

# **Finding the way forward: The lived experience of people with stroke after participation in a complex psychosocial intervention**

## **Abstract**

Stroke patients' well-being is threatened after stroke. A psychosocial intervention was developed for Norwegian stroke patients living in the community. Eight individual sessions between people with stroke and a trained health care professional were conducted one to six months post-stroke with one group of participants and six to twelve months post-stroke with another group. Subsequently, nineteen of these stroke patients were interviewed to gain an in-depth understanding of their lived experience of the influence of the intervention on their adjustment process. Interview texts were analysed using Ricoeur's interpretation theory. Two participants did not personally find the intervention useful. The remaining participants greatly appreciated dialogues with the empathetic intervention personnel, feeling free to discuss their fears and worries. The intervention raised these participants' awareness of their needs and resources. They were guided to resume their everyday life and adopt a future-oriented attitude. The intervention facilitated their meaning-making endeavours and post-stroke adjustment.

## **Keywords**

Antonovsky, guided self-determination, intervention, lived experience, phenomenological hermeneutics, psychosocial, Ricoeur, stroke

## **Background**

A stroke may greatly decrease a patient's quality of life (Hackett, Duncan, Anderson, Broad, & Bonita, 2000; Leach, Gall, Dewey, Macdonell, & Thrift, 2011). The physical, cognitive and emotional changes following stroke may entail role limitations, loss of meaningful occupations and diminished social participation, all of which decrease psychosocial well-

being (Martinsen, Kirkevold, Bronken, & Kvigne, 2013; Norstedt, 2017; Woodman, Riazi, Pereira, & Jones, 2014). A stroke can threaten identity and lead to feelings of uselessness, and non-acceptance of the disability is strongly associated with stroke patients' depressive mood (Townend, Tinson, Kwan, & Sharpe, 2010). The life changes following stroke may lead to a biographical disruption in taken-for-granted assumptions and behaviour. The early post-stroke stage involves attention to altered bodily states and decisions about seeking help (Bury, 1982; Ellis-Hill, Payne, & Ward, 2000). Fatigue, aphasia and cognitive problems may interfere with a stroke patient's self-concept and social participation and at worst may lead to existential loneliness (Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Flinn & Stube, 2010; Kitzmüller, Häggström, & Asplund, 2013; Nystrøm, 2006).

The experience of living with and accepting loss is closely related to grief and post-stroke depression (PSD) (Kouwenhoven, Kirkevold, Engedal, & Kim, 2012). Nearly one-third of stroke patients experience depression following stroke (De Man-van Ginkel, Gooskens, Schuurmans, Lindeman, & Hafsteinsdottir, 2010; Mitchell et al., 2017). PSD is considered a strong predictor of quality of life and is related to poorer rehabilitation outcome and increased mortality (Paolucci, 2008). Anxiety is also a common mood disorder after stroke and patients suffering from aphasia are especially at risk (Mitchell et al., 2017).

A large number of studies have explored interventions to improve stroke patients' psychosocial health and to prevent anxiety and depression (Bronken, Kirkevold, Martinsen, Wyller, & Kvigne, 2012; Jones, O'Keeffe, Kingston, & Carroll, 2013; Kirkevold, Martinsen, Bronken, & Kvigne, 2014; Lawrence, Booth, Mercer, & Crawford, 2013; Watkins et al., 2011). Post-stroke adjustment has been portrayed as a long-term and non-linear process including progress and setbacks, where personal characteristics as well as practical and mental strategies seem to play a role (Kirkevold, 2002; Sarre et al., 2014, p. 721). In addition,

relational support and structural issues are important for a smooth adjustment process (Sarre et al., 2014, p. 722).

It has been documented that a positive emotional state leads to a higher degree of participation (Berges, Seale, & Ostir, 2012) and increases the likelihood of improved functional status after stroke (Seale, Berges, Ottenbacher, & Ostir, 2010). Therefore, rehabilitation efforts addressing patients' psychosocial well-being after stroke are needed (Hackett et al., 2005). Information (Forster et al., 2012), emotional support (Northcott & Hilari, 2017), practical advice (Kautz, 2007), and motivational support (Watkins et al., 2011) all seem to be important. Until now, motivational interviewing is the only intervention showing a significant effect in supporting adjustment after stroke (Auton et al., 2016; Watkins et al., 2011). Complex psychosocial interventions should therefore be developed and evaluated to identify factors promoting positive rehabilitation outcomes and psychosocial well-being after stroke.

