

EMPIRICAL STUDY

## The lived experience of stroke survivors with early depressive symptoms: A longitudinal perspective

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### Abstract

*Purpose:* The aim of the study was to describe the lived experience as it develops over time in stroke survivors suffering from early depressive symptoms.

*Method:* This paper presents a phenomenological hermeneutical interview-study of nine participants at 6, 12, and 18 months after stroke.

*Findings:* The participants related the depressive symptoms to the consequences of the stroke, and the experience of loss was crucial. Depressive symptoms was not meaningful on its own, but formed the backdrop of the experience of stroke. Our findings revealed three patterns of experience: (1) finding a restored self; (2) trapped in a different life; and (3) fighting to regain self.

Two groups of stroke survivors are particularly vulnerable and should receive special attention: (a) old adults living alone; and (b) adults experiencing serious threats to their commitments such as to work, family, and children.

*Conclusion:* Depressive symptoms have a severe impact on life after stroke. Life circumstances, degree of residual impairment from a stroke, and social context were found to influence people to move along different paths. Older adults living alone and adults experiencing serious threat to their commitments should receive special attention, in terms of further research and in terms of follow-up in clinical practice.

More studies investigating the experience of post-stroke depression (PSD) over time and the association between depressive symptoms and loss/grieving are needed. There is also a need for continued empirical research on the identification of effective interventions aimed at prevention or improved coping with PSD.

**Key words:** *Depression, post-stroke depression, stroke, grief, longitudinal studies, qualitative method*

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Post-stroke depression (PSD) is considered to be one of the most prevalent affective symptoms after stroke and occurs in at least one quarter of stroke survivors during the first year (Hackett, Yapa, Parag, & Anderson, 2005). PSD might complicate and delay stroke rehabilitation and signals a poorer outcome and increased functional dependence compared to non-depressed stroke survivors. PSD could also become chronic in nature or even lead to death (Almeida, Waterreus, & Hankey, 2006; Gaete & Bogousslavsky, 2008; Nys et al., 2005; Paolucci et al., 2001; Sinyor et al., 1986; Van de Weg, Kuik, & Lankhorst, 1999). The phenomenon has created a

degree of controversy in the literature, in terms of diagnosis, its cause, risk factors, and pattern of progression in the post-stroke period (Bhagal, Teasell, Foley, & Speechley, 2004; Carson et al., 2000; Gaete & Bogousslavsky, 2008; Hackett & Anderson, 2005; Hackett, Anderson, & Housen, 2005; Hackett, Yapa, et al., 2005; House, 1987; Sinyor et al., 1986).

Depression following stroke is a complex phenomenon. Depressive symptoms could be seen as a result of the brain injury as well as a psychological reaction (Aben & Verhey, 2006; Whyte & Mulsant, 2002). Cognitive consequences might blur the picture

(Carson et al., 2000; Robinson, 2006). Several longitudinal studies have found the incidence of PSD to be higher within the first month than at later stages (Aben et al., 2002; Aben & Verhey, 2006; Niedermaier, Bohrer, Schulte, Schlattmann, & Heuser, 2004). An association is seen between early depressive symptoms and continued PSD at 12 months (House et al., 1991; Nys et al., 2006; Townend et al., 2007).

The term PSD covers depressive symptoms measured with different screening tools and depressive disorder diagnosed by qualified professionals. Depressive symptoms in stroke survivors could be seen in relation to the defined factors of the diagnosis of clinical depression, but depressive symptoms could also be seen as natural reactions to the specific situation referred to as “normal sadness” (Horwitz & Wakenfield, 2007). Several authors have emphasised the association between normal sadness and acute disability and/or stroke (Alaszewski, Alaszewski, & Potter, 2004; Niemeier & Burnett, 2001; Thomas & Siller, 1999). In a meta-analysis of qualitative studies, Salter, Hellings, Foley, and Teasell (2008) found loss to be one of the major themes in relation to stroke survivors’ experiences (Salter et al., 2008). Having a stroke has been described as “a small death” (Wade, Langton Hewer, Skilbeck, & David, 1985) or a personal catastrophe (Backe, Larsson, & Fridlund, 1996).

Three qualitative studies were found focusing on stroke survivors’ experience of being depressed. Robinson-Smith (2004) examined depressed patients’ comments on screening instruments for depression and interviewed seven participants at 1 and 6 months after stroke. Five main themes were found: (a) turning to negative emotions; (b) having nightly symptoms; (c) feeling changes in bodily sensation; (d) feeling down about oneself; and (e) asking for spiritual help. Robinson-Smith suggested that better instruments are needed; especially to attend to items that address spirituality (Robinson-Smith, 2004). In a prospective cohort mixed study with quantitative and qualitative design, Townend, Tinson, Kwan, and Sharp (2010) studied the association of acceptance of disability with depression following stroke. Qualitative, semi-structured interviews were conducted 1 month after stroke with a subsample of 60 participants. Participants with and without depression were compared. Non-depressed patients commonly reported having accepted the stroke-related disability, whereas depressed patients tend to say that they “should still” be capable and sometimes referring to themselves as useless: depressed stroke survivors expressed stronger thoughts and emotions of sadness and frustration such as feeling “trapped” or “helpless” in relation to their

dependence on others (Townend et al., 2010). In a previous study, based on in-depth interviews with stroke survivors suffering from depressive symptoms in the acute phase (2011), we found that the experience centred on loss, despair, and grief. The study revealed two main themes generating the feeling and description of “living in shades of grey”: (1) being trapped; and (2) losing oneself. “Shades of grey” could be understood as being confined or trapped in a new lifeworld and losing oneself as the person one knew. The feeling of a lost body was at the centre of every interview, which influenced life as a whole. From this perspective, the experiences could be understood as a natural reaction to loss (Kouwenhoven et al., 2011b).

