

Facilitating learning and change in the daily lives of stroke survivors: A comparative analysis of municipal stroke rehabilitation services in Norway and Denmark

Abstract

Purpose: This study describe and compare the ability of professionals working in municipality stroke rehabilitation services to facilitate learning and change in the daily living of stroke survivors in two regions: one in northern Norway, the other central Denmark.

Materials and Methods: Semi-structured individual interviews were conducted with survivors 3 and 9 months after discharge from in-patient care. By contrast, field observations and focus group interviews were completed with professionals on multidisciplinary teams in the two regions. A sociocultural perspective on learning was applied during data analysis. *Results:* Altogether, the ability of municipal health services to facilitate learning and change for stroke survivors during the first year generally depended upon developing comprehensive integrated rehabilitation plans and ensuring access to coordinated, qualified multidisciplinary teams with professional knowledge and skills to support the survivors and their families during processes of adjustment, learning and change. However, Danish stroke survivors seemed positioned to be more active, proactive and empowered, and their processes of learning and change seemed more closely co-constructed with professional support. *Conclusion:* Findings reveal considerable differences in municipal stroke rehabilitation services in northern Norway and central Denmark and their ability to support stroke survivors in performing self-management.

Keywords: Municipal stroke rehabilitation services, multidisciplinary team, patient experience, learning, self-management. Scandinavian context

Introduction

Often a cause of long-term disability, stroke can have considerable physical, cognitive, emotional, social and financial ramifications for the individuals it affects, their families and the daily lives of both (1, 2). Consequences of stroke arise from mechanisms as complex as the process of stroke rehabilitation, even if the medical condition seems straightforward. Although the complexity of stroke rehabilitation typically requires long-term support from specialised multidisciplinary teams (3), therapeutic initiatives are relatively brief compared to the processes of adjustment, learning and change for individuals who have had a stroke and their families (4).

Despite their importance, learning and change within those processes have rarely been studied (5), especially concerning how they supportively enable stroke patients' social re-integration and participation in everyday life (6). Following a stroke, re-integration into daily living and community engagement is essential for the patient's wellbeing and quality of life. However, stroke survivors have reported that re-integration into the community is nevertheless the most challenging part of recovery (7, 8), during which time the extent of stroke-related disability typically becomes most apparent (9). Many stroke survivors report social isolation, exclusion and inactivity in their daily lives (10, 11), a condition which people 5 years post-stroke have termed *home-bound life* (12).

During in-patient stroke rehabilitation, physical recovery is the top concern for both patients and therapists (9, 13). After returning home, patients realise, however, that managing their daily lives requires more than improved physical skills. During that phase of recovery, professionals are absent, and patients realise that they have not learned skills necessary to cope with the cognitive, emotional and social challenges of post-stroke living (6, 9, 14). Although patient-centred approaches to rehabilitation acknowledge stroke patients as unique individuals with multifaceted experiences and recognise the importance of supporting,

challenging and developing their identities during rehabilitation (15), models of community-oriented stroke rehabilitation that similarly develop survivors' identities, enable their empowerment and facilitate their involvement in everyday life are scarce.

In policy, the continuity of rehabilitation services has been deemed essential for people with chronic, long-term needs (16, 17). Nevertheless, research has reported that those needs remain unmet, as well as that major challenges obstruct the delivery of community services to stroke survivors and their families after hospitalisation (18, 19). Many European countries in particular struggle with the fragmentation of stroke services in the community as well (18, 20, 21).

One reason for those unmet needs and challenges is uncertainty regarding what constitutes community services for stroke survivors, how they should be organised, what level of specialisation they require and how long they should be available (18). Although the early supported discharge approach, which provides a substantial part of rehabilitation to patients in their homes, is recommended (22), its form and content remain insufficiently described. Moreover, it focuses primarily on functional outcomes, not providing long-term services that assist stroke survivors and their families with adjusting to their new circumstances and becoming (re-)engaged in meaningful activities and valued roles (23).

In Norway and Denmark, which are based upon the Scandinavian welfare model and thus offer free, accessible services to all citizens (24, 25), stroke rehabilitation services have continually undergone profound organisational changes the last decade. Municipalities in both countries have been assigned new tasks and expanded responsibilities related to offering care in the form of stroke rehabilitation services (16, 17). In community-based rehabilitation services, such changes have called for new models especially arranged to accommodate the long-term needs of stroke survivors and their families, as well as to enable their daily living and participation in the community.

The aim of the study reported here was thus to determine whether professionals in municipalities in northern Norway and central Denmark support processes of learning and change in the daily lives of stroke survivors and their family members and, if so, then to also describe and compare services in the two countries. The study this is part of a Norwegian and Danish research collaboration comparing stroke rehabilitation services in northern Norway and central Denmark.

Materials and Methods

A sociocultural learning perspective on stroke rehabilitation

An abductive approach was chosen to explore the professionals' support of processes of learning and to describe and compare services in the two countries. The study viewed stroke rehabilitation from the sociocultural learning perspective, in which stroke rehabilitation is an ongoing, complex and often puzzling process. In that process, the perspective maintains, learning and change occur via survivors' involvement, negotiations, exploration and experimentation in their daily lives. The perspective also views learning as an incorporated part of person's embodied and sociocultural practice (29). Sociocultural learning has an interactive character and views meaning-making to be mutually co-constructed with others involved in the process (26).

Participants

Survivors who participated in the study were adults aged 25–65 years in need of rehabilitation services in response to mild or moderate disability caused by a confirmed diagnosis of stroke. To be included in the study, survivors had to have lived active independent lives before their stroke and be discharged to their homes after hospitalisation. Any survivors with major cognitive and communication impairments that would hinder them from sharing their experiences during an interview were excluded from participating. Patients admitted to a rehabilitation unit and met the inclusion criteria were included continuously.

