struggling to continue life and preserve the self following a stroke

To explore how female stroke survivors experienced their life following stroke and how they managed their altered situation.

- Phenomenological approach
- Participants interviewed in-depth 3 times:
  - First interview in hospital during the first 6 weeks after the stroke
  - Second and third interviews in participants’ homes at 6 months and 1 year after they returned home

- 24 women suffering first time stroke
- 3 women died before second interview
- 1 woman died between second and third interview
- 20 women completed all 3 interviews
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The women was included:
- Age range from 37 to 78 years

16. Lui and Mackenzie (1999) Chinese elderly patients’ perceptions of their rehabilitation needs following a stroke

To explore Chinese elderly patients’ perspectives of their health needs following a stroke in three stages of their rehabilitation: acute, rehabilitation and after discharge.

- Ethnographic approach
- Semi-structured interviews
- 3 interviews: first week after admission to the rehabilitation ward, 1 week before discharge from the rehabilitation ward and 1 month after discharge
- Barthel Index was used to assess functional status

- 15 Elderly Chinese patients with first stroke, mentally alert, and able to communicate
- Age range between 60 and 77 years

17. Nilsson et al. (1997) To meet with a stroke: patients’ experiences and aspects seen through a screen of crises

To elucidate the experiences of stroke victims during the course of the disease and the first few months after discharge.

- Phenomenological hermeneutic approach
- A deductive approach was applied on the basis of the theory of developmental crises according to Erikson
- Interviews approximately 1 month and

- 10 participants, first time stroke
- Age range 53–81 years

To disclose and reflect concerns emerging after a stroke related to the existential dimension of life

- Phenomenological hermeneutic approach
- A deductive approach was applied on the basis of the theory of developmental crises according to Erikson
- Interviews approximately 1 and 3 months after discharge

This study revealed the individual’s struggle to manage in various dimensions of life. The situation was metaphorically depicted as 'a struggle in the darkness' in a 'boundary situation' where issues ultimately touched on life and death, fate and future, meaning and meaninglessness. The study indicates the significance of existential issues pervading the concrete struggle to manage life after stroke.

19. Olofsson et al. (2005) 'If only I manage to get home I’ll get better’ – Interviews with stroke victims after emergency stay in hospital on their experiences and needs

To find out about the experiences of stroke patients concerning their falling ill, their stay in hospital, discharge and homecoming, plus their needs and contacts with healthcare after their stay in hospital

- In-depth interviews
- 9 individuals
- 4 months post stroke
- Discharged home after care at the stroke centre
- Able to communicate

The patients saw coming home as an important factor for their recovery and rehabilitation. The healthcare system needs to develop strategies to use the patients’ own milieu in rehabilitation after stroke.


To explore stroke survivors’ perceptions and responses to eating-related stroke sequelae

- Semi-structured interviews
- 113 Stroke survivors
- 6 months post stroke
- Mean age 67.5 years

The importance of food and eating within the wider experience of life post-stroke was evident. Two emergent themes were 'getting back to normal' and 'getting by'. The study demonstrated non-linear and inconsistent effects of impairments within the patient’s lives and the importance of this topic for health care providers.


To enhance understanding about quality of life after a stroke, from the perspective of patients themselves

- Loosely Structured interviews at 3 time points during the first 3 months post stroke
- 32 interviews in total
- 13 participants
- Age range 40–81 years
- Mild to moderately affected by stroke

This study confirms the suffering that emerges with unaccustomed restrictions and losses after stroke. This study also indicates how quality of life can be enhanced by appreciation for the ordinary, hopes and dreams.
22. Pound et al. (1998) A patient-centred study of the consequences of stroke To explore subjective accounts of the consequences of stroke Semi-structured interviews • 40 participants, from an area of high unemployment in London • 10 months post stroke • Mean age 71 years

23. Proot et al. (2000) Facilitating and constraining factors on autonomy: the views of stroke patients on admission into nursing homes To pinpoint which dimensions of autonomy are identified by stroke patients rehabilitating in nursing homes and to determine which factors, in the stroke patients' perception, facilitate or constrain patient autonomy on admission Grounded theory • Interviews (2–8 weeks after admission) • 58 interviews in total • 22 participants • Mean age 72 years

24. Robinson-Smith (2002) Prayer after stroke: its relationship to quality of life To determine post-stroke patients' use of prayer in coping with the effects of stroke and to examine the prayers used following stroke Semi-structured interviews with three open-ended questions • 8 participants • Age range from 57 to 85 years • Religious preferences reported included: Roman Catholic (4), Lutheran (1), Episcopal (1), and no reported religious affiliation (2) • 7 were Caucasian and 1 African American • 1 year following stroke

25. Secrest and Thomas (1999) Continuity and discontinuity: the quality of life following stroke To investigate the quality of life as experienced by stroke survivors In-depth interviews • 14 stroke survivors • From 9 months to 2 years following stroke

The major themes identified: connecting to God, ways of praying now, reaching back to early family, and finding strength through prayer, depict stroke survivors' use of prayer to cope 1 year after stroke

A model of changing autonomy was developed from the study with three dimensions of autonomy identified: self-determination, independence, and self-care. This study highlights how, on admission, lack of information constrains patients' autonomy of new possibilities

Home visits particularly to those living alone, would help reduce people's isolation after stroke. The use of rehabilitation to overcome disability and addressing the environmental obstacles which imprison people in their homes would help decrease the loneliness and isolation experienced after stroke
following rehabilitation

23 years post stroke (median 2 years)
• All living at home

A fundamental aspect of these themes is a sense of continuity that coexists with discontinuity in the experience of self.

26. Trigg et al. (1999) Social reintegration after stroke: the first stages in the development of the Subjective Index of Physical and Social Outcome (SIPSO)

To ensure at outset the content validity of a measure (to be developed) of social integration following stroke

• In-depth interviews least 6 months following stroke
• Carers and/or relatives were invited to take part in the interviews
• 30 stroke survivors discharged at least 6 months previously from a neurological rehabilitation unit
• Mean age 65.4 years

An individual's level of social integration can be affected by stroke in a wide variety of areas and along many different dimensions. Data highlights the importance of the patient's subjective impression of the quality of both functional and social performance.

27. Wiles et al. (2002) Patients' expectations of recovery following stroke: a qualitative study

• To examine the information exchanged between physiotherapists and patients in relation to recovery
• To explore the factors, associated with the physiotherapists' provision of information that may contribute to patients' high expectation of physiotherapy

• In-depth case studies – 3 semi-structured interviews
• Motor function assessed with the Barthel Index and the Rivermead Motor Assessment (RMA)
• Psychological well being assessed with the Hospital Anxiety and Depression Scale (HADS)
• 16 participants

Improved communication strategies, informed by an evidence base of recovery, should be used to encourage realistic expectations of physiotherapy without destroying the process of active participation and skill acquisition.