In Norway, a complex intervention has been designed to promote psychosocial well-being and prevent depression and anxiety after stroke (Kirkevold et al., 2018). Psychosocial well-being is defined as a combination of intra-individual experiences, processes, values and external resources (Kirkevold, Bronken, Martinsen, & Kvigne, 2012, p. 392). The overall aim of the intervention was to promote psychosocial well-being. The intervention consisted of eight individual 1-1½ hour sessions between people with stroke living in the community and an experienced registered nurse or occupational therapist. Each session was guided by work sheets addressing evidence-based concerns for people with stroke (bodily and emotional challenges, relationships, activities, values and existential issues). The intervention personnel received a three-day training programme on how to implement the intervention, which prepared them to act as coaches rather than therapists. Additionally, the intervention personnel received supervision during the intervention period. The intervention was

previously tested in feasibility studies (Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Kirkevold et al., 2012; Kirkevold et al., 2014; Martinsen et al., 2013). Subsequently, the intervention has been tested in a community care setting in South-Eastern Norway. An RCT involving 322 patients, of which 166 were randomized to receive the intervention at one to six months post-stroke, was conducted in South-Eastern Norway. Furthermore, the intervention has been tested on a smaller scale in Northern Norway, where five participants received the intervention from six to twelve months post-stroke.

Adding qualitative research to health intervention studies is important to gain an in-depth insight into participants' lived experience of the intervention (Johnson & Schoonenboom, 2016). Therefore, the aim of this study was to gain rich understanding of the participants' lived experience of the influence of the intervention on their adjustment process.

## **Methods**

A phenomenological hermeneutic framework inspired by Ricoeur's philosophy was chosen to interpret the meaning of the participants' lived experience of the intervention (Ricoeur, 1976; Ricoeur & Thompson, 1981).

### **Participants and recruitment**

We used the following inclusion criteria: minimum 18 years of age, medically stable, received the intervention within the past year, sufficient cognitive function to participate (as assessed by the stroke team) and to give informed consent, able to understand and speak Norwegian.

People with moderate to severe dementia, serious physical or mental illness or severe aphasia were excluded. We applied a reiterative purposive sampling procedure (Palinkas et al., 2015).

Recruitment procedures were concluded when a sufficient number of participants with different demographic and stroke-related characteristics were included. The participants were recruited from two different geographical areas in Norway. Upon completion of their

participation in the RCT, thirty-nine participants in the intervention arm who lived in the South-Eastern area (SEA) of Norway were invited to participate. Fourteen of these participants (five women, nine men) who had received the intervention one to six months post-stroke gave their informed consent to participate. It is not known why the remaining persons did not want to participate. Due to the research ethics rules in Norway, people are not asked about their reasons to refrain from participation. All the five participants (four women, one man) from Northern Norway (NA) who had received the intervention six to twelve months post-stroke gave their informed consent to participate. We included these two sample sub-groups to study possible differences in how the intervention is experienced during different phases of the illness trajectory, which often takes a circular rather than a linear course with new challenges at different points in time (Kirkevold, 2002; Sarre et al., 2014).

Demographics, SEA group ( $n=14$ ):

The participants' ages ranged from 42 to 80 years ( $M=61$ ). Four participants had completed upper secondary school, eight had completed college or university and two had left school at the age of about fourteen to fifteen. Ten participants lived with a partner while four participants lived alone. Six participants cared for children. Before stroke onset, seven participants had full-time employment, two worked part-time and five had retired. At one year post-stroke, one participant had full-time employment, five participants had retired, four were on 100% sick leave, three combined a part-time job (20-40%) with sick leave and one worked part-time and was searching for a full-time job.

Nine participants had suffered an ischaemic stroke (left hemisphere:  $n=4$ ; right hemisphere:  $n=5$ ) and four had suffered a haemorrhagic stroke (left hemisphere:  $n=3$ ; right hemisphere:  $n=1$ ). For one participant the location of the stroke was missing. Eight participants had suffered a minor stroke and four had suffered a moderate stroke, according to the NIH stroke

scale. Information on two participants was missing. At twelve months post-stroke, five participants were still receiving rehabilitation services (physiotherapy:  $n=5$ ; home help:  $n=1$ ; speech therapy:  $n=2$ ).

#### Demographics, NA group ( $n=5$ )

The participants' ages ranged from 52-83 ( $M=72$ ). One had completed upper secondary school, two had completed college or university and two had left school at the age of about fourteen to fifteen. Three lived with a partner while two lived alone. Two participants cared for children. Before stroke onset, three participants had retired and two participants had full-time employment. At one year post-stroke, one of the latter was on 100% sick leave and the other one combined a part-time job (30-45%) with sick leave.