The staff recruited the planned 5-6 participants and all who was asked consent to participation. The number of patients was chosen due to the project's rather extensive data collection and long time to recruit patients in Northern Norway limited the inclusion number to five.

The Norwegian participants included one woman and four men who were followed during the first year post-stroke and had been discharged to resume living in five different communities. One lived in a city with 70,000 inhabitants, whereas the others lived in municipalities with 3,500–10,000 inhabitants. In Denmark, the participants included three men and three women who were discharged to resume living in two communities with 48,000 and 61,000 inhabitants, respectively. Table 1 presents details about the survivors who participated.

[Insert Table 1 about here.]

Follow-up interviews with stroke survivors

To gather data about the stroke survivors' experiences, semi-structured interviews were conducted 3 and 9 months after the survivors' discharge from in-patient rehabilitation. The interview guide used focused on their level of functioning, significant lifestyle changes, social involvement and goal achievement, as well as their relatives' and caregivers' involvement in their rehabilitation process. The 22 interviews were conducted mostly in the survivors' homes, and in some interviews, survivors' spouses joined in the discussion. The interviews lasted 60–90 minutes each and were audio-taped and transcribed in full.

Focus group interviews with professionals

Focus group and one individual interview were conducted with healthcare practitioners, social workers and others in the municipality who were most central to the participating survivors' rehabilitation trajectories (see table 2). Professionals involved in case 11 declined focus group participation and for case 4, we only had the opportunity to interview

one of the professionals involved. Focus group interviews facilitate dialogue and the elaboration of experiences and ideas among colleagues (27). An interview guide prepared jointly by the two Norwegian and two Danish researchers was used as a checklist in all the interviews. The interview guide focused on professional's reflections on their own practices and efforts to promote the patients' ability to live a meaningful everyday life. The interviews lasted 60–90 minutes each and were audio-taped and transcribed in full.

[Insert Table 2 about here.]

Field notes

Each participant was field observed by the authors (the researchers followed 2-3 participants each for up 1-5 days in the middle and the end of their rehabilitation stay) during sessions of rehabilitation interventions at the specialist health care and at interdisciplinary meetings at the healthcare centre. Some were also followed up 1-2 days in their homes or in other settings in the community. Field notes (about 10-20 pages per participant), which detailed situations, participating survivors' activities and their interaction with professionals or others, were written in full immediately following the observations.

Analyses

Systematic text condensation – a descriptive and explorative method for thematic cross-case analysis of different types of qualitative data – was used for data analysis (28). Analysis proceeded in four steps. First, all of the researchers read and discussed all collected data during four workshops lasting 2–3 days. The discussions offered a bird's-eye view of the data and facilitated the identification of preliminary themes and primary areas of focus. The approach was inductive, sought open-mindedness and allowed the voices of survivors and professionals guide the analysis. Second, the first author identified and sorted all of the individual interviews and focus group interviews line by line into meaning units, which were

thereafter marked with codes. Commonalities and differences within and across the coded groups were investigated in and across the interviews. Third, empirical data reduced to a de-contextualised selection of meaning units sorted as thematic coded groups across the survivors and professionals revealed aspects of the survivors' trajectories of learning and change and the professionals' ability to support the survivors' self-management. During workshops the co-researchers validated the analyses performed by the first author. Their amendments, clarifications and supplementary information deepened the analysing process. Fourth, the inductive data driven themes and sub-themes were re-conceptualised as narratives, patterns and types of inequality. To that end, applying Arthur Frank's concept of illness narratives (29) and Lave and Wenger's concept of communities of practice (26) allowed new interpretations. The field notes served as sounding board in the interpretation of the professionals practice and reflections.

Ethical considerations

The study was approved by the Regional Committees for Medical and Health Research Ethics [2013/1920] and the Danish Data Protection Agency. Reflection on ethical aspects was a continuous aspect of the study. Informed verbal consent was obtained from both the survivors and the professionals. It was important to establish trusting relationships with the participants to ensure that participation did not unduly burden them. In general, participants reported that they were glad to contribute to developing knowledge that might help themselves and others.

Results

1. Different narratives of learning and change

Diverse, inter-related impairments posed challenges for the survivors' daily lives. Some survivors coped with sensorimotor injuries that had either reduced their hand function or impaired their balance, strength and coordination, if not both, and thus complicated their

mobility. All survivors reported experiencing exhaustion, fatigue, noise sensitivity and difficulties with concentration and attention. Some struggled with reduced memory, lack of initiative and difficulties with planning, and many struggled to structure their daily lives. Whereas some felt depressed, others reported feeling better after the stroke than before and credited the stroke with reawakening them. Other had developed aphasia, and many described being more sensitive, vulnerable and less able to control crying, which had affected their social lives.

In the initial phases of rehabilitation, many survivors had set the same goal – resuming their ordinary, daily lives – and, accordingly, had focused on recommencing valued professional or leisure activities or, for example, re-validating their driver’s licenses as soon as possible. At that stage, most survivors had not realised, however, how long recovery would actually take. During in-patient care, many remained unaware of the difficulties that they would encounter upon returning home and how those struggles would colour their attitudes towards managing recovery on their own. Survivor 7 says, “The situation is new, so I don’t know what to expect”. By contrast, Survivor 8 reported:

I’ve had to take care of myself since I was 13 years old. My mom had a stroke, and my dad died at sea when I was little. I had to be a grown-up at an early age. I consider myself to have a good mind-set; I’m a solution-oriented person and have a positive attitude towards life. I was prepared for this to happen. I have experience. I know what it takes.

