

# Young and Midlife Stroke Survivors' Experiences With the Health Services and Long-Term Follow-Up Needs

Randi Martinsen, Marit Kirkevold, Unni Sveen

## ABSTRACT

The aim of this qualitative study was to explore young and midlife stroke survivors' experiences with the health services and to identify long-term follow-up needs. Sixteen participants from two cohorts were interviewed in-depth. The interviews were analyzed applying a hermeneutic–phenomenological analysis. The participants struggled to gain access to follow-up health services. They felt that whether they were systematically followed up was more coincidental than planned. Young and midlife stroke survivors thus appear vulnerable to falling outside the follow-up system. Those participants who received some follow-up care perceived it as untailored to their specific needs. To be considered supportive, the follow-up programs must be in line with their long-term needs, take into account their particular challenges as young and midlife stroke survivors, and be planned in close collaboration with the individual patient. To secure systematic and follow-up health services tailored to the individual, knowledgeable and committed healthcare professionals should play a prominent role within the community health services.

**Keywords:** experiences, follow-up needs, health services, hermeneutic–phenomenological analysis, long-term, midlife, psychosocial, rehabilitation, stroke survivors, young

The mortality rates among young and midlife stroke survivors are lower than among elderly stroke survivors; thus, young and midlife survivors live longer with the consequences of the stroke (Naess, Tatlisumak, & Kõrv, 2011). Because the psychosocial challenges endure for years (Kouwenhoven, Kirkevold, Engedal, Biong, & Kim, 2011; Martinsen, Kirkevold, & Sveen, 2012; Stålnacke, 2007), living with a stroke over the long-term necessitates reconciliation with the new life (Jumisko, Lexell, & Söderberg, 2009).

The comprehensive physical and psychosocial consequences of a stroke require an extended follow-up (Robison et al., 2009; White et al., 2012). Stroke survivors thus frequently require community health services after discharge from specialized, hospital-based rehabilitation services (Ministry of Health and Care Services, 2011), suggesting a need for establishing relationships

between stroke survivors and healthcare professionals during rehabilitation (Alve et al., 2012).

In line with the international guidelines (Adams et al., 2007), the Norwegian guidelines for the treatment and rehabilitation of stroke emphasize an early, flexible, person-centered rehabilitation to gain physical, psychological, social, and occupational independence (Indredavik, Salvesen, Næss, & Thorsvik, 2010). The guidelines do not specifically address the needs of young and midlife stroke survivors or the need for psychosocial rehabilitation but recommend provision of information and supportive conversations as topics of importance.

Shortcomings have been found in the follow-up needs of young and midlife stroke survivors during their rehabilitation. Differences have been identified between the rehabilitation goals of the stroke survivors themselves and those of the health professionals. Whereas health professionals tend to emphasize biomedical problems, the stroke survivors themselves tend to focus on both biomedical and psychosocial issues during their rehabilitation (Alasewski, Alasewski, & Potter, 2004; Bendz, 2003; Medin, Barajas, & Ekberg, 2006; White, Magin, & Pollack, 2009).

Topics that have been insufficiently focused are information about the stroke and the consequences of living with a stroke (Low, Kersen, Ashburn, George, & McLellan, 2003; Röding, Lindström, Malm, & Öhman, 2003; White et al., 2009). Röding et al. (2003) found that younger stroke survivors felt invisible and overlooked in their situations as stroke survivors. Challenges related to family life and the return to work have also

Questions or comments about this article may be directed to Randi Martinsen, PhD, at randi.martinsen@hihm.no. She is an Associate Professor at Hedmark University College, Elverum, Hedmark, Norway.

Marit Kirkevold, EdD, is a Professor at Institute of Health and Society, Oslo, Norway.

Unni Sveen, PhD, is a Professor at Faculty of Health Science, Oslo and Akershus University College of Applied Sciences, Oslo, Norway.

The authors declare no conflicts of interest.

Copyright © 2015 American Association of Neuroscience Nurses

DOI: 10.1097/JNN.000000000000107

been identified as topics of importance to younger stroke survivors (Gilworth, Phil, Cert, Sansam, & Kent, 2009; Kitzmüller, Asplund, & Häggström, 2012; Martinsen et al., 2012; Medin et al., 2006). The shortcomings appear to be especially prominent during transitions between health service institutions (Cameron, Tsoi, & Marsella, 2008; Hickey, Horgan, O'Neill, & McGee, 2012; Leith, Phillips, & Sample, 2004; Salisbury, Wilkie, Bulley, & Shiels, 2010; White et al., 2009). To the best of our knowledge, young and midlife stroke survivors' specific long-term needs and how they are addressed by the health services have received little attention thus far.