Although earlier studies suggest PSD as one of the major problematic experiences in the months after stroke there are few studies describing the experience in detail. To acquire a thorough understanding of the phenomenon, it is crucial to obtain new and supplementary in-depth knowledge on how depressive symptoms develop over time for this group of patients and how this is experienced by the stroke survivors themselves.

## The study

The aim of this study was to describe the lived experience as it develops over time of stroke survivors suffering from depressive symptoms in the acute phase. The specific research questions were:

- What is the nature of depression as experienced by post-stroke patients at 6, 12, and 18 months?
- How do the experiences of PSD change over time?
- What are the impacts of depression on post-stroke patients’ everyday life?

## Design

This longitudinal, qualitative study is methodologically grounded in hermeneutic phenomenology, as described by van Manen and Ricoeur (Kristensson Ugglå, 1992; Lindseth & Norberg, 2004; Ricoeur, 1976, 2002; van Manen, 1997). The descriptive methodology of phenomenology has been described as how one orients to lived experience, and the interpretative methodology of hermeneutics as how one interprets the “texts” of life (van Manen, 1997).

*Participants.* Recruitment took place between November 2007 and September 2008. All stroke patients were systematically screened and potential participants requested from several hospital stroke units and rehabilitation units in southern Norway. The inclusion criteria were: adults; first-ever stroke;

Beck Depression Inventory II (BDI II) score > 14 or judged to be depressed by their physician; cognitively able to participate in interviews; and proficient in Norwegian. The exclusion criteria were: pre-existing diagnosis of terminal disease; receiving medical antidepressant treatment prior to stroke; or treatment for a bipolar diagnosis at the onset of stroke.

BDI II is a well-known and frequently used 21-item questionnaire for measuring depressive symptoms in stroke patients (Carson et al., 2000; Hackett & Anderson, 2006; Kouwenhoven, Kirkevold, Engedal, & Kim, 2011a) According to the BDI II manual, a score of 14–19 indicates mild depression, 20–28 indicates moderate depression, and 29–63 indicates severe depression (Beck & Steer, 1971, 1996).

The recruitment process resulted in a sample of nine participants with various backgrounds generating a rich and substantial material (Table I).

*Ethical considerations.* Oral and written information was given in order to acquire informed consent. The participants were assured that participation in the project would not influence their treatment, that they could withdraw from the study at any time and that confidentiality would be maintained. There were no clinical relationship between the interviewer and the participants. Ethical approval was obtained from the South Norway Regional Committee for Medical Research Ethics (S-07264a, July 2007). Depressed stroke survivors might be particularly vulnerable. The interviewer carefully considered the situation of each participant and ended some interviews because the participant appeared very tired. She recognised that topics could be difficult to talk about, and she treated the participants' hope and expectations with respect.

*Data collection.* Repeated in-depth interviews with open-ended questions were performed guided by a thematic interview guide (Table II). The interviews were dialogical and adjusted to the responses of the individuals.

The first interview took place in the acute phase after stroke and is described elsewhere (Kouwenhoven et al., 2011b). Follow-up interviews were conducted at 6, 12, and 18 months after the stroke. The interviews lasted between 30 and 90 min, primarily took place in the participants' homes, and two at the participants' work-place. Three interviews were conducted by phone. Two of them because in one case the participant did not want the interviewer to come to her home at that point, and in the other because it was impossible to find a

mutually convenient date and time. The interviews were conducted by the first author. During most of the interviews only the participant and the interviewer were present in the room. In two interviews though, the wife of a participant went in and out of the room during the interview commenting and underscoring some of the themes the participant and the interviewer talked about. The participant was a man who said little and often gave keywords or surface descriptions. His wife helped him to provide a more detailed description and if he disagreed with her description, he said so.

This paper is based on the 6-, 12-, and 18-month interviews conducted between January 2008 and March 2010. The interviews were recorded and transcribed verbatim by the first author.

### *Data analysis*

Analysis and interpretation occurred at three levels (Lindseth & Norberg, 2004): (1) naïve reading; (2) structural analysis; and (3) comprehensive understanding. First, to uncover the self-understanding of the interviews and describe the phenomenon from the perspective of the participants, every interview was read several times in order to grasp the meaning as a whole (*naïve reading*). The main findings of every interview and the understanding of every participant's story were summarised in a short text of 900–1400 words.