However, earlier experience was also liable to hinder recovery. Survivor 1 had suffered a stroke 18 years prior and reported, “I didn’t get any help then, so I said ‘No thanks’ when they offered me a rehabilitation plan”. However, she later reconsidered and was glad that she did. “I thought, ‘You have to manage all by yourself again’. But it was really worth getting the rehabilitation plan, because I got some useful tools and learned how to do things the right way. The first time, I just stumbled around by myself”.

In the survivors' everyday life practices, their learning trajectories took new directions. Upon returning home, new bodily experiences surfaced, negotiations in close relationships occurred, and the survivors gradually discovered how stroke disrupts daily living. New needs emerged, focuses changed, and most survivors had to adjust their goals. Survivor 4 reported her incapability to concentrate on her everyday activities and how it influenced all aspects of her life. At the 3-month interview, she described her life as being chaotic and out of control: "I'm really looking forward getting my own routine. . . . I just want my normal life back. . . . What satisfies me now is that we're going to work as a family again".

During the first year of the learning trajectory, most survivors had to reorient their lives; expectations were adjusted, goals were modified, and the focus, values and activities of life were changed. The survivors' stories of recovery illustrate the emotional, relational and identity-focused work that survivors undertook, as well as their incorporation of strategies and actions towards achieving progress and wellbeing. Many survivors also reported learning to re-balance work and rest and to employ new strategies to manage their lives.

Nevertheless, stories of learning and change differ considerably between the Norwegian and Danish survivors, most noticeably among ones who experienced cognitive challenges post-stroke. The recovery narratives of Danish survivors with cognitive impairments position the survivors as being more active, proactive and empowered than the stories of Norwegian ones. In Denmark, Survivor 4 received professional support to structure her everyday life:

I've learned not to do too many tasks at once. I make plans in advance. Instead of going shopping, which was a huge stress factor for me, I shop online. I get the groceries delivered, and that works really well for me. I've also become better at recruiting my kids to help out instead of doing all of the tasks myself.

In Norway, Survivor 9, however, described the lack of professional support for managing her everyday life at the 9-month interview:

When I wash myself, cook or clean, all of my energy just gets sucked right out of me, because I have to think so much. . . . ‘How do I do this or that?’ I get so confused. My head gets confused. . . . I’ve always been a handy woman, so it’s so weird to not be able to do those ordinary things anymore. I’m not getting better. . . . Everything has stopped . . . my head, my tongue and my voice. . . . I get so angry. I need help!

Processes of learning and change seemed to be more closely co-constructed with professional support among the Danish participants than the Norwegian ones. The Danish professionals seemed to be more engaged in processes of adaptation and adjustments to minimise the effect of the survivors’ functional limitations. The co-construction of empowerment both initiated and followed-up by Danish professionals made different tools and strategies available to survivors and their families, which enabled them to make progress, learn and experience positive changes. Some of those changes involved resuming previous activity in a modified form, reckoning with new limitations, maintaining positive self-perceptions and developing new self-defining roles and activities. Differences in the recovery narratives from different countries could have stemmed from forms of support offered by municipal healthcare services.

2. Efforts of municipal health services to facilitate self-management

All of the Danish survivors reported experiencing excellent professional support during the first year post-stroke. Survivor 5 stated, “The rehabilitation plan has been good. The system works”; and Survivor 4 even said, “I’ve never before experienced such professional, competent people or been taken so seriously”. As most of Danish survivors, Survivor 4 had readily obtained services attuned to her changing needs: “They [the healthcare professionals] have been fantastic. . . . They were always present, good to talk to, and managed to reassure me and tell me what I needed to do to move on”.

Of course, survivors in both countries also reported unsatisfactory aspects of the healthcare services that they received, including disrupted continuity of services, professionals with whom they did not get along and interventions unsuited to their perceived

needs. However, among the Norwegian survivors, those negative experiences did not seem to be limited to single events and episodes with particular healthcare professionals but to be system-wide failures. Structural differences seemed to characterise rehabilitation services in the two countries, particularly concerning their ability to facilitate learning and change among survivors.

2.1. Supporting complex, evolving needs

In the focus group interviews with professionals, some rehabilitation trajectories characterised as simple and self-administrated guided survivors with defined sensorimotor difficulties or ones who understood their situations, set realistic goals and knew what was required of them. As a case in point, Survivor 1 said, “You have to make something out of it [rehabilitation] yourself. Six hours in the rehabilitation centre is not enough!” Her occupational therapist added,

She [the survivor] has been involved in the process from the start. She’s the one who’s set the goals and told me what she wants to work on. I just help her systematise her recovery. . . . She knows what she needs and where the responsibility for progress lies. She got training ideas from us and put them into action by herself at home.

All survivors were offered physical therapy upon returning home, and municipal services in both countries were most similar in terms of the follow-up of physical impairments. Therapy sessions were primarily one-on-one follow-up sessions in professional settings or supervised self-training in the gym, if not both. Sessions focused on strengthening, endurance, balance and walking. For survivors whose physical ability was not the main challenge, physiotherapy was nevertheless provided in order to modify lifestyles, lose weight or support cognitive recovery. Many survivors reported being satisfied with the therapy offered, although some ended physiotherapy for various reasons, including not getting along with the therapist, disagreeing about the focus of therapy provided too much effort in travelling to and from training sessions or needing support more closely related to managing

everyday life e.g.. The physiotherapist of Survivor 9 reported that the survivor needed support with managing her daily routine, which she could not provide at the clinic.

Services in response to stroke survivors' complex and changed needs showed the greatest differences between the two countries. Overall, three elements shown to be crucial for the ability of health services to facilitate self-management for stroke survivors during the first year: comprehensive integrated rehabilitation plans, access to qualified multi-disciplinary teams of professionals and professionals' attitude towards rehabilitation as a process of learning and change. The healthcare professionals in Denmark seemed to provide those three elements, as a healthcare professional serving Survivor 3 remarked in the focus group interview:

What's been most rewarding for this group is the dialogue with others and the reflection that occurs when there are others who say something and experience something [in response]. You become more reflective of yourself and your process by listening to others.