Four participants had suffered an ischaemic stroke (left hemisphere:  $n=3$ ; right hemisphere:  $n=1$ ). For one participant the location of the stroke was missing. Four participants had suffered a minor stroke and one had suffered a moderate stroke. At twelve months post-stroke, two participants were still receiving rehabilitation services (physiotherapy:  $n=2$ ; home help:  $n=1$ ).

Although eight of the participants in the SEA group and one participant in the NA group reported communication difficulties prior to the intervention, only two had slightly reduced scores on the Ullevaal aphasia screening test (UAS) (Thommessen, Thoresen, Bautz-Holter, & Laake, 1999) and none of them showed substantial communication problems during the interviews. The participants had all been screened for depression using the Yale single item screening tool (Watkins et al., 2007). Three participants in the SEA group and one in the NA group had suffered from depression prior to the intervention.

#### Data Collection

All authors took part in developing the interview guide and eight authors conducted the interviews from January 2016 to June 2017. All interviews were conducted within one year after the intervention was completed. We started the interviews by encouraging participants to convey their experiences using narratives (Brinkmann & Kvale, 2015). Later on in the interviews, we used a semi-structured interview guide to explore the participants' lived experience of the influence of the intervention on their adjustment process (Brinkmann & Kvale, 2015). Participants were encouraged to tell about the following: their relationship with the intervention personnel, the influence of the intervention on their adjustment process, changes in the comprehensibility of the post-stroke situation, coping strategies, the meaning of sharing illness experiences, motivation and life courage, the meaning of their relatives' participation in the intervention, the meaning of the work sheets and other details regarding the intervention (number and length of the sessions, time of onset, duration). Most interviews took place in the participants' homes and lasted from 28 to 92 minutes (median 55 minutes). The interviews were tape recorded and transcribed verbatim.

### Analysis

The analysis was guided by Ricoeur's (1976) interpretation theory, which involves the three steps of naïve interpretation, structural analysis and critical interpretation.

All authors read the interviews several times and a working group of five members (Gabriele Kitzmüller, Margrete Mangset, Anne Svelstad Evju, Sanne Angel and Lena Aadal) performed the analysis. The preliminary results were discussed with all authors, as were the final themes. When consensus was reached, all authors contributed to the critical interpretation of the findings.

According to Ricoeur (1976), the reading and rereading of texts is essential to reach a naïve understanding of the text. The naïve interpretation is a first grasp of the meaning of the text

(p. 75). During the structural analysis, the interview texts were read sentence by sentence or paragraph by paragraph. Meaning units were clustered across the interview texts to form themes. The structural analysis played a mediating role between the surface interpretation of the naïve reading and the critical interpretation (p. 87). The naïve interpretation, the themes and subthemes derived from the structural analysis and the researchers' preunderstanding formed the starting point for the critical interpretation of the interview text as a whole. According to Ricoeur (p. 75), the third step of critical interpretation is a result of the earlier analytical steps and the dialectical move between the parts and the whole of the text. The aim is to arrive at a deeper understanding of what the text is about, i.e. the reference of the text (p. 87). To achieve the most probable of various possible interpretations (p. 78-79), we used relevant literature to expand our understanding of the text (Ricoeur, 1974, 1976).

*Insert Table 1 Examples of the structural analysis process*

## Ethics

This study was approved by the Regional Committee for Medical and Health Research Ethics Southeast (2013/2047) and the privacy protection ombudsman responsible for the hospitals involved in the RCT (2014/1026). The participants gave their informed consent. Information about the study and the participants' rights was repeated prior to the interview. All research procedures complied with the Helsinki Declaration (World Medical Association, 2000).

## Results

### Naïve interpretation

Although the perception of being lucky compared to other worse-off stroke survivors is prominent, suffering from a stroke means facing multiple consequences, such as fatigue, cognitive and functional decline, depressive mood and pain. For the most part, the encounters



with the experienced professionals facilitated a better balance between possibilities and limitations after stroke and provided a clearer focus on relevant post-stroke issues. The empathetic relationship with the intervention personnel helped the person with stroke to focus less on fears and worries and to adjust to future life despite the continued challenges. For those who consider themselves recovered, there seems to be no need for the intervention.

### Structural analysis

The results of the structural analysis did not reveal any differences regarding the experiences of the participants from the two different geographical areas. The analysis revealed variations in participant experiences of the influence of the intervention on their adjustment process.

Participants reporting major functional decline and fatigue or those with a limited network reported a stronger influence of the intervention on their adjustment process than participants who had either a supportive network or reported minor functional decline.