During the *structural analysis*, every interview was read as a whole and divided into meaning units. The texts were then thematically structured in order to identify and formulate more general themes. Text units from different interviews were gathered thematically and further condensed. The meaning units behind every theme were read in order to grasp their essence and reveal sub-themes. This process led to a deeper understanding of essential themes in the text.

During the naïve reading and structural analysis of the longitudinal data, we discovered the two main themes found in the acute phase interviews to be essential later on. The themes vacillated from “being trapped” to “being free”, and from “losing oneself” to “being oneself”.

In the third *comprehensive understanding phase*, the themes were summarised and reflected upon in order to reach an interpreted whole. The texts were discussed in relation to the four life-world existentials of van Manen: lived body, lived space, lived time, and lived relation to others. van Manen maintains that when the experience of one existential is changed, the experience of the life-world as a whole will be different (van Manen, 1997). Applying van Manen's lifeworld existentials as reflective

Table I. Demographic characteristics of each participant at 18 months.

Participant	Sex & age	Lesion side & type	Living situation	Functional disabilities in the acute phase	Functional disabilities at 18 months	Physical treatment <sup>a</sup>	Psychological treatment <sup>b</sup>	Education	Employment
Sigrid	F	L	With husband	None	None	None	None	No higher education	Pensioner
Ingrid	75 F	Infarction R	Alone, widow	None	None	None	None	Vocational training	Pensioner
Nora	75 F	Infarction R	With husband	Limited function of the left upper extremity	Improved function of the left upper extremity	Physiotherapy	Antidepressant	Vocational training	Employed, working 100%
Jon <sup>c</sup>	58 M	Haemorrhage L	With wife	Limited function of the right upper extremity	Still limited function of the right upper extremity	Physiotherapy	None	Vocational training	Prevocational training
Peter	30 M	Infarction R	Alone, widow	Able to walk with aids	Able to walk with aids	None	None	Vocational training	Pensioner
Ellen <sup>d</sup>	85 F	Infarction R	Alone, widow	Limited function of the left upper extremity Able to walk with aids	Improved function of the left upper extremity, but still some limitations Able to walk with aids. The function of the left upper extremity had worsened	None	None	Vocational training	Pensioner
Anne	75 F	Infarction L	Alone, divorced	Limited function of the left upper extremity Communication difficulties/aphasia	Improved communication skills, but still some limitations	None	None	Vocational training	Disablement receiver
Erik <sup>e</sup>	67 M	Infarction R	With wife and children	Able to walk with aids	Able to walk without aids	Physiotherapy	In treatment of a psychiatrist	University	Employed, working 50%
	54	Infarction		Limited function of the left upper extremity Communication difficulties	Better function of the left upper extremity No communication difficulties	Occupational therapy Speech therapy	Antidepressant		
Hedda	F	R	With husband and children	Limited function of the left upper extremity Communication difficulties	Better function of the left upper extremity No communication difficulties	Physiotherapy Speech therapy	Antidepressant	Vocational training	Prevocational training
	45	Infarction							

Notes: In order to make the participants confidentiality, fictive names were chosen.

<sup>a</sup>Between the acute phase and 18 months after the stroke.

<sup>b</sup>Between the acute phase and 18 months after the stroke.

<sup>c</sup>His wife was present in parts of the 12- and 18-month interviews.

<sup>d</sup>The 6 month interview was conducted by phone.

<sup>e</sup>Six-month interview was conducted by phone. The 12- and 18-month interviews took place at his office.



Table II. Interview guide.

Introduction	The aim of the study Clarify the roles as researcher and participant
Present situation	As a whole—How do you feel right now? Tell me more about your experiences?
From last interview to present	How have you been since the last time we spoke? Have there been any changes, episodes? Can you tell me more?
The impact of depressive symptoms on daily life	Tell me about your days; What do you do? What did you do yesterday? How was a typical day for you before you had the stroke? Do you have other challenges or limitations now compared to last time we spoke? Can you tell me more? Tell me about the changes after stroke (in relation to depressive symptoms, e.g., interests, feeling of joy, restlessness, decreased libido, energy, sleep, tiredness, etc.) How do these changes impact your days?
Future	How do you imagine your future will be? Important things?

restored self; (2) trapped in a different life; and (3) fighting to regain self.

#### *Finding a restored self*

The stories of four of the participants reflected this pathway; Nora, Sigrid, Jon, and Ingrid. For this group, having a stroke was threatening and a shock that made them “lose their footing” for a while, however, they soon regained balance and found a restored self. Six months after stroke the participants described few and mild depressive symptoms, which persisted throughout the period. The depressive symptoms were expressed as tiredness and fatigue, sleepiness, and the experience of being labile. The physical and cognitive changes after stroke improved early. Although there still were some limitations, they managed to live with them. Acceptance of the situation and the limitations was an important issue.