2.2. Comprehensive integrated rehabilitation plans

All Danish survivors has rehabilitation plans and are followed-up by a municipal interdisciplinary rehabilitation team of professionals. As a municipal physiotherapist in Denmark explained,

When we [municipal health services] get a rehabilitation plan [from specialist health services], physiotherapists and occupational therapists are automatically contacted. The coordinator is on task before we get the plan, and if the patient is under 65 years old, a job coordinator is contacted. In more complex trajectories, a teacher, housing assistant and specialist counsellor is part of the team and sometimes also a smoking cessation instructor.

By contrast, no survivor in Norway had an individual plan. As the physiotherapist of Survivor 10 attested,

He [Survivor 10] should have had an individual plan, placed all of us [the healthcare professionals] around the table, collaborated and put things in order. In his case, an occupational therapist and general practitioner should have been involved, as well as a physiotherapist, a speech therapist, his employer and NAV [Norwegian Labour and Welfare Administration] services.

Both survivors and professionals in Norway reported a lack of rehabilitation plans as well as challenges with cooperating and coordinating services both horizontally and vertically. For example, an error in the referral process delayed Survivor 10's support from a speech therapist until 6 months after his discharge. For Survivor 8, who has received intensive care from both a specialist health service and the municipal reablement team, another consequence of the lack of planning and coordination was over-exertion: "I could have had a rest period between the arrangements. I had arm pain. I think it [services provided] was too much for me." The municipal coordinator of Survivor 9 added,

There are many interventions we [municipal services] can offer, but we must follow her [the survivor's] process. We may need to offer reablement and an individual plan. Perhaps we will need to meet more often, make a plan and find a way of cooperating.

Support after discharge for participants in Norway was governed by coincidences, the availability of professionals and their priorities and competencies. Conversely, support for survivors in Denmark is secured via pre-defined rehabilitation plans implemented at the municipal level, which encourages professionals to reflect on their practices, choices and priorities. In Denmark, professional incentives are consistently substantiated as well. Professionals in Denmark also demonstrated a different understanding of rehabilitation services as a whole and had clearer knowledge of survivors' and their families' changing needs. In Denmark, however, intensive and comprehensive follow-up often also caused feelings of abandonment and uncertainty for survivors when follow-up plans ended and the professionals withdrew their support.

2.3. Access to qualified multidisciplinary teams

The Danish municipalities in the study offer inter-disciplinary neuro-rehabilitation. The coordinator of one such team explained that the team had "11 people in total: one nurse, one visitor, two social advisers, a job consultant, a neuropsychologist, three occupational therapists, a physiotherapist, a speech therapist and a housing assistant who is an educator".

Another coordinator in Denmark added that: “We consider ourselves highly specialised. We have a lot of skills”. The teams share a common understanding of the problems faced, apply the same concepts and use the same vocabulary. By contrast, regarding access to qualified personnel, the four small municipalities in northern Norway had no rehabilitation teams, and available personnel lacked specialised expertise in neurology and rehabilitation.

However, good access to interdisciplinary personnel in the municipalities in Denmark caused challenges different from those apparent in northern Norway. In the case of Survivor 4, according to her housing assistant, “Maybe there were slightly too many professionals offering help. . . . We noticed that she couldn’t handle it”. A physiotherapist in Denmark added, “In some processes, I experience that we spend more time on coordination than on the stroke survivor. In some cases, there may be overlaps in the services and a risk of overload”.

The greatest difference in municipal services between Norway and Denmark was related to support for survivors’ psychosocial needs and for living day-to-day with cognitive challenges. Survivor 4 attested, “I’ve been really happy to be able to work with my cognitive challenges. . . . That’s probably the program that has helped me most.” Denmark affords ready access to occupational therapists for stroke survivors, and in recent years, they have worked systematically to develop competence in cognitive issues, though the most complex cases still need closer cooperation with neuro-psychologists.

Apart from speech therapists who follow up on language issues, no occupational therapists or others follow up on survivors’ cognitive or psychosocial needs after returning home in northern Norway. The coordinator of Survivor 9 reported, “The plan had an occupational therapist from the start, but here in the municipality, we have given up. Everything goes to assistive technology. . . . They do not have that competence”. In small municipalities, it appears that occupational therapists are not traditionally part of the follow-up team for survivors when they return home.

2.4. Understanding of learning trajectories

Professionals' in the two countries frames the process of rehabilitation differently. The coordinator of the municipality [Survivor 9] said,

If she [Survivor 9] had wanted an individual plan and a team of responsibilities, we would have had meetings more often. She did not want help from the reablement team. . . . It's a shame that we can't manage to give the appropriate support unless she takes the initiative.

Other survivors in Norway opted out of services that could have prevented unfortunate consequences in the long term. Survivor 7 clarified that he wanted only physical rehabilitation and no interference in the way that he solved practical daily tasks. He reported being creative and able to identify practical solutions and execute tasks without using his paretic hand. However, the professionals working with him lament that he will thus establish new daily routines that will diminish his ability to improve his hand function. Despite the various potential consequences of not receiving more extensive support with rehabilitation, he has opted to receive training sessions totalling only a few hours per week, which have little meaning if the principles of rehabilitation remain unincorporated as patterns in his daily life. However, those consequences have not been communicated clearly to him by the professionals administering his care. As a result, Survivor 7 continues to practise inappropriate movement patterns because professionals have not involved him in a community of practice that would teach him the consequences of not using his paretic hand.