The structural analysis resulted in three main themes and seven subthemes: benefitting from the empathetic relationship with the intervention personnel (*someone who would listen to your story, someone capable of filling the gap*); adjusting to the post-stroke condition (*becoming aware of one's needs, gaining support to face the impact of stroke on family life*); resuming everyday life with professional support (*reflecting on basic values, taking control, using one's resources to look forward*).

*Insert Table 2: Themes and subthemes of the structural analysis*

### **Benefitting from the empathetic relationship with the intervention personnel**

The participants emphasized the importance of the trusting and empathetic relationship with the intervention personnel. They valued them as experienced stroke experts and dedicated and friendly fellow human beings. The participants appreciated that the intervention personnel had time, had the patience to listen to them and kept calm. Even participants with caring family

relationships stated that the intervention personnel had a deeper understanding of their condition.

*Someone who would listen to your story*

Since most participants had not previously talked about their illness experience, they appreciated sharing their illness narratives. Putting words to these experiences and getting a response and recognition from an experienced professional had been meaningful. At the beginning, not all participants had expected a personal benefit from participation. They had participated to support research for the benefit of others with stroke. Nevertheless, during the sessions some of them reconsidered their initial expectations as they found the intervention helpful: “I thought the intervention wouldn’t help me at all. I did it for their [*other stroke patients*] sake and then it helped me [*laughter*].”

Together with the intervention personnel, the participants had been able to reflect on their life post-stroke, their bodily changes and role changes and on other people’s reactions to their illness.

Some participants had felt that others had been overprotective or stigmatizing: “In the beginning I kept to myself, completely. I didn’t dare to go shopping or to take a walk. I felt that everyone was looking at me. I was afraid of meeting people, especially my colleagues. It was strange and tough and made my everyday life even more difficult.”

It was important for the participants to share their grief, worries and fears with someone who was familiar with stroke, had good communication skills and showed interest: “She showed that she had time, a smile on her face, these communication skills that people who’ve had a stroke really need [...]” Similarly, they needed someone apart from family members with whom they could discuss problematic issues, as they felt it was difficult for their spouses to understand how they felt. The trusting and understanding relationship with the intervention

personnel enabled the participants to be open and emotional when dealing with grief, sorrow and depressive thoughts: “There was this great sorrow and I sat and cried and cried. It was a crisis reaction in a crisis.” The participants emphasized the meaningfulness of talking to professionals who were experienced in working with stroke patients, someone outside their family and network.

### *Someone capable of filling the gap*

Although the participants were generally satisfied with the medical treatment and care in hospital, some lacked information and dialogue with health professionals and missed follow-up from the hospital after discharge: “After the hospital door was closed [...]. I haven’t heard from them. There hasn’t been any follow-up. I wasn’t even asked to visit my GP [...]. Maybe that’s usual?” Sometimes the participants found that they had to struggle on many fronts at the same time when health care, social services and vocational rehabilitation in the community did not meet their needs. This came on top of their multiple challenges of adapting to an altered body and life situation: “Your spirits get low when you get one refusal after the other; it’s kind of brutal and rotten.” “I realized that I couldn’t keep my job and that I’d lose most of my income. How would I cope with that?” In view of their struggles, they welcomed the empathetic advice and actions of the intervention personnel. Not all participants who felt abandoned and had to rely on their own resources after discharge were capable of asking for support from the health or social care system. In that case, the intervention personnel provided practical advice or took specific action to support the participants’ rehabilitation efforts. In addition, the participants could rely on the intervention personnel returning the following time and knew that they had someone to turn to if a problem arose.

The supportive relationship with the intervention personnel was especially important for those who had withdrawn from their network due to fatigue, aphasia or cognitive disabilities: “I have to protect myself more from social life [*cries*]. I’m a sociable person but now I withdraw [...]. I prefer to stay at home [...]. I’m pretty much alone and I talk a lot to myself [*laughs*].” Losing parts of the social network could entail feelings of grief and loneliness. Sharing thoughts and emotions with the intervention provider brought some relief. For the participants who had a small network and lived alone, the dialogues with the intervention personnel meant a break in their loneliness: “You pretty much carry on alone here, so how shall I put it, the loneliness is quite overwhelming [...].” “It was nice when [name] came. I will miss her [...]. Yes, I’d say that if you’re sitting here alone it’s good to have someone to talk to.” Most participants found it important that the intervention personnel had visited them in the familiar environment of their homes. Overall, the participants were content with the duration of the intervention. Nevertheless, six participants who experienced multiple challenges post-stroke wished for an extended follow-up period.