Jon was a truck driver, for whom getting his driving license back was the central goal. For his family and friends these seemed unattainable, but 12 months after the stroke he had regained his driving licence for regular cars, which gave him an immense feeling of freedom. At 18 months he was in a customised programme, and had started to work as a “henchman” on the truck he used to drive. This was not an optimal situation, but close. Crucial physical and cognitive limitations could still be observed. Despite these obvious changes, Jon and his wife had accepted the situation:

*Researcher: If you think back on how your life was before you had the stroke, is your life very different now?*

Jon: No, I wouldn't say so (...)

Wife: Things do take a little longer. They do.

Jon: Yes.

Wife: And then there are some lapses in the short-term memory. Otherwise, it's the same. Just a few extra challenges along the way.

*Researcher: Like what, do you think?*

Wife: That things take a little longer and ... The right arm doesn't work properly quite yet (...)

*Researcher: But otherwise, your life is the same as it was before?*

Wife: Yes.

Jon: Yes. Uh-huh

Wife: And I just have to learn that things take a little longer (18 months)

guides helped us to separate themes, as well as to see the complexity as a whole.

We also elaborated on several metaphors. To our participants, the acute phase was understood as “living in shades of grey” (Kouwenhoven et al., 2011b). From a longitudinal perspective, some of the informants obtained their original colours, some continued to live in shades of grey, while for some the colours turned clearer and showed distinct contrasts. Another metaphor was *the journey in oneself*, a metaphor also used by others (Bauman, 2005). Different journeys could be seen as travelling in well-known scenery, travelling without control and being on a mission of rehabilitation. The metaphors were useful for capturing the essence of the longitudinal perspective and grasping the complexity of the stories of each participant.

### **Findings**

The aim of this study was to describe the lived experience as it develops over time of stroke survivors suffering from early depressive symptoms. The comprehensive analysis of the 6-, 12-, and 18-month interviews revealed patterns in which the participant's experiences developed over time: (1) finding a

All the participants described episodes of increased exhaustion and tiredness. Ingrid felt that she was not an efficient housewife anymore. Before, she could do housework for hours, now her abilities were limited and family members helped her doing the heavy

tasks in the house. She described herself as an old lady and she accepted the situation as a natural development.

Acceptance also included the necessity of doing things in a different way after stroke in order to reach the same goal. Nora experienced great difficulties understanding the content of texts as quickly as she did before. This created much frustration in the acute phase, particularly when it came to different tests during her rehabilitation. Although she still found it challenging to read at 18 months, she had accepted the necessity of reading a document several times in order to understand it.

After her stroke, Sigrid experienced being labile. She used to be a calm, balanced old woman. After stroke she had episodes where she all of a sudden turned angry, yelled at her husband or children, and then started crying. She experienced losing control and felt very uncomfortable with these episodes. However, her relatives accepted the episodes and treated her with care. Support and understanding from the surroundings were crucial to all of the participants. The experience of a close and supportive relationship with their spouses and/or families was common to all.

The experience of being free distinct from being dependent on others was crucial to the participants. None of them received community health support. Regaining the driving licence was an important part of achieving independency and being able to do the things they did before. Nora said: "I felt like the walls were falling down on me (...) before I got my driving licence back. You know what, it was so terrible. I felt so isolated" (6 months).

The participants emphasised the importance of being able to participate, contribute, and do something useful in their daily life. At 12 months, Nora started to work full time. She described being on sick leave and staying home as a "vicious cycle":

I do notice that I became very happy and very ... I changed a lot when I started working. It's just so lovely getting out—away! And to know that I'm useful. Doing something positive or productive, or anything, yeah. Just staying around here at home, that's not me! (...) the more you stay at home and do nothing, the worse it becomes.

The experience of finding a restored self included two main aspects: (a) the participants gradually improved and regained most of their functions; and (b) by accepting the limitations and finding new solutions they were no longer trapped, but had the ability to do more or less the same things they did before the stroke. At 18 months Nora said: "I don't

think I can be better than this! I feel like I am the one I was."

In addition, several of the participants described having a stroke as a positive reminder. They became aware of what they described as the important things in life: being grateful for the things they have achieved, taking care of own health, and being together with their loved ones. One example was Nora who for several years had been struggling with obesity. After stroke she managed to do something about her situation. She stopped smoking, started on a healthy diet, and began to exercise. To her, having a stroke became an important "wake up call."

### *Trapped in a different life*

The experiences of three of the participants reflected this pathway; Peter, Ellen and Anne. For this group, life totally changed after stroke. They felt like they were victims and had lost themselves to the stroke; they were trapped in a different life. Compared to group 1, the participants in groups 2 and 3 experienced more severe physical and cognitive consequences after stroke. But unlike group 3, this group received no treatment and rehabilitation after returning to their homes.

The participants in group 2 continued to show approximately the same depressive symptoms during the entire period. The symptoms were related to sadness, loss of pleasure, indecisiveness, self-criticism, loss of energy, changes in sleep patterns, and suicidal thoughts.

The experience of being trapped was crucial to this group. While the participants in group 1 managed to take action and regain command, the participants in group 2 were passive bystanders, and seemed to have given up. The participants could decide and plan to do something, but were not able to pull themselves together to actually doing it. Being tired and having a lack of energy was a problem throughout the entire period. This was connected to the experience of indecisiveness. Ellen described things she was no longer able to do, such as cooking. She said: "Well, I am probably able to, but I don't feel like doing it". Experiencing a lack of energy or to "not feel like doing it" influenced her ability to act, and to make the effort.