Survivors in Norway do not seem to have access to communities of practice that would facilitate learning trajectories. The professionals who help them are rarely involved in administering tasks that would increase insight and understanding and help the survivors to make more informed decisions about their rehabilitation. Consequently, survivors are solely responsible for their rehabilitation processes, and when professionals find their choices to be misguided, they nevertheless remain passive or withdraw. The survivors' decisions are thus not made in light of professional judgement.

A major reason why the recovery narratives of survivors in Denmark differed from the ones from Norway relates to the professionals' understanding of rehabilitation as a process of learning and their role in facilitating change. Different therapeutic services offered generate learning and change and can be important sources for learning and gaining insight. In Denmark, although the occupational therapist of Survivor 1 reported disagreeing with the survivor about the priorities of therapy, she added:

They don't always see the point [of services] at the time, or either I come in at the wrong time or I'm just an occupational therapist sitting on the other side of the table and saying something. . . . When they're in a group and they're sitting and hearing things from others in the same situation, they may reconsider.

Municipal health services in Denmark, given their pedagogical and process-oriented understanding, play a central role in stroke survivors' processes of learning and change through dialogue, exploration and trial and error. Several survivors described being part of breakthrough processes involving the re-negotiation of the self. The housing assistant of Survivor 4 reported:

I've spent a lot of time on her. Above all, it's about meeting her as a human being and hearing about her background. It may well be that there is a brain injury, but it's also her personality. To establish strategies are immensely important, and they have to match the individual.

Healthcare professionals in Denmark reported that learning trajectories take time and that it is crucial to support stroke survivors and families in identifying obstacles, defining needs and empowering them to discover suitable strategies for daily living. Survivor 4 illustrated how professional support allowed her to establish new, fruitful routines:

I avoid situations that I can't handle anymore. I always have my husband with me when I go shopping. That way, I have one side free. He takes one of the kids and guides us around the store. . . . if suddenly I look down to the ground and find it difficult to orient myself and I'm disoriented, then he can say, 'It's time'

Survivor 3 described his experience with professional rehabilitation services as follows:

I haven't felt the pressure to do things at a certain pace. There has been dialogue with me . . . 'What would you like?', 'How do you feel?', 'How are you doing?' . . . So I take part in making decisions about when I want to start and in what way. I've been taken seriously.

A coordinator in Norway added, “We’re quick to offer services, but we’re not so good at following her [a survivor’s] process, mapping her needs and defining goals”.

Professionals’ ability to facilitate changes, mobilise resources and actively engage stroke survivors, their family members and others in their daily lives differs in Denmark and Norway. In that sense, professionals in Norway and Denmark do not have a common understanding of the learning trajectories of survivors and their families or their own role as agents of change. Those underlying differences influence how services are organised, who is involved and how municipal services are designed and delivered.

Discussion

Overall, stroke survivors’ narratives of learning and change during the first year post-stroke differed between the samples in Norway and Denmark. Most evident were differences among survivors with cognitive and psychosocial challenges. The Danish participants seemed to position themselves in a more active, proactive and empowered way, and survivors’ learning trajectories seem to be more closely co-constructed with professional support. The Professionals in Denmark were more focused on co-constructing meaning and identity, and they made different tools available for stroke survivors and family members that enabled them to better self-manage their lives.

Dissimilarities discovered between the Danish and Norwegian narratives of learning and change, especially among survivors with cognitive impairments, can be understood according to Arthur Frank’s (29) concept of illness narratives. Among them, the *chaos narrative* signifying hopelessness dominated the narratives of survivors in Norway during the first year post-stroke, while the *restoration narrative* focused on recovery and the *quest narrative* that involves making opportunities for growth visible were more prevalent among the narratives of survivors in Denmark. Arthur Frank (29) assumes that individuals become

more aware of themselves when they are active and presumably even more so when such activity reveals problems – for example, with orienting oneself in new surroundings, as participants in the study showed. Arthur Frank proposes identifying five dimensions of such activity and relating them to action taken in response: control, driving force, inclination, relationships with others and self-reliance. Each individual must adapt his or her strategies and actions to those dimensions. In that sense, municipal services in Denmark seem to encourage joint pedagogical methods that support those particular processes.

Bergström et al. (30) describe how enabling agency in stroke survivors is a complex process involving the survivor's realisation of the situation and how thoughts, plans, decisions and actions cooperate to make certain activities possible. The results of the study reported here show that enabling agency in that way in the first year post-stroke seems to have emerged differently between survivors in Norway and Denmark, possibly because municipal health service professionals support the process of learning and change. By interacting closely with professionals, survivors in Denmark seem to have been more empowered to make changes and seek out solutions to overcome their practical and emotional difficulties. Other researchers have shown that seeking external support, restoring normality and positive reflection are important elements to moving on after a stroke and adjusting to a new daily routine (31). Findings of the study reported here show how professionals play a crucial role in those processes.

The findings also reveal that, in Norway, a dominant tendency is that healthcare systems, professionals and some patients and their families tend to overlook possibilities for activity and participation by instead focusing solely on preventing relapse. Despite the complex issues living with challenges after stroke, rehabilitation services tend to focus solely on physical aspects of recovery (6, 9, 23, 32). Findings suggest that professionals in Norway are more grounded in a biomedical frame of reference, whereas their counterparts in Denmark

supplement that approach with a pedagogical and holistic methodology. Following the biomedical framework can have consequences at the political, organisational and professional levels, as well as for survivors. Above all, the model has a pervasive cultural influence that promotes a particular set of behaviours and attitudes, in which stroke survivors are perceived as passive recipients of treatment, and they and their families thus expect that therapy is critical to making them better. However, many remain unwilling to exert enough personal effort to achieve mastery or remain unaware of strategies for handling their complex situations. They limit their obligations to attending therapy sessions, for example (33). As shown, some survivors in Norway do not consider everyday life activities to constitute treatment and do not comply with advice to perform such activities. By contrast, survivors in Denmark advanced from a passive to an active position by interacting closely with healthcare professionals. Although some cases offered little evidence of partnership during rehabilitation (23), services in the Danish communities generally followed a partnership-oriented practice. Some researchers have added that stroke survivors should play an active role in their recovery and that their goals and needs have to guide the services provided (34). Goalsetting improves recovery processes as well as survivors' perceptions of their self-care abilities and engagement in rehabilitation (35). Among Danish participants, reciprocal relationships involving dialogue and shared decision making between survivors and professionals was prominent. Group-based programs available only in Denmark were described to benefit professionals, survivors and their family members. Studies have shown that group-based self-management programs can improve wellbeing, mitigate health distress and feelings of loneliness, encourage cognitive management and thus prevent feelings that needs remain unmet (36).