### **Adjusting to the post-stroke condition**

The intervention raised the participants’ awareness of their limits in terms of fatigue, pain, loss of gait function and cognitive decline and they learned how to regulate their capacity. Depending on the severity of the illness, the stroke was a more or less life-changing experience. For those who felt exhausted from work and from family obligations, the intervention was helpful to find strategies and make decisions to reduce their workload and to talk more openly with their family about their needs. They became aware of setting limits to their own and to others’ expectations.

Two participants reported not having felt any personal need for the intervention although they had enjoyed sharing their experiences with the intervention personnel. They had given their

consent to contribute to research. One of the participants from the South-Eastern area lived with and had been trained by a health care worker experienced in stroke care. He perceived the intervention as superfluous although he still had some complaints after the stroke: “The sessions were relevant, but I didn’t feel a need for it. I felt I’d recovered 99%. If the situation had been more difficult, if I hadn’t got back to normal, it would have been of great value.”

Another participant from the Northern area stated:

For me the intervention was unnecessary because I’d got over it then. But I’ve been lucky because my three children who live here were there for me, that means a lot [...]. If you’d come earlier maybe there would have been a lot more things I wanted to know but I felt I was experienced already.

Although these two participants had had severe paralysis post-stroke they shared a common proactive attitude on their changed life situation and they put a great deal of effort into exercising:

I drew up the balance sheet, I looked down at myself and I thought you still have your left side, your speech and your memory are still there, it’s better than nothing [...]. I exercised a lot, I tried to think positively. I’ve been an active person my whole life, so my brain wanted to go on.

### *Becoming aware of one’s needs*

The participants disclosed various examples of how their extreme tiredness and reduced capabilities interfered with their daily life. They used metaphors to explain how it felt to suffer from fatigue, feeling like a run-down battery, like the “Sleeping Beauty” or like a corpse: “I have to sleep much more and I have a headache, I’ve been so exhausted that I thought I would die. I felt like a living corpse or like I’d been poisoned. I just don’t feel up to anything.” The metaphors revealed how the extreme tiredness influenced their bodily functions on different levels. The intervention taught these participants that it could be counterproductive to try to speed up the rehabilitation process and that it was more beneficial

to slow down after the stroke: “It wasn’t until now, one year after the stroke, that I began to understand that it’s true, I have suffered a serious illness and it’s still having consequences. I have to adapt my life to that fact.”

Most participants felt an existential threat during the first months after stroke onset, because they experienced symptoms that could indicate another stroke. The sessions with the intervention personnel helped them to overcome those fears: “It was good for me to hear that the things I mentioned were consequences of the stroke. Especially the emotional thing, as I never had any problems with that before. Now I understand it’s part of the illness, so it’s easier to accept it. It’s a fact.”

The dialogues with the intervention personnel had supported the participants in dealing with emotional changes, cognitive problems, fatigue, fears and worries after stroke and helped them to understand that their post-stroke experiences were common for stroke survivors. During the sessions, the participants learned more about the post-stroke condition and it became easier for them to judge when things were normal and when they had to take action.

#### *Gaining support to face the impact of stroke on family life*

Several participants living with a partner stated that the stroke had also had an impact on their partners’ lives. Role changes occurred and surrendering their former roles to the healthy partner was not easy for all. Those who had young children had to leave their parental roles to their spouses. Not all families received information and support regarding their children’s needs. Sharing these thoughts and emotions with the intervention personnel made it easier to confide things to family members afterwards. One participant recalled how the dialogues with the intervention provider had helped him to make his son realize that he needed his help. Sharing his needs with his son had improved the father-son relationship.

Mood changes after stroke were stressful for the partner and had a detrimental effect on the couple's communication: "I've been severely depressed. I cried every day for the slightest thing. It's been difficult for me and my wife to discuss things in a normal way because I got so emotional." The empathetic understanding of the intervention provider had helped this participant to realize that he needed treatment for his depression, which had been important for regaining a positive outlook on life: "From having been deep down until today [*there is a difference*]. Now I feel motivated to live and be there with my grandchildren. I feel good now about my mental health and yes, I enjoy life [...]."

The people with stroke agreed that their spouses or other close relatives would have benefitted from participation in a similar intervention: "I think it's [*cries, silence*] I want to hide things from my family and they want to hide things from me [...] we think it's better like that. So I think they also have a need to say how it feels to have a sick wife or mother."

Although the participants could choose to ask their spouse or another significant person to join part of the intervention, few spouses were invited. Some participants felt that they needed to talk with the intervention personnel in private. Those who had invited a significant other found that this was beneficial and had enhanced that person's knowledge of stroke: "I think some of the most important things are that she comes to realize why I don't do the things I promise to do and that she learns not to get annoyed about the setbacks. Because I seem normal, you know [...]."