### **Aim**

The aim of this study was to explore young and midlife stroke survivors' experiences with the health services and to identify their long-term follow-up needs. In this study, young and midlife stroke survivors are defined as stroke survivors between the ages of 18 and 67 years.

### **Methods**

This qualitative study applied a hermeneutic-phenomenological approach.

#### **Sampling Procedure**

The study was performed in Norway. A purposive, maximum variation sampling procedure was used, and 16 stroke survivors were included.

Eight of the study participants were recruited from a previous feasibility study that ended 1 year before this current study. The overall aim of the intervention study was to promote psychosocial well-being after stroke. The intervention was composed of eight dialogues with patients during the first 6 months after stroke. The psychosocial intervention supplemented "usual care" in the specialist and community health services. The findings from the initial study are reported elsewhere (Kirkevold, Martinsen, Bronken, & Kvigne, 2014). At the time of this study, the patients had lived with the stroke for approximately 1.5 years.

The other eight study participants had provided an in-depth interview 1 year before participating in this current study. These participants had received usual care in the specialist and community health services after their stroke. Because of challenges in identifying stroke survivors after discharge from hospital, the study participants in this study were recruited by placing a notice on the Web site of the National Stroke Foundation. The participants in this group were individuals who had experienced living with stroke from 2 to 10 years after the stroke and thus represented experienced stroke survivors over the longer term, giving us a possibility to attain a variety of the long-term experiences after a stroke.

---

In this qualitative study, these Norwegian researchers explore the experiences of young and midlife stroke survivors as they navigate health services and identify their long-term follow-up needs.

---

In the current study, we aspired to include study participants with a variation in age, gender, and time since stroke onset. We judged that our study participants provided rich insights about their experienced follow-up needs over time after the stroke. The rationale for including patients who had participated in the intervention study was an expectation that they would provide insights into the follow-up needs up to 1.5 years after stroke. The patients who did not participate in the intervention were expected to highlight the specific follow-up needs over a time span of 2–10 years after stroke. Because of their varied and long-term experiences, the participants were considered experts on how the challenges of living with stroke had been addressed by the health services. Thus, they were in a unique position to provide input regarding actions that may be necessary to address stroke survivors' long-term needs. In addition, we assumed that data from these two diverse groups would enable a qualitative comparison of whether participation in a dialogue-based intervention shortly after stroke onset could promote psychosocial well-being during the follow-up period and reduce the need for long-term follow-up.

#### **Presentation of the Participants**

All sixteen participants (11 men and 5 women), who were aged between 21 and 67 years (mean = 48 years) at the time of the interview, consented to continuing inclusion at the time of the preceding interview. Thus, all participants were contacted by telephone 1 year later.

The participants, who lived in rural or urban areas of southern Norway, were diagnosed with an occlusion or hemorrhage of an artery in their left or right brain hemisphere. The consequences of their strokes varied from severe to moderate effects at the time of stroke. All participants lived at home before the stroke onset, and all but one lived at home when the current study was conducted. Twelve of the participants were employed part time or full time before the stroke onset, two were students, one was unemployed, and one was retired. At the time of the current interviews (1.5–10 years after stroke onset), five were employed

full time or part time, one had recommenced studies, one was unemployed, six were on security benefits, and three were retired (for further details, see Table 1).

### *Data Collection*

The initial interviews with each participant were transcribed, read, and analyzed before the follow-up interviews to prepare a topical interview guide based on items from the first interview. However, as a point of departure, the participants were encouraged to provide an open narration on their experiences of living with stroke during the preceding year. During the interviews, the participants were encouraged to provide in-depth narrations. When necessary, participants were probed to describe their experiences with the health services and to uncover their follow-up needs during their rehabilitation.

All interviews were conducted by the first author during the period from December 2008 to April 2011 and lasted between 35 and 84 minutes. Eight of the interviews were conducted in the participants' homes, six in a "learning and mastery center," one in a nursing home, and one in the participant's place of work.

### *Analysis*

All interviews were tape-recorded and transcribed verbatim.

A hermeneutic–phenomenological analysis composed of three main interpretative steps was conducted (Lindseth & Norberg, 2004; Ricœur, 1976). Initially, all texts were read to develop an overall "naive" understanding of the study participants' expressions of how they viewed life during the preceding year. Our previous analyses had shown us that, at the end of the intervention, the participants in the intervention study had expressed that the intervention had supported them through a difficult period and had provided support during their attempts to cope with the situation. The stroke survivors reported that the intervention provided the opportunity to tell and create their personal stories (Kirkevold, Martinsen, Bronken, & Kvigne, 2014). In this light, we expected to find a difference in how the two cohorts summarized their follow-up experiences and needs after stroke. During the initial analysis, we investigated this working hypothesis. We did find some differences in how they described their subjective well-being at the time of the second interview (1 year after the intervention for the intervention group); a greater number of intervention participants described their well-being in positive terms compared with participants who had received usual care. Nevertheless, in general, their descriptions of their relations with and follow-up from the health services did not differ substantially. Rather, the experiences of the two cohorts were found to be very similar.

