

Body, participation and self transformations during and after in-patient stroke rehabilitation

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This study explores stroke survivors' experience of being part of an institutional rehabilitation context and what it means for the immediate experience of discharge home. The aim is to develop a deeper understanding of how the dynamic phenomenon body, participation in everyday life and sense of self interrelates and changes through stroke survivors' movement in and between the two contexts and what this phenomenon means for stroke survivors' process of change and well-being in the early rehabilitation trajectory. Repeated, retrospective, in-depth interviews were conducted with nine persons living with moderate impairment after stroke and their closest relatives. Phenomenological and critical psychological concepts are used for analysing the data. Stroke survivors' experience indicates that their time as in-patients is important for their safety in the early juncture. Being part of an institutional rehabilitation context mobilizes stroke survivors' to optimize focus, energy and hope of physical recovery. At the same time it appears to postpone feelings of uncertainty and grief as well as reflection on their situation. However, immediately after homecoming a critical passage in the stroke survivors' rehabilitation trajectory appears because the perception of body, participation in everyday life and the sense of self undergo profound changes. This study stresses the importance of broadening the scope of professional initiative and paying attention to the post-rehabilitation context of everyday life during the in-patient stay.

Keywords: stroke; embodiment; discharge from rehabilitation unit; participation in everyday life; sense of self

Introduction

Stroke is one of the leading causes of disability and the third cause of death in the Western world (Truelsen et al. 2003). In the next 25 years, it is assumed that the prevalence of stroke will double (Ellekjær and Selmer 2007). Survivors' with a moderate or severe stroke often transfer to an in-patient rehabilitation unit where they are treated by a multidisciplinary team. Approximately 80% of stroke survivors return home after an in-patient stay (Pringle, Hendry, and McLafferty 2008), and 50% of stroke survivors experience different degrees of long-term disabilities (Wiles et al. 2004).

Few studies have investigated the patients' experience of rehabilitation in an in-patient unit (Olofssons, Andersson, and Carlberg 2005; Pound et al. 1995; Røding et al. 2003). One study, which explored people's experience of hospital admission a short time

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after acute stroke, found that participants placed great trust in professionals. The health professionals' routines, expertise and set of responses to their crises gave them confidence and helped them make sense of the overwhelming event. Both patients and spouses were glad to hand over responsibility to a trusted professional team in this difficult situation (Pound, Bury, Gompertz, and Ebrahim 1995). Another study found that during the hospital stay, patients take a passive role and put themselves in the hands of the staff (Olofssons, Andersson, and Carlberg 2005). In contrast, other researchers found that younger stroke patients felt they had to take on too much responsibility and that the surroundings and activities they were offered did not match their needs and desires (Röding, Lindström, Malm, and Öhman 2003). In-patient rehabilitation settings focus primarily on improving short-term functional abilities and basic activities required for daily living, and pay less attention to enabling the patient to regain valued roles and to return to meaningful activities in daily life. In addition, little attention is paid to the personal and social implications inherent to the disrupted body after stroke (Cott, Wiles, and Devitt 2007).

A systematic review finds that most studies focus on the long-term needs following stroke while fewer studies investigate the experiences immediately after discharge from hospital (Pringle, Hendry, and McLafferty 2008). Research demonstrates little continuity and overlap between the in-patient and out-patient services and stroke patients report feelings of isolation and abandonment in the community immediately after discharge (Cott, Wiles, and Devitt 2007). Other researcher describes the transition from hospital to home as a critical period in the stroke survivors' recovery trajectory (Hinojosa et al. 2008; Rittman et al. 2004). In these studies, the early experiences of discharge revolved around the struggle to establish new routines for daily living and coping with increased free time. The process of transition from hospital to home is, in other studies, described as a chaotic and stressful period filled with great uncertainty (Ellis-Hill et al. 2009; Pringle, Hendry, and McLafferty 2008; Proot et al. 2000). The homecoming was, in one study, described as essential for developing insight into and understanding of the illness and its consequences (Olofssons, Andersson, and Carlberg 2005). Others find that patients often hand over the responsibility of their life and decision-making to professionals, while returning home involves reassuming responsibility for their own recovery process (von Koch, Wottrich, and Holmqvist 1998). Others show how daily life proceeds in a different way for both the stroke survivors and their spouses and how new demands emerge during transition from hospital to home (Borg 2002).