Some participants experienced greater openness and understanding in their relationship with the participating spouse or relative.

The loss of work due to residual disabilities was hard to accept: "When you realize that your 40-year-long working life is suddenly finished it's hard, but you have to accept it [...]."

The return to work was a struggle for those with residual disabilities. They had to balance their

excessive expectations with their functional limitations. Discussing these struggles with the intervention personnel helped the participants to reflect upon how to balance work with family obligations and the post-stroke condition: “I wanted to get healthy again. My aim was to go back to work [...] [*the sessions*] have helped me to be more realistic.”

### **Resuming everyday life with professional support**

The participants’ systematic application to the work sheets and their dialogues with the intervention personnel made them aware of their still available resources and encouraged them to make use of their strength. The participants described how the intervention had helped them to adapt better to their situation, and some felt that it had speeded up their rehabilitation process.

#### *Reflecting on basic values*

Commonly, the participants used the term ‘reflection’ in the interviews. They felt that the intervention had enhanced their understanding of their needs and of how they could reach their goals: “I reflect more and I go deeper into things.” “After the things [*work sheets*] we went through, I started to think by myself. There were steps to take on the way to the goal. You had to set goals for yourself.”

The participants’ involvement with the work sheets made them more aware of their values: “I remember [*the work sheet*] where we had to put in our values in life [...] The values of faith, family, nature and the joy of life were important to me. To be rather than to do.”

Some participants experienced a shift in the way they valued things after the stroke. They compared themselves with other people with stroke they had met and perceived themselves as lucky despite struggling with functional decline. Some perceived the illness as a valuable experience: “I think having a stroke can be enriching. You change, and good things may evolve.”



### *Taking control*

The personnel's guidance and encouragement raised the participants' awareness of the resources they still had and how they could use them to improve their quality of life: "You get a different perspective on things; you were able to see things from different perspectives, not only the negatives but also the positives and the things that mattered." The participants became aware that the role of the intervention personnel was to help them realize their potential to take on an active role in their recovery process: "There were no ready solutions but I had to reflect and find the solutions myself." Nevertheless, some had needed the push and pull of the personnel to get them started:

She saw things. Obviously, if you sit by yourself, you get a one-track mind. She gave me lots of encouragement [...], she was the one who pushed me." "Actually, I think it was a push forward. After the sessions, I felt it was 'up and go'. I took a step further each time, I did that due to the sessions, I let go of my fear.

Participants who experienced depressive mood or fear reported that the intervention had improved their psychosocial health. Using less energy on such draining emotions gave them more strength to focus on positive issues like exercising and improving their diet. These participants felt that the stroke was a turning point in their lives to take better care of their health.

### *Using one's resources to look forward*

Fatigue and the loss of cognitive functions, family roles and employment had affected the participants' self-perception. Some felt mentally weaker and perceived that their personhood had changed: "My self-image hasn't got better, not at all, no [*laughs*]. I feel I'm of less value and I cannot do the things I want to do [...] not of less value as a human being, but of less value for the community." The participants found the intervention important to support involvement, gaining control of the process and boosting their self-perception: "In some

matters we talked like peers. Still, she [*intervention provider*] kept to her script, she kept everything in order, [...] and that helped me to be focused”. “She was very good at making me think by myself instead of deciding for me.”

Sometimes the intervention shifted the participants’ perception of their situation, making it easier to realize how they could sort things out: “The advice I got has helped me turn around my way of thinking. It’s helped me to see things from a different angle [...]. You get another perspective [...].” Sometimes, thinking back on the intervention personnel’s advice helped the participants to focus on new challenges and deal with them better or faster. One participant who had felt depressed said that the conversation with the intervention provider had convinced him to accept medical treatment, which had greatly improved his quality of life.

The participants thought that setting goals and focusing on their future life was valuable:

We talked about how life would proceed, what I missed and what I felt. We did it every time, we talked about the future and I thought that was important.” “The conversations and questions made me think of my future earlier. You got through things earlier because you had to think about where you were in the trajectory.

The intervention encouraged the participants to look forward. Some stated that the metaphors used in the work sheets, such as the “Great Trial of Strength” [*a well-known bicycle race in Norway*] had helped them to focus on their future challenges.

### **Critical interpretation and discussion**

The interviews revealed the post-stroke trajectory as an experience of struggling on different fronts simultaneously, with a general lack of professional follow-up from the established health care services. The participants who suffered from various forms of functional decline and were struggling to piece together the puzzles of their lives welcomed the dialogues with the experienced and empathetic intervention personnel. They needed support to find a path between the various obstacles the life-changing illness had thrown in their way. We

interpreted the meaning of the intervention as a means to focus on the participants' strengths and to help them integrate their limitations into their post-stroke self-image.