During the next step, the structural analysis, the two cohorts were therefore merged and analyzed as one

sample. The specific experiences revealed through the structural analysis were divided into meaning units, subthemes and two main themes. During the third step, the critical analysis, we compared and contrasted the initial subthemes and themes in light of the research literature and the original narratives. This led to a comprehensive understanding of the stroke survivors' long-term needs. This step ended when consensus was achieved within the research group (Lindseth & Norberg, 2004; Ricœur, 1976).

### *Ethical Considerations*

When the participants were contacted, information on the study was repeated. The participants were assured that any information provided was confidential and that they could withdraw from the study at any time without consequences, as stated in the Helsinki Declaration (World Medical Association, 2008). In line with these ethical requirements, additional verbal consent was obtained (Usher & Arthur, 1998). Appointments were made detailing the time and place of the interviews. Finally, the participants signed a written consent form before the interviews. This project was approved by the Regional Medical Ethics Committee (Project No. 2.2007.37) and the Social Science Data Service in Norway (Project No. 16369).

### *Findings*

Four of the study participants from the intervention study described their lives as satisfactory, whereas the other four stated that they were less satisfied with their lives at 1 year after the intervention had ended. Three of the eight participants who did not participate in the intervention study but who had received usual care after stroke stated that their lives were satisfactory during the 2–10 years after the stroke. The remaining five participants stated that their lives were better than 1 year ago but that they remained unsatisfied.

The stroke survivors struggled to understand their own life and situation although they had lived with the effects of stroke for periods ranging from 1.5 to 10 years. During the analysis, it became obvious that difficulties accessing the health services and a lack of tailored follow-up services increased their struggles by limiting their opportunities to address questions about their own life after the stroke, talk about their individual needs, and discuss health-related concerns. The opportunity to establish a relationship with a "helper" to enable them to voice their experiences and concerns on living with the consequences of stroke was stated as essential. The two primary themes are described below.

### *Difficulties Accessing Health Services*

This theme includes the participants' statements on their struggle to find methods to contact the health service

TABLE 1. Participants' Characteristics

Gender	Civil Status	Age, Years	Time Since Stroke Onset, Years	Consequences of Stroke	Working Status Before Stroke Onset	Working Status When Conducting Interview
Male	Married	55	1.5	Thrombosis, right hemisphere; mild aphasia	Employed	Social security
Male	Married	58	1.5	Hemorrhage, left hemisphere; neglect; memory affected; visuospatial impairment	Employed	Employed
Male	Single	50	1.5	Hemorrhage and thrombosis, left hemisphere; hemiplegic right side; neglect; visual field defect	Employed	Social security
Female	Married	56	1.5	Thrombosis, right hemisphere; mild aphasia	Unemployed	Unemployed
Male	Married	44	1.5	Hemorrhage, right hemisphere; numbness, left hand	Employed	Employed
Male	Married	65	2	Thrombosis, right hemisphere.	Employed	Retired
Female	Married	67	1.5	Thrombosis, right hemisphere; hemiplegic left side; visuospatial impairment	Employed	Retired
Male	Married	62	2	Hemorrhage, right hemisphere; reduced balance	Retired	Retired
Female	Divorced	56	3.5	Thrombosis, left hemisphere; concentration affected	Employed	Social security
Female	Divorced	39	5	Hemorrhage, right hemisphere; concentration and memory affected	Employed	Social security
Male	Single	28	4	Thrombosis, left hemisphere; hemiplegia, right side; aphasia; concentration and memory affected	Student	Social security
Male	Married	33	2.5	Emboli, right hemisphere and cerebellum; concentration and memory affected	Employed	Employed
Male	Married	39	5.5	Hemorrhage, right hemisphere; hemiplegia, left side; epilepsy	Employed	Employed
Male	Married	51	4.5	Thrombosis, right hemisphere; mild aphasia	Employed	Employed
Female	Single	21	2	Thrombosis, right hemisphere; hemiplegia, left side	Student	Student
Male	Married	44	10	Hemorrhage, right hemisphere; hemiplegia left side; memory affected; epilepsy	Employed	Social security

system to obtain support to better manage their lives after a stroke. Delayed access led to experiences of “being left in the lurch” in their struggles.