The participants described life as boring and empty without pleasure. The stories were described without colours, just greyness. Ellen was dependent on a walker and lived in an apartment on the second floor without an elevator. Before the stroke she often went shopping and visiting cafés with her girl friends. Now she only left home when it was crucial, and only with help from others. Her daughter visited

twice a week, but except for this she hardly had visitors. She described her present life: "It's boring, y'know. You get used to it (...) So it's just watching TV a lot. And then I lie down for a short rest and stuff. That's it. No, I can't manage to do anything, really" (18 months).

In addition to stroke, the participants in this group all experienced other diseases. After stroke Peter regained some of his walking capacity and at 6 months he was able to walk short distances using ski poles. At the 12-month interview his lung disease worsened and limited his ability to walk. Six months later his condition was even worse, and he was no longer able to do everyday chores he previously considered simple and obvious. He was trapped in a life of diseases and he was frustrated:

I can't really manage anything, so I feel. After that stroke, it seems to have spread to my entire body. In the fingertips, even. You're trying to write and work on some small things. No, that's over (...) if I want to do something. Repair stuff. Screwdrivers and such, then you don't have it. I can't do it right, the way I used to.

Having a stroke changed the way the participants felt about themselves. They became self-critical. Being dependent on others was difficult. They were old, living alone, and received restricted community support in relation to solving everyday issues. Although life was hard, Anne told her family she was fine. She did not want to be a burden, and pretended that her life was under control.

In every interview, Peter talked about life before stroke and things he had achieved. By highlighting the past and comparing with the present, Peter expressed the experience of being less attractive, being of less use, and therefore less valued. Another example was Anne experiencing that close acquaintances stopped contacting her after the stroke. Due to this she felt less valued. All of the participants experienced cognitive changes related to concentration and remembering. Peter did not trust himself anymore. He was afraid that he would not be able to take full responsibility for himself.

Peter: I would like to travel, but I don't dare to because I feel a little insecure. I'm not sure whether I can cope with it. For example, taking a trip to some warm place. That would've been lovely ... to feel the sun on my body. But ... I'm uncertain of whether I can cope with it. There's a lot of people at an airport, y' know. It's crowded and stuff when you go abroad. I may not be able to cope with it (...) I don't know if I dare, quite frankly.

*Researcher: What are you afraid of not being able to ...?*

Peter: To pay attention properly (18 months).

After having a stroke the participants also experienced being insecure in social settings. Peter felt vulnerable when a lot of people were present.

*Researcher: Do you feel that this is different after your stroke?*

Peter: Sure, I do notice that if there's a lot of people I feel more uncertain.

*Researcher: Why do you feel uncertain? Do you know why?*

Peter: There's a lot of chit-chat. A lot of noise.

*Researcher: Does that tire you, or do you have trouble following what is said?*

Peter: No, I don't. Well, it's okay really ... but sometimes I have the feeling that I don't dare to stand up, if I may use that expression.

*Researcher: Do you behave differently in social settings now; compared to before you had the stroke?*

Peter: Yes. I have noticed, I'm more uncertain, a lot (12 months).

Anne had problems with communication, especially finding words and expressing her thoughts. She avoided social gatherings and situations where she had to talk to people who were not close to her. She was afraid of not being able to answer correctly and making a fool of herself. Eighteen months after her stroke she still avoided these situations, even though her communication skills improved: "But I don't go out if I know that I'll meet somebody and all that."

The experience of being trapped included several aspects: (a) the consequences after the stroke mainly continued; (b) additional diseases worsened the situation; (c) it was difficult to take action, and they experienced indecisiveness; (d) lack of energy was dominant; (e) the experience of self-criticism and insecurity in relation to others were crucial; and (f) life was experienced as empty.

#### *Fighting to regain self*

The stories of two of the participants, Hedda and Erik, reflected this pathway. Both had significant cognitive and physical limitations after stroke. They were middle-aged, and had families with children living at home. Compared to groups 1 and 2, these participants received the most extensive treatment involving several healthcare professionals over a longer period of time. A lot was at stake in terms of work, economical situation, and families.

Six months after the stroke the participants described approximately the same depressive symptoms as in the acute phase; sadness, depressive thoughts, loss of energy and changes in sleep patterns. In addition other symptoms were present, such as irritability, agitation, loss of pleasure, and loss of interest in sexuality. At the same time the participants revealed a “fighting spirit”; they were focusing on the goal of regaining self.

At the 12-month interview the situation seemed brighter and the depressive symptoms were less dominant. But shortly after the 12-months interview, the rehabilitation process was seriously challenged. Hedda described returning to work life as heavy and restricted:

My friends who see me often, they say that they can see that I've lost the spirit that I had for thinking positively. I have fallen down into something, and it's tiresome. It isn't me. I don't feel good about being like this. And I think it's very hard, it's hurting my marriage, it's hurting ... most things. Cause I don't feel like doing anything at all (...) I really just like to be on my own. And I have never been like this before (...) I started, like, thinking about how much I've lost because of all this. The price is too high. I feel that I've lost so much ... in terms of work, and ... less money, and ... because my pay was cut in half. I can't drive a car, either ... I've become more, like ... apathetic. I see life as rather gloomy these days. It's tiresome (18 months).