Sharing their illness experiences and their worries with an experienced and caring professional strengthened the participants' self-determination and helped them fight anxiety and depressive mood. As experienced stroke professionals, the intervention personnel were aware of the difficulties the participants had to face and they knew how to guide the participants without being prescriptive. Particularly for lonely participants who lacked a social network, the relationship with the intervention personnel represented a necessary lifeline. These participants did not reveal how they had experienced the conclusion of the intervention. Nevertheless, the number of participants who had wished for the intervention to continue and the fact that no differences were seen regarding the need for the intervention at different time points post-stroke indicate a long-term follow-up need after stroke. The latter finding has been documented previously (Maratos, Huynh, Tan, Lui, & Jarus, 2016; Martinsen, Kirkevold, & Sveen, 2015; McKevitt et al., 2011).

The salutogenic approach of the intervention focused on the three elements of Antonovsky's (1987) sense of coherence (SOC), making the participants' illness experiences more comprehensible, manageable and meaningful. The reflective process facilitated by the systematic use of the work sheets enhanced the participants' comprehension of their post-stroke condition and supported their identity work, which was necessary due to their losses and role changes post-stroke. They became more aware of the meaningful issues in their lives, their values, their wants and their needs. In this manner, a thread of coherence and continuity was woven between the former and the post-stroke life.

The intervention personnel's empathetic attitude combined with the guided self-determination approach (GSD) (Zoffmann & Kirkevold, 2012) prepared the ground for the problem-solving

endeavour and inspired participants to take action towards a meaningful future orientation. In a GSD approach, problem solving is facilitated by an empowering attitude of the professional while difficult matters are discussed and reflected on (Zoffmann & Kirkevold, 2012). The relationship between the participant and the professional in GSD is characterized by an “I-you-sorted mutuality”, in which the health care professional’s knowledge and communication skills are combined with a straightforward attitude that facilitates participants’ decision-making and problem-solving processes (Zoffmann & Kirkevold, 2007). The reflective and problem-solving elements of the intervention aimed at improving the participants’ skills in adjusting to and managing their illness (Zoffmann & Kirkevold, 2012; Zoffmann & Lauritzen, 2006). Further on, the participants received support to reconcile their goals and adjust inappropriate strategies if needed, which might have influenced their general adjustment process.

Our findings emphasize the importance of the inter-personal resources of the intervention personnel as knowledgeable professionals and compassionate dialogue partners. How the intervention personnel developed their role and relationship with the participants will be explored in a focus group study in progress. In general, it is known that a caring relationship furthers the possibility of growth despite adversity and suffering (Priebe, Wiklund Gustin, & Fredriksson, 2018; Thorkildsen, Eriksson, & Råholm, 2015). There is an agreement between our findings and those of other stroke studies that a mutual understanding of the situation between the participant and the intervention provider together with an empathetic attitude in the latter has a positive effect on participants’ abilities to deal with their condition (Allen, Burbach, & Reibstein, 2013; Ranner, von Koch, Guidetti, & Tham, 2016). In a caring relationship, patients may need to be pushed to help them see future benefits that they cannot perceive by themselves (Scott, Scott, Miller, Stange, & Crabtree, 2009). Our findings confirm that the participants appreciated being “pushed”. Nevertheless, participants were encouraged

to make their own decisions and taking control of their post-stroke life strengthened their sense of self.

Several of the participants emphasized the importance of receiving the intervention in their homes. The familiar environment may have strengthened the positive influence of the intervention. The professionals were able to give the participants their undivided attention without any other stressors present and the participants did not need to spend time and energy on meeting them at different locations.

According to Antonovsky (1987, p. 17), manageability, one of the three elements in SOC, is the extent to which one perceives having adequate resources available to cope with a stressful situation. Such resources play an important role in adjustment (Sarre et al., 2014). Our findings reveal that the participants experienced a lack of structural resources from health, social and employment services after discharge from hospital. This finding confirms the results of previous stroke studies (Maratos et al., 2016; Martinsen et al., 2015; McKeivitt et al., 2011; Röding, Lindström, Malm, & Öhman, 2003). For many participants, the lack of follow-up support from the general health care system turned the post-stroke trajectory into a struggle on several fronts, which is in accordance with findings in other studies (Felten & Hall, 2001; Sadler, Sarre, Tinker, Bhalla, & McKeivitt, 2017).