Some stated that they waited for a follow-up call from the health services but that the call never came. Having waited in vain for long periods, some contacted the health services by telephone after 1–2 years and asked whether they could obtain a checkup, which was often received in a positive manner. They wanted a health check because of worries about and uncertainty regarding their physical condition. Some had obtained medical information from the Internet and had the impression that their bodies should be checked by a brain scan or assessed by a neuropsychologist, a physiotherapist, an occupational therapist, or a general practitioner. One of the men, who was aged 39 years and who did not participate in the intervention study, stated the following at 5.5 years after stroke onset:

[I] heard at the hospital and found a document about stroke [on Internet] that suggested a [brain scan] once a year during the following five years to check [if the brain] was [normal]. But that’s probably for the elderly. I haven’t been offered this, so I’ve asked about it. I haven’t heard anything.

The study participants who did not receive an expected follow-up appointment with the health service questioned the quality of the follow-up services. Their need for contact with a follow-up system was highlighted. They stated that this follow-up would ensure that they did not feel left alone or that they only had coincidental encounters with professionals:

I’m wondering how I’m going to get in touch to get some help. [...] Because I want to talk with a doctor specialised in epileptic disease. And it’s a pity, I feel I am a rather well-informed patient but I haven’t managed to get in contact with those making decisions, those who know, so I can ask directly: what is it about? That’s troublesome (man, forty-four, intervention study participant, one and a half years after stroke).

One of the women, who was 67 years old and who participated in the intervention study, spoke about her difficult life 1.5 years after stroke. She stated that she felt no joy in her daily life. She felt tired, “empty,” and alone and lacked the will to get up in the mornings to face her boring and unbearable life. The health services paid attention to her physical condition but not to her psychological well-being, which resulted in despair. She missed a professional who could listen to her, help her express her problems, and find solutions to persevere:

It’s foolish things I’m going through just now. I think the health services, the GP examines my blood pressure and such. [...] Everybody is concerned about my physiotherapy, checking my arms and legs, but who is checking what’s going wrong in my head? [...] I feel afraid when waking up in the mornings and I don’t want to get up.

One of the men, 33 years old, was offered the opportunity to attend a peer group at 2.5 years after stroke. He was surprised to receive this offer so long after the stroke but wanted to attend the group. He wanted to talk about and obtain ideas on how to manage life with stroke as a busy father and employee with others. He questioned why it took all that time to obtain access to this group:

I thought I was going to attend [a rehabilitation stay]. [...] But it was only an examination, not any intervention. [...] But that doesn’t help me much [...] I want to progress. But that is just up to me. It makes me upset and frustrated that receiving sufficient information and managing my situation is just up to myself. [...] I think it’s okay to hear others’ stories and narrations [...] I think that’s great. But why did [this offer] not come until now? (nonintervention participant at 2.5 years after stroke).

The informants also expressed frustration on the lack of contact with the social security system. Many spoke of their lack of having a designated coordinator or their frustration at the lack of understanding of the challenges after a stroke among health professionals. They questioned the competence of the health service practitioners to some extent and also their willingness and ability to offer relevant support to address the patients’ concerns.

### *Lack of Tailored Follow-Up Services*

This theme summarizes the stroke survivors’ expressions on the lack of being followed up as individuals. Although Norwegian legislation stipulates that all citizens in need of long-term complex follow-up health services receive a coordinated service guided by a designated coordinator, only one of the participants in this study had an individual plan, that is, a personal document drawn up to outline individual objectives, resources, and required health services to those in need of long-term coordinated health services. Some were aware of this tool and underlined that a systematic follow-up service was lacking. A woman aged 39 years who had not participated in the intervention study said at 5 years after stroke:

The follow-up should have been better and more frequent [...] I would have felt calmer, been helped and supervised [if followed up more closely].

The youngest participant was offered an individual plan and a personal coordinator at 1 year after her stroke. However, the expected regular meetings with her designated coordinator disappointed her. Some regular meetings did not occur, and when they did, her coordinator did not address her personal questions or did not seek other professionals who were qualified to answer her questions. At 2 years after stroke, she said:

We didn't meet the last time. That was a long time ago. [...] But I still have my coordinator [...] who is supposed to help me if I'm wondering about something. She helps me with phone calls and such [...] but if you ask me, it doesn't work! [...] She forgets to call. [...] She does not have much knowledge, so she doesn't offer me much help. If I send her an e-mail, she needs weeks to answer and then it is [wasted] (woman, 21 years old, nonintervention participant).

Several of the study participants worried that their lives would "come to nothing." They had found that the consequences of the stroke threatened their return to a normal social and work life. The inner thoughts on these intangible topics were expressed as difficult to manage and influenced their motivation to continue with life. The participants wished to contact professionals interested in helping them deal with these distressing thoughts:

I'm trying to work through these unhappy, "be sorry" periods [...] It's about [...] the general life. I miss someone that [I] can have a serious conversation [with] about that (woman, 56 years old, nonintervention participant at 3.5 years after stroke).