At the 18-month interviews both described the depressive symptoms as deeper and more dominant. They started to question their loss and the realism of their goals. It seems like the process of accepting the consequences after stroke first started at 12 months for these participants.

To Erik, the main goal was to return to work. The role as a leader in a big company was a large part of his identity. After the stroke Erik experienced cognitive changes in relation to problem solving, concentrating, and strategically thinking. The limitations first became real to him when he started working. On one hand, he believed that everything would be as before: “The whole period I have been fighting for my rehabilitation so that I could be able to come back. I hope so. But it will not be until next summer” (18 months). On the other hand, he realised he was a different man: “The problem is that you are not the one you used to be ... I am not able to, you know. I am not. You have got some injuries! (...) Well, the super quick and most intelligent and skilled man, he is not here right now” (18 months).

In the 18-month interview Hedda described that her feelings towards herself had changed. She had become more self-critical:

I have a bad relationship to myself because of all this. I feel a little damaged, sort of. I feel like I'm different from everybody else ... I'm kind of not so happy about the person I've become. The one I am now. I sort of feel that I ... like yesterday I felt like a ... kind of a geek. With a poor balance and stuff.

The participants experienced different challenges in terms of meeting and dealing with the expectations of others. Erik felt degraded as an employee and a man, because his colleagues, leaders, healthcare professionals, friends, and family did not support his goals of returning to work. He felt misunderstood:

I have other reactions now than before. I'm more emotional. And I'm more aggressive, sometimes (...) more of that frustration over not being ... treated like ... before. Not being surrounded by the same respect, y'know. That's the hardest thing to cope with. I was a boss that everybody came running to, and then suddenly it's over and nobody's talking to you and you're completely isolated and neutralised (18 months).

Challenges in relation to close relationships and intimacy were only described by one participant. Hedda felt trapped by her husband's expectations. This made her feel like walking on tiptoes. The relationship between Hedda and her husband had been difficult for several years. After the stroke, she felt that he let her down. His expectations, particularly in terms of sexual activity, increased and things became more and more difficult as time passed by. She was not able to take action, so she just waited for him to move out. She experienced being on a different level compared to him, occupied with totally different aspects of life. The emotional process she had gone through increased the space between them:

After my stroke, the differences between us have started to stand out. Really. We have very different views of what gives meaning to life. I think much more than he does about lots of things that leave him cold. Compared to me, he has a very narrow range of interests. And we have totally different views on everything! (...) How can I give him so much attention and love, when I can't even love myself? I'm not able to give myself so much ... I'm fully occupied by looking after myself and



keeping myself up . . . He doesn't understand that. It hurts him (18 months).

Tiredness and a lack of energy were dominant for both Erik and Hedda during the entire period. Lack of energy complicated family life and social gatherings. When Erik started working, all his energy was put into work, and he had no energy left for his spare time, his wife and family. In social gatherings Erik was so tired that he was not able to focus, concentrate, and be an active part of a conversation. This was experienced as:

I'm really not accustomed to that, because I think it's unacceptable compared to what I used to be like. Being social and active was always my strong point, so that . . . that's a little annoying, not having that anymore (6 months).

During the time period between 6 and 18 months Hedda and Erik fought hard to regain self and to become as they were before the stroke. After 12 months they started to question their expectations and at 18 months the situation was still uncertain. They were still in the middle of the difficult process of accepting and dealing with the consequences of stroke and the experience of depressive symptoms had increased. The experience of fighting to regain self included several challenges: (a) the experience of hope versus realism; (b) own expectations versus the expectations of others; (c) lack of energy versus desire for effort; and (d) the challenges of external structures.

## Discussion

In the previous section, we presented three patterns in which lived experiences of stroke survivors suffering from depression in the acute phase might develop over the time period of 6, 12, and 18 months. All the three patterns were present in male and female participants. The question of gender was not a main focus of our study and the material did not reveal gender specific topics.

During the acute phase interviews, we discovered that the depressive symptoms were not explicitly described, but were woven into the stories (Kouwenhoven et al., 2011b). This was also the case during the follow-up interviews. To the participants, the experience of depression was not understood as meaningful on its own. Depressive symptoms formed the *backdrop* whereas the experience of stroke was *in front* of the stories. The lived experience of stroke interacted with the experience of depressive symptoms, and resided in the stroke survivors shaping of their daily life. The depressive

symptoms developed in line with how the participants related to themselves and the rehabilitation process.