Steihaug et al. (19) have shown that stroke survivors are seldom rehabilitated in their homes and that professionals identified lack of time as the top reason for not providing

individual, home-based rehabilitation. Although most therapy sessions offered in the community services in Norway and Denmark observed in the study reported here were administered in professional settings, rehabilitation initiatives embedded in survivors' real-life contexts were more prevalent in Denmark. Interestingly, both survivors and professionals highly valued interventions conducted in the home or workplace. Reed et al. (7) has reported that community services can be effective if delivered in the context of the survivors' social world, and other researchers have found that supporting patients' performance of activities in real-life contexts facilitates their ability to be self-managers (37).

Coordinated rehabilitation plans help stroke survivors, their families and professionals working with them to strive towards meeting common goals and help them to exchange experiences and allocate tasks and responsibilities (3). Both Norway and Denmark demonstrated different strategies for strengthening professional interaction and coordination, service user involvement and integrated coordinated pathways. In Norway, individual plans aim to ensure that survivors with complex, long-term needs receive proper, targeted and coordinated follow-up care (38). Although individual plans have been practised for nearly 20 years, they have had little impact on rehabilitation practices, as the study reported here has shown. After discharge in Norway, municipalities become responsible for delivering additional rehabilitative services, whereas in Denmark, specialist services need not devise a rehabilitation plan for each survivor (39). That difference is pivotal to the organisation and coordination of professional support offered after stroke survivors return home.

A major element of delivering quality, effective post-stroke rehabilitation services is the close collaboration of various healthcare professionals that mobilises their collective knowledge and special skills (40). Other researchers have shown that services in other European countries have not been tailored to meet stroke survivors' needs in the community (18). A national survey in Ireland has highlighted major gaps in the provision of inter-

disciplinary community-based services for people with stroke and shown that where services existed, they were general in nature, rarely inter-disciplinary in function and deficient in input from salient disciplines. Challenges to optimal care included the lack of strategic planning, funding for healthcare staff, team resources and teamwork itself (18). Community-based services in rural areas of northern Norway show the same tendency, with a relatively large number of physiotherapists available for stroke-related services and far fewer speech and language therapists and occupational therapists, while psychologists are rare. Nevertheless, faced with such poor coordination and the fragmentation of services, stroke survivors and family members have developed innovative ways of managing their lives (41), and the findings of the study reported here suggest a tendency of the activation of informal modes of support in Norway.

The findings can be understood in a sociocultural learning perspective. We have shown that the interactive character of learning and change shapes in mutual co-constructed embodied processes among the participants involved. The concept *communities of practice* from Lave and Wenger (42) can be helpful describing differences in learning trajectories between the two countries. Aspects of being engaged in *communities of practice* are *mutual engagement* and shared *repertoire* (42), both of which clarify learning trajectories noted in the municipal services in Denmark. Mutual engagement concerns active involvement in joint activities in which survivors share different skills, competencies, understandings and experiences. As the study reported here has shown, learning trajectories develop when professionals make arrangements for mutual engagement to occur, which can involve offering group interventions in which different opinions, competences, experiences and reflections help survivors to move on, or when professionals align their advice with the complex processes of the survivor and his or her family. Both survivors and professionals contribute to the diversity of solutions via their common involvement, which is critical for change to occur.

Involvement in mutual practices forges a common repertoire of routines, behaviours, narratives, concepts and symbols. Among survivors in Denmark, concepts, understandings and solutions were discovered or developed and, over time, formed a shared repertoire among survivors, their family members and the professionals. Stroke survivors are legitimate peripheral participants and should be included by professionals as part of communities of practice in which learning occurs. The lack of access to such communities of professionals and systems in the Norwegian municipalities can be detrimental. Service development in municipalities in Norway should focus on enabling learning trajectories via stroke survivors' participation in communities of practice, especially for survivors unable to take initiative to seek those kinds of involvement themselves.

New concepts are needed in Norway's municipality healthcare delivery for stroke survivors and their families that focus on changing needs in the long term and facilitate processes of enablement in the context of everyday life instead of simply copying acute care models meant for short-term impairments. Models addressing outcomes via participation in a community can be better indicators of change over time than models of pathophysiology or impairment (23). Care models for managing stroke in Norway have not yet anticipated that shift in understanding, and many services remain entrenched in acute medical ideologies (40). Basic elements of new models needing development are rehabilitation plans, access to qualified multidisciplinary teams with a shared understanding of the process of rehabilitation and tools for supporting self-management.

Methodical considerations

The focus group interviews consisted of 2-4 participants, which are few compared to recommended sample size (6-8 participants) (27). The sample size depended on involved professionals in municipality, whether they agreed to participation and the opportunity to joining the interview. In case 4 (DK) we only succeed getting an individual interview and for

case 11 (NO) we were not able to include the professionals involved. The individual interview differs from the others, but we chose to include the interview because it provided very rich data on learning and change supporting processes. Throughout, the focus group interviews generated rich discussions both about each case, but also more general discussions on about practice, collaboration and organization of stroke rehabilitation in the municipality.