The perception that the healthcare professionals did not take the participants' emotions into account made the stroke survivors question the willingness and ability of the professionals to offer relevant support. The stroke survivors were unsure what to expect from the health services but expressed a need for assistance to provide direction in their lives when they were unable to find solutions by themselves. Using different words, they questioned why they should continue with rehabilitation when recovery did not occur. They lacked information on why it was necessary to continue and stated that they were unable to contact someone who could motivate them. One of the study participants, who did not find the follow-up particularly helpful but experienced the encounter with one of the health professionals helpful, explained:

I think it should have been someone experienced, knowing stroke patients, [...] someone with expert knowledge, not only able to listen. [...] I found it [motivated me]. I think that is important to be able to go on. [...] It was due to her [the health professional] manner that we became mates, and not only a therapist and a patient (man, 51 years old, nonintervention participant at 4.5 years after stroke).

During the interviews, the participants highlighted their experiences with a follow-up system that was not tailored to their specific needs as young and midlife stroke survivors. They highlighted that their age and specific life situation should be taken into account when offering a rehabilitation service. The youngest study participants spoke of the challenges of attending rehabilitation together with older individuals not because of their age but rather because of their differences in interests and daily-life concerns:

I liked that rehabilitation centre because of its youthful environment. [Then] you don't feel like a patient. It's more like a training camp, going out in the evenings, eating and so on. That's nice. [...] At [another rehabilitation centre] where all patients had strokes [...], it was only me and the eighty-year-old men. [...] It was not fun to stay there! [...] I feel that I have more in common with others although they are not exactly at my age. [When they were] somewhere between twenty and forty, I had more in common with them although they had other diagnoses (woman, 21 years old, nonintervention participant at 2 years after stroke).

The participants also highlighted that the follow-up system had to be flexible and had to be adjusted to their total life situation. Some had minors at home, and the changing needs and activities of their children were difficult to reconcile with a strict and inflexible rehabilitation service. Others were students and had to meet study obligations. It was therefore critical that the follow-up be adjusted to their daily life to enable them to meet their other obligations to family life, student life, and work life:

I think it's difficult to deal with [rehabilitation services]. [...] Life changes from week to week. [...] And now she [the wife] has started to work, twenty per cent. Then I can't tell her, that she should not [go to work] because I'm going to my follow-up. [...] So [the follow-up system] has to be flexible, if it's going to work (man, 44 years old, intervention study participant at 1.5 years after stroke).

A nonflexible, general follow-up service was termed frustrating and demotivating. One of the females, 56 years old, spoke about two rehabilitation stays that she was offered. She had not carried through because her aphasia had not been considered. Her stays in the rehabilitation units did not meet her expectations of support for her communication challenges. She was afraid to express herself, but because both rehabilitation institutions had lacked speech therapists, her stays were unhelpful in developing her communication skills. Consequently, she interrupted both stays and went home earlier than planned:

One and a half weeks [two times]. [...] I think it was only confusing [...]. It did not help. It was during summer holidays so they lacked people. [...] I think I could have learned to talk more by staying at home talking with my husband. [...] Because I did not talk much there [during the rehabilitation stay]. They [the personnel] were only complaining that they didn't have people [i.e., speech therapists] (intervention study participant at 1.5 years after stroke).

## Discussion

The participants in this study included two different cohorts; half had participated in a dialogue-based psychosocial intervention during the first 6 months after stroke in addition to usual care, and the other half had received usual care only. The participants had lived with the consequences of stroke for between 1.5 and 10 years. Together, their experiences shed light on young and midlife stroke survivors' encounters with the health services and their unique follow-up needs. Thus, the findings presented here provide knowledge that may assist in evaluating and developing interventions tailored to the follow-up needs of this subgroup of stroke survivors.

The stroke survivors' perception was that they had more or less been left in the lurch. We found it interesting that this experience appeared to be independent of the length of time since the stroke. Those who had lived with the consequences of stroke for many years described their follow-up care as very limited. However, even the stroke survivors who had experienced stroke more recently, that is, at 1.5 years before the interview, expressed similar experiences. Nevertheless, several of the stroke survivors who had participated in the psychosocial intervention described their lives as satisfactory when interviewed at 1.5 years after their stroke despite the fact that they had lived with the consequences of the stroke for a shorter period and thus had had less time to adjust to the new life situation. This may suggest that participating in the intervention may have provided some assistance in adapting to the new situation, although it was clearly not sufficient to address all the participants'

follow-up needs. After the intervention ended, at 6 months after the stroke, the participants' experiences of a limited and fragmented follow-up service made the gap between needs and actual services delivered very obvious. Irrespective of cohort, these findings highlight that stroke recovery is protracted and that shortcomings exist in follow-up of young and midlife stroke survivors, which is consistent with previous studies (Röding et al., 2003; Salisbury et al., 2010).