Our findings reveal that the narrative component of the intervention (Frank, 2013; Hydén, 1997; Polkinghorne, 1988), involving telling illness stories to a devoted and skilled professional, had been important for the participants. Conveying their experiences and reflecting on the intervention personnel's responses was a meaning-making endeavour that probably furthered the participants' biographical work and adjustment, as shown previously (Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Faircloth, Boylstein, Rittman, & Gubrium, 2005; Faircloth, Rittman, Boylstein, & van Puymbroeck, 2004; Sarre et al., 2014). Telling

their stories may also have strengthened their feeling of being valued by others and enhanced their meaning-making endeavours after stroke as reported by Gubrium, Fiddian-Green, Lowe, DiFulvio and Del Toro-Mejías (2016). The participants emphasized the importance of “telling” to a professional who was familiar with the post-stroke condition. The intervention personnel’s responses furthered participants’ reflections on their situation, improved their own self-understanding (cf. Polkinghorne, 1988) and strengthened the thread between their past and future life (Ellis-Hill, Payne, & Ward, 2008). According to Frank (2013), a person’s “chaos narratives” reveal the consequences of the illness for the person. These narratives are especially important to share with an ‘empathetic other’ in order to move on to quest narratives that indicate an acceptance of the consequences of illness. The findings of France, Hunt, Dow, and Wyke (2013) indicate that chaos narratives may persevere for a long time after stroke onset in persons who suffer from severe permanent disabilities and lack support from health care professionals. Frank (2013) argues that the act of telling enables relationships both with others and with one’s self to be reaffirmed (p. 56) and a sense of coherence to be restored (p. 61). Thus, the narrative component of the intervention may have strengthened the relationships between the people involved and enhanced the participants’ self-concept and sense of coherence.

### **Methodological considerations**

The fact that the interviews were retrospective might have influenced the results, as some participants had difficulty in recalling the intervention in detail. Although the sample sub-group from the RCT included participants with various demographic and stroke-related characteristics, we do not claim that it was representative of all the participants in the RCT. The redundancy of the interview themes during the analysis confirmed our decision regarding the sufficiency of the number of participants in the sample sub-group from the South-Eastern

area (Morse, Barrett, Olson, & Spiers, 2002). The sample sub- group from the Northern area consisted of all persons who had received the intervention six to twelve months post-stroke.

The analysis of the two sample sub-groups were compared to avoid missing possible differences between the groups. Nevertheless we could not find any differences in how the intervention was perceived at different time points post-stroke. Perceived usefulness of the intervention in both sample sub-groups seemed to depend more on participants' perception of the severity of their remaining disabilities and whether or not they could rely on supportive network resources.

As different researchers were involved in the interview process, we included all researchers in the development of the interview guide. We made sure that the interviewers followed the interview guide while keeping in mind adjustment of follow-up questions to individual participants. The use of different interviewers probably added to the richness of the data, as did the participants' willingness to communicate their experiences. All authors were involved in the analysis and frequent discussions to provoke our preunderstanding facilitated our final interpretation. We aimed at being open and inquiring to tease out the underlying meaning of the text. At the same time, we tried to keep close to the participants' own perceptions and refrained from viewing their statements in the light of their diagnosed stroke aetiology and location. The authors are experienced in stroke and chronic illness, which we consider to be a strength. Six of the authors had acted as intervention personnel. Therefore, we strove to avoid blending the roles of intervention personnel and interviewer.

### **Conclusion with implications for practice**

The aim of this study was to gain an in-depth understanding of the participants' lived experience of the influence of the intervention on their adjustment process. Our findings illuminate the post-stroke trajectory as a struggle on several fronts simultaneously, where

most participants were in need of long-term support to promote their psychosocial well-being. The intervention had helped 17 of the 19 participants to consider their limitations, focus more on their abilities and to adopt a future-oriented attitude. The empathetic relationship with the experienced and dedicated intervention personnel prepared the ground for the GSD approach to support these participants in dealing with the psychosocial challenges post-stroke. Telling their illness narratives was revealed as an important meaning-making endeavour and a means to develop a mutual relationship between the patient and the professional. The supportive actions of the intervention personnel seemed to help the participants to cope with loneliness, anxiety and depressive mood after stroke. The use of the GSD approach and the narrative approach in the intervention seemed to benefit the participants' post-stroke adjustment process. It might be useful to incorporate these elements when planning standard health care procedures to support the psychosocial health of people with stroke. A long-term follow-up of those who report functional decline influencing their psychosocial well-being should be considered and should last as long as needed.

### **Authorship**

All authors have contributed to this work according to the ICMJE guidelines, and accept direct responsibility for the manuscript.

### **Declaration of Conflicting Interests**

The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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