The two countries were chosen because they are part of the Scandinavian welfare model and the free public services are regulated by similar national guidelines and knowledge base. The specific geographic areas were chosen to explore how cultural, structural and geographical differences influences stroke rehabilitation trajectories'. As expected, we found that access to qualified interdisciplinary organized rehabilitation specialist in rural areas in Northern Norway are challenging compared to the central areas in Denmark. More interesting is, however, how cultural differences and access to health service were expressed by the participants through expectations of the health service and the families as well as local communities' mobilization in the absence of services in the small municipalities. The cultural differences are obvious. In Northern Norway people have been used to manage by themselves, often with little support from authorities. This may explain why some still reject health care professionals' involvement. Another explanation may be that lack of involvement of dialogue and discussions about treatment strategies and consequences between stroke survivors and professionals in Norway may as well be reflected in refusal of treatment.

One surprising finding is the great variation in the management, organization and coordination of the rehabilitation service between the two countries, which extends beyond rural and urban issues. It is challenging to compare countries, as well as different areas in these countries. The results and comparison of health services must be interpreted with carefulness.

Conclusion:

Altogether, the ability of municipal health services to facilitate learning and change for stroke survivors during the first year generally depended upon developing comprehensive integrated rehabilitation plans and ensuring access to coordinated, qualified multidisciplinary teams with professional knowledge and skills to support the survivors and their families during processes of adjustment, learning and change. Findings reveal considerable differences in municipal stroke rehabilitation services in northern Norway and central Denmark and their ability to support stroke survivors in performing self-management. Most evident were differences among survivors with cognitive and psychosocial challenges. The Danish participants seemed to position themselves in a more active, proactive and empowered way, and survivors' learning trajectories seem to be more closely co-constructed with professional support. The Professionals in Denmark were more focused on co-constructing meaning and identity, and they made different tools available for stroke survivors and family members that enabled them to better self-manage their lives.

Acknowledgements

The authors wish to thank the survivors, their relatives and the healthcare professionals who made this study possible. The Danish part of the study was supported by the Danish Physiotherapists' Research Fund.

Declaration of Interest

The authors declare that they have no conflicts of interest and were jointly responsible for the writing and content of this paper.

References

1. De Wit L, Theuns P, Dejaeger E, Devos S, Gantenbein AR, Kerckhofs E. Long-term impact of stroke on patients' health-related quality of life. *Disabil Rehabil.* 2017;39(14):1435-40. doi: 10.1080/09638288.2016.1200676.
2. Haley WE, Roth DL, Hovater M, Clay OJ. Long-term impact of stroke on family caregiver well-being: a population-based case-control study. *Neurology.* 2015;84(13):1323-9. doi: 10.1212/WNL.0000000000001418.

3. Wade D. Rehabilitation-a new approach. Part four: a new paradigm, and its implications. *Clin Rehabil.* 2016;30(2):109-18. doi: 10.1177/0269215515601177.
4. Jones F, Mandy A, Partridge C. Reasons for recovery after stroke: a perspective based on personal experience. *Disabil Rehabil.* 2008;30(7):507-16. doi: 10.1080/09638280701355561.
5. Aadal L, Kirkeveld M. Integrating situated learning theory and neuropsychological research to facilitate patient participation and learning in traumatic brain injury rehabilitation patients. *Brain Inj.* 2011;25(7-8):717-28. doi: 10.3109/02699052.2011.580314.
6. Arntzen C, Borg T, Hamran T. Long-term recovery trajectory after stroke: an ongoing negotiation between body, participation and self. *Disabil Rehabil.* 2015;37(18):1626-34. doi: 10.3109/09638288.2014.972590.
7. Reed MC, Wood V, Harrington R, Paterson J. Developing stroke rehabilitation and community services: a meta-synthesis of qualitative literature. *Disabil Rehabil.* 2012;34(7):553-63. doi: 10.3109/09638288.2011.613511.
8. Teasell R, Mehta S, Pereira S, McIntyre A, Janzen S, Allen L, et al. Time to rethink long-term rehabilitation management of stroke patients. *Top stroke Rehabil.* 2012;19(6):457-62.
9. Arntzen C, Hamran T, Borg T. Body, participation and self transformations during and after in-patient stroke rehabilitation. *Scand J Disabil Res.* 2015;17(4):300-20.
10. Daniel DAK, Wolfe AC, Busch AM, McKeivitt AC. What Are the Social Consequences of Stroke for Working-Aged Adults? A Systematic Review. *Stroke.* 2009;40(6):431-40. doi: 10.1161/STROKEAHA.108.534487.
11. Woodman P, Riazi A, Pereira C, Jones F. Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors. *Disabil Rehabil.* 2014;36(24):2031-43. doi: 10.3109/09638288.2014.887796.
12. Pallesen H. Body, coping and self-identity. A qualitative 5-year follow-up study of stroke. *Disabil Rehabil.* 2014;36(3):232-41. doi: 10.3109/09638288.2013.788217.
13. Wood JP, Connelly DM, Maly MR. 'Getting back to real living': a qualitative study of the process of community reintegration after stroke. *Clin Rehabil.* 2010;24(11):1045-56. doi: 10.1177/0269215510375901.
14. Arntzen C, Hamran T. Stroke survivors' and relatives' negotiation of relational and activity changes: a qualitative study. *Scand J Occup Ther.* 2016;23(1):39-49. doi: 10.3109/11038128.2015.1080759.
15. Pallesen H, Buhl I, Roenn-Smidt H. Early rehabilitation and participation in focus – a Danish perspective on patients with severe acquired brain injury. *Eur J Phys.* 2016;18(4):233-6. doi: 10.1080/21679169.2016.1189594.
16. Danish Health Authority (Sundhedsstyrelsen). Brain injury rehabilitation - a health technology assesment. (Hjerneskaderehabilitering - en medicinsk teknologivurdering). 2011;13(1).
17. Norwegian Ministry of Health and Care Services. Samhandlingsreformen. Rett behandling på rett sted - til rett tid. (Proper treatment - at the right place and right time). 2009.
18. Hickey A, Horgan F, O'Neill D, McGee H. Community-based post-stroke service provision and challenges: a national survey of managers and inter-disciplinary healthcare staff in Ireland. *BMC Health Serv Res.* 2012;12(1) doi: 10.1186/1472-6963-12-111.
19. Steihaug S, Lippestad J-W, Werner A. Between ideals and reality in home-based rehabilitation. *Scand J Prim Health Care.* 2016;34(1):46-54. doi: 10.3109/02813432.2015.1132888.
20. Minkman MMN, Schouten LMT, Huijsman R, van Splunteren PT. Integrated care for patients with a stroke in the Netherlands: results and experiences from a national Breakthrough Collaborative Improvement project. *Int J of Integ Care.* 2005;5:e14.
21. Wade D. Community rehabilitation or rehabilitation in the community? *Disabil Rehabil.* 2003;25(15):875-81. doi: 10.1080/0963828031000122267.
22. Norwegian Directorate for Health. (Helsedirektoratet). Treatment and rehabilitation after stroke. Recommendations. National guidelines. 15-1688 (Behandling og rehabilitering ved hjerneslag. Anbefalinger. Nasjonale retningslinjer. 15-1688). 2010.