The difficulties in accessing health services led to several unaddressed physical, psychological, and social needs and challenges after the stroke. The stroke survivors' insecurities and anxieties related to their physical symptoms influenced their psychological well-being. Worrying about both the possibility of physical deterioration or experiencing a new stroke and the consequences of the original stroke, which could lead to their lives "coming to nothing," appeared to influence the participants' well-being negatively. The findings in this study suggest that access to psychosocial support is perceived as limited among young and midlife stroke survivors. Follow-up services should therefore be intensified and adjusted to individual patient needs to be helpful.

The occasional and fragmented follow-ups experienced by the participants in this study make the stroke survivors vulnerable to falling outside the system, especially those participants who were able to engage in independent daily activities. The challenges in accessing psychosocial support have also been reported elsewhere (Leith et al., 2004; Robison et al., 2009). Knowing that the psychosocial consequences of a stroke restrain daily living (Eriksson, Tham, & Borg, 2006; Röding et al., 2003), it is ethically indefensible to disregard the need for psychosocial support in younger and middle-aged stroke survivors. Working-aged stroke survivors face substantial challenges in meeting family and work obligations. Being unable to support children as well as the family has been found to be a challenge that influences well-being (Kitzmüller et al., 2012; Martinsen et al., 2012).

Among the participants in this study, a minority had returned to work or studies. Being unable to return to work also influences well-being (Gilworth et al., 2009; Vestling, Tufvesson, & Iwarsson, 2003). Family and work issues in younger and middle-aged stroke survivors should be addressed by follow-up services to prevent marginalization in family and work life. Offering psychosocial support may prevent common challenges, such as anxiety, depression, and social isolation (Gurr & Muelenz, 2011; Kouwenhoven et al., 2011), and it may prevent long-lasting psychosocial struggles, disability, and unemployment. It may also lead to reduced individual and community costs because more stroke survivors may be able to resume work and family responsibilities.

To have a say in one's own life appears critical for reentering daily life. However, the stroke survivors in this study experienced limited opportunities to play an active role in and influence the type of follow-up services that they received. Empowering individuals to assume an active role in their lives is a core premise in patient-centered rehabilitation care (Peoples, Satink, & Steultjens, 2011). Offering a follow-up where challenges and needs are listened to and responded to could contribute positively to strengthening the role of the patient (Ministry of Health and Care Services, 2009). To be successful, such follow-up care must acknowledge that stroke survivors are unique individuals with individual needs (Alve et al., 2012).

Some of the stroke survivors in this study questioned the quality and competence of their healthcare professionals. Although all Norwegian patients in need of coordinated care have the right to an individual plan (Ministry of Health and Care Services, 2009; Norwegian Directorate of Health, 2010), either it was not offered or it was considered to be unhelpful. The challenges of this tool have also been reported elsewhere (Alve et al., 2012; Slettebø et al., 2012).

Many of the stroke survivors in this study highlighted the challenge of moving from illness toward health and well-being and expressed a need to meet experienced and knowledgeable "helpers" to discuss their changed lives after stroke. A follow-up service that attends to the human beings' life worlds and that addresses the ambiguities of patient existence, consistent with a phenomenological approach (Dahlberg, Todres, & Galvin, 2009), could be beneficial. Collaboration between stroke survivors and healthcare professionals with the necessary skills to provide holistic care is necessary to initiate dialogues with these young and midlife stroke survivors on their daily life needs and challenges.

### Limitations

Although varied, the experiences of our participants do not necessarily represent the general population of young and midlife stroke survivors. Although we sought to recruit widely among young and midlife stroke survivors, there is a chance that stroke survivors who felt a stronger need for psychosocial follow-up were more prone to consent to the study (although we had few refusals to participate). Consequently, conclusions should be drawn with caution. Nevertheless, the participants' rich and varied descriptions provided opportunities to address our research aim and highlighted important challenges in this subpopulation. Representative quotes from in-depth interviews provide specific examples and help increase the fidelity of our interpretations. Validation of the findings was sought throughout the analysis process via continual and open discussions among the researchers (researcher triangulation).

The merging of the two cohorts gives rise to some methodological limitations and reflections. The stroke survivors participating in the intervention were equal in terms of time since stroke onset, whereas the time range between stroke onset and the interview varied in the group receiving usual care only. This made direct comparison impossible. Nevertheless, seen together, the two groups gave us valuable insights about the long-term experiences from 1.5 to 10 years after a stroke.