Having a stroke has been characterised as “a small death” (Wade et al., 1985), or a personal catastrophe (Backe et al., 1996). From one day to another, life is being changed. A stroke is a disruptive event involving the person's biography and self-concept, demanding a mobilisation of resources (Bury, 1982; Romsland, 2009). Suffering a stroke though might not be seen as an abrupt psychosocial process, but as a process gradually evolving and prolonged over time (Kirkevold, 2002). Kirkevold (2002) has described the illness trajectory within the first year after stroke in four phases starting with a trajectory onset characterised by surprise and suspense. Continue with an initial rehabilitation phase focusing on hard physical work, and a continued rehabilitation phase characterised by psychosocial and practical adjustment. The fourth phase takes place from approximately 6 months after stroke and is described as a semi-stable phase when the focus shifts from the stroke and its treatment to daily life activities. The stroke survivor is going on with life (Kirkevold, 2002). Having a stroke is “a continuum” and a stroke must be characterised as a chronic disease, as all consequences after stroke rarely can be cured or terminated (Kirkevold, 2002; Wahl & Hanestad, 2002). The process of “going on with life” includes coming to terms with the changes.

A stroke is often considered as “minor” or “mild” if the physical consequences are limited and the language is intact. Our study shows that also a “minor stroke” leading to, for example, problems in remembering and thinking strategically, concentration difficulties, lability, or tiredness, could cause depressive symptoms and major changes in the experience of the lifeworld. Kay, Newman, Cavallo, Ezrachi, and Resnick (1992) reported that even after mild traumatic brain injury a shallow sense of self would occur (Kay et al., 1992), and Becker and Kaufman (1995) stated that during the first months after a stroke, survivors might come to terms with the dysfunction and failure to return to “normal” and then move towards a redefinition of self (Becker & Kaufman, 1995). To our participants, the different ways of shaping the lifeworld over time was tied to the notions of “self” which was at the core of lived experience. There was a distinct relationship between the experience of the lived body—the ability of “doing”, and the concept of self—the experience of “being”.

According to Paterson (2001) living with a chronic disease could be described as an on-going, continually shifting process in which the individual experiences a complex dialectic between themselves

and their “world”. The model has two main perspectives: either the “illness in the foreground” and “wellness in the background”, or vice versa. The “illness in foreground” perspective is characterised by a focus on sickness, suffering, loss, and the burden, whereas the “wellness in foreground”-perspective includes an appraisal of the chronic illness as an opportunity for meaningful changes in relationship to others. Within the second perspective, the individual attempts to create consonance between self-identity and the new identity created by the disease (Paterson, 2001; Sutton & Treloar, 2007). The rehabilitation process after the stroke balances between reclaiming what has been lost, and dealing with permanent losses. Loss and grieving in relation to stroke has been described by several (Alaszewski et al., 2004; Horwitz & Wakenfield, 2007; Niemeier & Burnett, 2001; Thomas & Siller, 1999). The experience of loss after stroke will influence the lifeworld and notion of self in different ways. During the period from 6 to 18 months post-stroke the experience of the lived body developed differently in the three groups. Compared to groups 2 and 3, group 1 experienced less severe physical and cognitive changes, and shortly after the stroke they had attained much of their bodily functions. Group 1 dealt with the loss by accepting the limitations and finding new and suitable solutions. To these participants the “wellness in foreground” perspective became dominant. Some even looked at the stroke as a positive reminder that made them think about the important things in life. The group established a restored picture of themselves. The participants in group 2 felt like victims. Additional diseases and lack of energy worsened the situation. The group maintained the experience of being trapped in a changed body and a different life. They were occupied with their losses. In addition, the participants were self-critical, felt less valued and were afraid of being a burden. It seems as though this group was caught in the perspective of “illness in foreground”. The goal of group 3 was to regain the bodily functions, or as much as possible, to get their former life back. The group was fighting to regain self through recovery of the body. It seems as if this group did not enter what Paterson calls “the ongoing shifting process” within the first year. Between the 12 and 18 months post-stroke period they seriously began for the first time to relate to the things they had lost, and the “illness in foreground” perspective seemed dominant. A continually shifting process as described by Paterson might be important in order to “come to terms with” the stroke.

A rehabilitation process after a stroke could be seen as the process of dealing with and healing the disruption caused by the stroke, creating continuity

between the past, the present, and the future. The goal for the rehabilitation process is to go on with life. Biderman, Daniels-Zide, Reyes, and Marks (2006) explored reconstruction of “ego-identity” after a brain injury. They emphasise the persistence of the sense of sameness within oneself as one of the distinguishing components of the concept of ego-identity (Biderman et al., 2006). In relation to the three groups of our study, the lifeworld after stroke was shaped differently according to how the participants anchored the pre-stroke lifeworld in their present life. Group 1 was the only group with a view for the future. Shortly after the stroke the participants went on with life. The participants in group 2 were stuck in the present, not being able to overcome the barriers and move on. The third group of participants were hoping, longing, and fighting to become the ones they were, and regaining their former lives. They appeared to be fixated in the past. In a study of the experiences of individuals suffering from cognitive impairment after acquired brain injury, Romsland (2009) found that several of the participants struggled so hard with their chaotic present, that they were not able to think of or relate to the future (Romsland, 2009).