23. Cott CA, Wiles R, Devitt R. Continuity, transition and participation: Preparing clients for life in the community post-stroke. *Disabil Rehabil.* 2007;29(20-21):1566-74. doi: 10.1080/09638280701618588.
24. Sivesind KH, Trætteberg HS, Saglie J. The future of the Scandinavian Welfare model: User choice, parallel governance systems, and active citizenship. In: Sivesind KH, Saglie J, Sivesind KH, eds. *Promoting Active Citizenship. Markets and Choice in Scandinavian Welfare.* Oslo: Palgrave Macmillan, Cham: 2017:285-310.
25. Ministry of Health and Care Services. (Helse- og omsorgsdepartementet). *Obligation for habilitation and rehabilitation, individual plan and coordinator. (Forskrift for habilitering og rehabilitering, individuell plan og koordinator).* 2011:§ 14.
26. Lave J, Wenger E. *Situated learning: Legitimate peripheral participation.* Cambridge: Cambridge University Press; 1991.
27. Malterud K. *Fokusgrupper som forskningsmetode for medisin og helsefag.* Oslo: Universitetsforl.; 2012.
28. Malterud K. Systematic text condensation: A strategy for qualitative analysis. *Scand J Pub Health.* 2012;40(8):795-805. doi: 10.1177/1403494812465030.
29. Frank AW. *At the will of the body: reflections on illness.* Boston: Houghton Mifflin; 1991.
30. Bergström AL, Eriksson G, Asaba E, Erikson A, Tham K. Complex negotiations: The lived experience of enacting agency after a stroke. *Scand J Occ Ther.* 2015;22(1):43-53. doi: 10.3109/11038128.2014.954611.
31. Kuluski K, Dow C, Locock L, Lyons RF, Lasserson D. Life interrupted and life regained? Coping with stroke at a young age. *Int J Qual Stud Health Well-being.* 2014; 9: 10.3402/qhw.v9.22252. Published online 2014 Jan 23. doi: 10.3402/qhw.v9.222522014;9.
32. Röding J, Lindström B, Malm J, Öhman A. Frustrated and invisible: younger stroke patients' experiences of the rehabilitation process. *Disabil Rehabil.* 2003;25(15):867-74. doi: 10.1080/0963828031000122276.
33. Wade D. Rehabilitation – a new approach. Overview and Part One: the problems. *Clin Rehabil.* 2015;29(11) 1041–1050. doi: 10.1177/0269215515601174.
34. Salter K, Hellings C, Foley N, Teasell R. The experience of living with stroke: A qualitative meta-synthesis. *J Rehabil Med.* 2008;40(8):595-602.
35. Sugavanam T, Mead G, Bulley C, Donaghy M, Van Wijck F. The effects and experiences of goal setting in stroke rehabilitation: a systematic review. *Disabil Rehabil.* 2013;35(3):177-90. doi: 10.3109/09638288.2012.690501.
36. Lennon S, McKenna S, Jones F. Self-management programmes for people post stroke: a systematic review. *Clinical Rehabilitation.* 2013;27(10):867-78. doi: 10.1177/0269215513481045.37.
37. Satink T, Josephsson S, Zajec J, Cup E. Self-management develops through doing of everyday activities-a longitudinal qualitative study of stroke survivors during two years post-stroke. *BMC Neurology.* 2016;16. doi: 10.1186/s12883-016-0739-4.38.
38. Norwegian Ministry of Health and Care Services. LOV1999-07-02 no. 63: Lov om pasient – og brukerrettigheter [Patient and User Rights Act]. Entry into force 2001, most recently amended LOV 2011-06-24-30 [in Norwegian].
39. Danish Health Authority (Sundhedsstyrelsen). *Course program for rehabilitation of adults with acquired brain injury. (Forløbsprogram for rehabilitering af voksne med erhvervet hjerneskade).* 2011.
40. Clarke D, Forster A. Improving post-stroke recovery: the role of the multidisciplinary health care team. *J Multidis Healthcare.* 2015;8:433-42.
41. Hart E. System induced setbacks in stroke recovery. *Soc Health Illness.* 2001;23(1):101-23. doi: 10.1111/1467-9566.00243.
42. Wenger E, Nake B. *Praksisfællesskaber: Læring, mening og identitet.* København: Reitzel; 2004.