During the interviews, some of the participants expressed themselves in ways that may be interpreted as having clinical depressive symptoms. We did not formally screen for mood changes. Rather, the characteristics of the study participants were based on self-reporting. According to their self-reports, five took antidepressants, which support the interpretation that some participants had depressed mood. An objective assessment of mood status, applying an appropriate standardized measure, would have strengthened the study.

This study was conducted within a Norwegian context. However, we believe that the findings are transferable to some other Western contexts because the Norwegian health services have many similarities to other Western countries. Despite the limitations, we believe that our findings provide insights that may guide the development of relevant psychosocial interventions.

### Conclusion

Young and midlife stroke survivors struggled to gain access to follow-up health services. They felt that whether they were systematically followed up was more coincidental than planned. Young and midlife stroke survivors thus appear vulnerable to falling outside the follow-up system. Those participants who received some follow-up care perceived it as untailored to their specific needs. To be considered supportive, the follow-up programs must be in line with the long-term needs of the stroke survivors, take into account their particular challenges as young and midlife stroke survivors, and be planned in close collaboration with the stroke survivor. Furthermore, helpers must take the stroke survivors' own experiences and perspectives into account and support their motivation to continue with life via individualized and knowledge-based support and encouragement.

### References

- Adams, H. P., del Zoppo, G., Alberts, M. J., Bhatt, D. L., Brass, L., Furlan, A., ... Wijndicks, E. F. (2007). Guidelines for the early management of adults with ischemic stroke: A guideline from the American Heart Association/American Stroke Association Stroke Council, Clinical Cardiology Council, Cardiovascular Radiology and Intervention Council, and the Atherosclerotic Peripheral Vascular Disease and Quality of Care Outcomes in Research Interdisciplinary Working Groups: The American Academy of Neurology affirms the value of this