Our study emphasised two groups that were particularly vulnerable. Whereas the participants in group 3 were determined to fight, group 2 reacted with resignation. Even though they had ambitions in terms of their recovery process, they were not able to do what was necessary. Compared to group 3, the participants in the second group experienced fewer obligations in their lives. To group 3 a lot was at stake in terms of work, economical situation, and family life, whereas group 2 was on a pension and lived alone. Being old complicated by having a stroke may lead to a loss of strength, a reduced capacity, and the experience of less to fight for—or to fight with. Group 3 received extensive treatment in the time period from 6 until 18 months, while group 2 received nothing. It seems as though the community healthcare service had no ambition on behalf of them. Also when it comes to lived relation to others, the groups differ. While group 3 described close relationships and experienced challenges in terms of meeting and dealing with the expectations of others, group 2 described more distant relationships to others. They experienced insecurity in social settings, became isolated, and nobody was there to kindle their hope. These were closely linked to meaning of the contexts of the participants’ lives in relation to everyday living, family and social networks, and work.

The experience of post-stroke lifeworld from the longitudinal perspective is divergent on two accounts—the perspective with which people with

stroke experience self and self-identify, and the experiences in the life context. This provides the anchoring of how they move on with their lives after stroke.

### *Trustworthiness*

Malterud (2001) highlights three main areas of importance when it comes to evaluation of qualitative studies: reflexivity, transferability, and interpretation of analysis. By transferability Malterud emphasises the possibility of sharing and applying the findings beyond the study setting, and by interpretation of analysis she underscores the importance of identification of the systematic procedure. By reflexivity she means that the researcher's background and position will affect the study, e.g., the topics chosen, the angle of investigation, the methods, the meetings between participants, and researchers, etc. Openness and reflection in relation to all steps of the research process are required (Malterud, 2001).

The question of trustworthiness was taken into account in all stages of the process according to the character of our phenomenological study. In order to ensure that our participants suffered from depressive symptoms, a particular score on BDI II was chosen as an inclusion criterion. Studies have found that screening tools for depressive symptoms after stroke have some weaknesses (Kouwenhoven et al., 2011b; Hackett, Hill, Hewison, Anderson, & House, 2010; Kouwenhoven et al., 2011a). During the acute phase interviews some of the questions in the BDI II formula were "explained" or interpreted by the stroke survivors as stroke-related factors rather than experienced as expression of depression (Kouwenhoven et al., 2011b). This might have an influence on the sample of this study and the credibility of the material. No gold standard exists for screening assessment for depressive symptoms after stroke, and none of the screening tools is particularly developed for stroke survivors and their special situation (Carson et al., 2000; Kouwenhoven et al., 2011a).

Ricoeur claims that to become open, the researcher must seek to put the judgement about the factual "in brackets" (Lindseth & Norberg, 2004). Dahlberg refers to this process as "bridling" (Dahlberg, 2006; Dahlberg, Dahlberg & Nyström, 2008). The interviews were conducted by the first author who also is a registered nurse. Her clinical experience, the literature of previous research, and the analysis of the former participant interviews informed her pre-understanding. In both the data collection and data analysis, the pre-understanding of the researcher was made explicit. She attempted

to be sensitive, with an open attitude to allow participants to freely describe their unique experience in a natural and candid way.

To seek the self-understanding of the text, the researchers attempted to be open-minded and allow the text to speak. To validate the findings, two of the researchers read the texts separately and discussed their understanding repeatedly throughout the analytic process (SEK and MK). When presenting the findings we have "stayed close to" the participants' voices and described the context they live in.

Our findings are based on interviews with a limited sample of participants within a Norwegian context. Transferability of the results to other cultures and contexts must be handled carefully. However, our findings are consistent with a number of other studies that have explored the subjective experience of patients following a stroke.

### **Conclusion**

To our participants the experience of loss was crucial. They related the depressive symptoms to the consequences of the stroke. Our findings revealed two groups of stroke survivors were particularly vulnerable and should receive special attention: (a) old adults living alone; and (b) adults with commitments to work, family, and children. According to our material old adults received limited support from their community services and no help related to rehabilitation. It seems as though they were ignored and forgotten. The reason for this may be the limited recourses, lack of knowledge, limited potential, because they did not ask for help, or some combination of these. The younger adults received intensive healthcare during the whole period of 18 months. According to their high ambitions and the experience of failure 1 year after stroke, one might ask: Was the healthcare good enough? Or, according to all the elements at stake; was the process simply delayed making the participants not able to deal with the situation at an earlier time point or more expediently?

Our findings reveal that it might not always be a matter of how one copes with illness, body functions and rehabilitation, but also on how one relates to the changed body and the new life situation, and the ability to find meaning in the situation. Old adults might be in need of nurses maintaining hope, and finding abilities. Younger adults might need support later in the process, especially when returning to work or experiencing other demands. We believe that rehabilitation after stroke must be considered a long-term process of adjustment. Measuring depressive symptoms in the acute phase is of no use unless the healthcare system has the ability to follow-up over



time. This process could not be standardised, but must be based on the person's experience of his or her lifeworld.

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