- guideline as an educational tool for neurologists. *Circulation*, 115(20), e478–e534.
- Alasewski, A., Alasewski, H., & Potter, J. (2004). The bereavement model, stroke and rehabilitation: A critical analysis of the use of a psychological model in professional practice. *Disability and Rehabilitation*, 26(18), 1067–1078.
- Alve, G., Madsen, V. H., Slettebø, Å., Hellem, E., Bruusgaard, K. A., & Langhammer, B. (2012). Individual plan in rehabilitation processes: A tool for flexible collaboration? *Scandinavian Journal of Disability Research*, 15(2), 1–14.
- Bendz, M. (2003). The first year of rehabilitation after stroke—From two perspectives. *Scandinavian Journal of Caring Sciences*, 17, 215–222.
- Cameron, J. I., Tsoi, C., & Marsella, A. (2008). Optimizing stroke systems of care by enhancing across care environments [scope review]. *Stroke*, 39, 2637–2643.
- Dahlberg, K., Todres, L., & Galvin, K. (2009). Lifeworld-led healthcare is more than patient-led care: An existential view of well-being. *Medicine, Health Care and Philosophy*, 12(3), 265–271.
- Eriksson, G., Tham, K., & Borg, J. (2006). Occupational gaps in everyday life 1–4 years after acquired brain injury. *Journal of Rehabilitation Medicine*, 38(3), 159–165.
- Gilworth, G., Phil, M., Cert, A., Sansam, K. A., & Kent, R. M. (2009). Personal experiences of returning to work following stroke: An exploratory study. *Work*, 34(1), 95–103.
- Gurr, B., & Muelenz, C. (2011). A follow-up study of psychological problems after stroke. *Topics in Stroke Rehabilitation*, 18(5), 461–469.
- Hickey, A., Horgan, F., O'Neill, D., & McGee, H. (2012). Community-based post-stroke service provision and challenges: A national survey of managers and inter-disciplinary healthcare staff in Ireland. *BMC Health Services Research*, 12(1), 111.
- Indredavik, B., Salvesen, R., Næss, H., & Thorsvik, D. (2010). *Nasjonale retningslinje for behandling og rehabilitering ved hjerneslag* [National Guidelines for treatment and rehabilitation of stroke]. Oslo, Norway: Norwegian Directorate of Health.
- Jumisko, E., Lexell, J., & Söderberg, S. (2009). The meaning of feeling well in people with moderate or severe traumatic brain injury. *Journal of Clinical Nursing*, 18(16), 2273–2281.
- Kirkevoll, M., Martinsen, R., Bronken, B. A., & Kvigne, K. (2014). Promoting psychosocial wellbeing following stroke using narratives and guided self-determination: A feasibility study. *BMC Psychology*, 2, Article 4. doi:10.1186/2050-7283-2-4
- Kitzmüller, G., Asplund, K., & Häggström, T. (2012). The long-term experience of family life after stroke. *Journal of Neuroscience Nursing*, 44(1), E1–E13.
- Kouwenhoven, S. E., Kirkevoll, M., Engedal, K., Biong, S., & Kim, H. S. (2011). The lived experience of stroke survivors with early depressive symptoms: A longitudinal perspective. *International Journal of Qualitative Studies on Health and Well-Being*, 6(4). Available from <http://www.ijqhw.net/index.php/qhw/article/view/8491>
- Leith, K. H., Phillips, L., & Sample, P. L. (2004). Exploring the service needs and experiences of persons with TBI and their families: The South Carolina experience. *Brain Injury*, 18(12), 1191–1208.
- Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145–153.
- Low, J., Kersen, P., Ashburn, A., George, S., & McLellan, D. (2003). A study to evaluate the met and unmet needs of members belonging to young stroke groups affiliated with Stroke Association. *Disability and Rehabilitation*, 25(18), 1052–1056.
- Martinsen, R., Kirkevoll, M., & Sveen, U. (2012). Younger stroke survivors' experiences of family life in a long-term perspective: A narrative hermeneutic phenomenological study. *Nursing Research and Practice*, 2012.
- Medin, J., Barajas, J., & Ekberg, K. (2006). Stroke patients' experiences of return to work. *Disability and Rehabilitation*, 28(17), 1051–1060.
- Ministry of Health and Care Services. (2009). *Samhandlingsreformen: Rett behandling—På rett sted - til rett tid* [The Coordination Reform: Proper treatment—At the right place and right time]. Oslo, Norway: Ministry of Health and Care Services.
- Ministry of Health and Care Services. (2011). *Nevroplan 2015: Delplan til Omsorgsplan 2015*. [Neuro Plan 2015: A part of Care Plan 2015]. Oslo, Norway: Ministry of Health and Care Services.
- Naess, H., Tatlisumak, T., & Körv, J. (2011). Stroke in the young. *Stroke Research and Treatment*, Article ID 271979. doi:10.4061/2011/271979
- Norwegian Directorate of Health. (2010). *Individuell plan 2010—Veileder til forskrift om individuell plan* [Individual plan 2010: Regulations of individual plan]. Oslo, Norway: Norwegian Directorate of Health.
- Peoples, H., Satink, T., & Steultjens, E. (2011). Stroke survivors' experiences of rehabilitation: A systematic review of qualitative studies. *Scandinavian Journal of Occupational Therapy*, 18(3), 163–171.
- Ricœur, P. (1976). *Interpretation theory: Discourse and the surplus of meaning*. Fort Worth, TX: Texas Christian University Press.
- Robison, J., Wiles, R., Ellis-Hill, C., McPherson, K., Hyndman, D., & Ashburn, A. (2009). Resuming previously valued activities post-stroke: Who or what helps? *Disability and Rehabilitation*, 31(19), 1555–1566.
- Röding, J., Lindström, B., Malm, J., & Öhman, A. (2003). Frustrated and invisible—Younger stroke patients' experiences of the rehabilitation process. *Disability and Rehabilitation*, 25(15), 867–874.
- Salisbury, L., Wilkie, K., Bulley, C., & Shiels, J. (2010). "After the stroke": Patients' and carers' experiences of healthcare after stroke in Scotland. *Health and Social Care in the Community*, 18(4), 424–432.
- Slettebø, Å., Hellem, E., Bruusgaard, K. A., Madsen, V. H., Alve, G., & Langhammer, B. (2012). Between power and powerlessness—Discourses in the individual plan processes, a Norwegian dilemma. *Scandinavian Journal of Disability Research*, 14(3), 270–283.
- Stålnacke, B.-M. (2007). Community integration, social support and life satisfaction in relation to symptoms 3 years after mild traumatic brain injury. *Brain Injury*, 21(9), 933–942.
- Usher, K. J., & Arthur, D. (1998). Process consent: A model for enhancing informed consent in mental health nursing. *Journal of Advanced Nursing*, 27(4), 692–697.
- Vestling, M., Tufvesson, B., & Iwarsson, S. (2003). Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *Journal of Rehabilitation Medicine*, 35, 127–131.
- White, J. H., Gray, K. R., Magin, P., Attia, J., Sturm, J., Carter, G., & Pollack, M. (2012). Exploring the experience of post-stroke fatigue in community dwelling stroke survivors: A prospective qualitative study. *Disability and Rehabilitation*, 34(16), 1376–1384.
- White, J. H., Magin, P., & Pollack, M. R. P. (2009). Stroke patients' experience with the Australian health system: A qualitative study. *Canadian Journal of Occupational Therapy*, 76(2), 81–89.
- World Medical Association. (2008). *Ethical principles for medical research involving human subjects*. Seoul, Korea: Author.