One study describes how, during their stay in hospital, stroke survivors experience their body as a separate entity divorced from self, and how this particular experience appeared to be a dominant focus of life during the first year (Ellis-Hill, Payne, and Word 2000). Another study investigated how discharge affected patients. It found that stroke survivors work on their own model of recovery based on their life situation and on their perception of themselves, their bodily experience and understandings conceived through interaction with health care professionals (Ellis-Hill et al. 2009). This particular study is on the same topic. It aims to further develop perspectives providing new knowledge about the shifts, nuances and ongoing changes in the interaction between bodily perception, participation in everyday life and sense of self in stroke survivors as they move between the two different contexts in their early rehabilitation trajectory. This study explores stroke survivors' experience of being part of an institutional rehabilitation context and the immediate effect this experience has on them after discharge and their return home. The aim is to develop a deeper understanding of how the dynamic phenomenon body, participation and self interrelates and changes through stroke

survivors' movement in and between the two contexts and what it means for stroke survivors' process of change and well-being. The research questions explored are: (1) does the institutional rehabilitation context construct specific ways of negotiating the body, participation and self? And if so, (2) what does it mean for the stroke survivors' immediate experience of discharge home?

How body, participation and self are negotiated through stroke survivors' long-term engagement in and between different contexts in everyday life will be further explored in a subsequent paper.

The theoretical framework

The embodied and socially situated agent

To develop an understanding of how persons perceive, live with and through their injured bodies, participate in institutional rehabilitation and everyday life and at the same time try to understand themselves, these theoretical approaches have been chosen: Merleau-Ponty's phenomenological conception of the body (Merleau-Ponty 2002), critical psychology's conception of participation (Dreier 2008) and a conception of the self, according to the two author's epistemological views (Arntzen 2009; Dreier 2008; Merleau-Ponty 2002). In the following section, a brief account of the theoretical approaches will be given.

Our concept of the body is derived from the phenomenological tradition that was first developed by Maurice Merleau-Ponty (2002). A central notion in the investigation of stroke survivors' experiences is that the body appears to the subject as an ambiguous phenomenon. The lived body is never just a material object in the world; it is first and foremost a lived and experienced body; a bodily subject and the very medium whereby our world comes into being (Merleau-Ponty 2002). Drew Leder, who built many of his theories on Merleau-Ponty (2002), states: 'It is via my sensorimotor powers that I encounter a world charged with meaning and organized into significant gestalts' (Leder 1990, 5). For this reason, the body is the basis for self-reflection, for the understanding of others and a precondition for participation in everyday life. The ambiguity that characterizes the lived body consists of simultaneously being this particular bodily subject and having a (physical) body; simultaneously being one's own embodied self and sensing more unfamiliar aspects of the bodily biological processes, simultaneously being an active, capable body ready to attain goals and put plans into action and being a passive body that creates obstacles and problems in everyday life. These bodily ambiguities become especially visible in the case of bodily disruptions caused by illness where, for a while, bodily unfamiliarity and incapability dominate the agents' experience. Leder shows how the body 'disappears' for the agent when functioning unproblematically, and how one's own body demands attention when becoming a hindrance in performing daily activities becoming a force that stands in opposition to the sense of self (Leder 1990). Dwelling in the world rests upon a person's bodily know-hows and functional capabilities. This bodily intentionality, described by Merleau-Ponty (2002), constantly changes and becomes more robust through the person's way of inhabiting the world, incorporating tools, and absorbing new patterns and principles of actions. But, as Merleau-Ponty (2002) points out, it is this which 'goes limp' in illness. In other words, these integrated, dynamic and meaningful structures anchored in the lived, habitual and practically oriented body can be dramatically challenged by a stroke (Arntzen and Elstad 2013).

The chosen framework behind the second key concept – participation – is critical psychology (Dreier 2008). As embodied agents, persons participate with other embodied persons in specific contexts in ongoing everyday life. In this study, the rehabilitation context and the person's home contexts are of special interest. To understand a person's action, thoughts and emotions involves adopting a first-person perspective on the social contexts in which the person is located. The person conducting his everyday life participates in and across the particular contexts. The links and separation between the contexts constitute an infrastructure in the ongoing everyday life of the person (Dreier 2008). Dreier stresses:

We cannot understand individual possibilities and change processes on the basis of purely individual conception of subjectivity and action. When we are theorizing a person as participant, we are propelled to consider personal modes of functioning and meaning of personal participation as particular parts of social practice. (Dreier 2008, 30)

Seeking a deeper understanding of how body, participation and self are being negotiated, it is necessary to go beyond the individual and investigate how specific social arrangements and forms of social practice create scope of possibilities and barriers.

The concept 'sense of self' represents the third and last key dimension in the theoretical approach. The sense of self refers in this study to the self-concept identified from the stroke survivors' description of the early rehabilitation trajectory. In the two mentioned frames of reference, the sense of self is basically an embodied, a social and a materially situated self, which means that the concept is rooted in the agents' bodily and practically situated being (Merleau-Ponty 2002) as well as their socially situated being (Dreier 2008). Materiality, perceptions, relations, emotions and habitual modes of action are interrelated aspects of the construction of sense of self (Charmaz 1995; Charmaz 2002). The multifaceted self is possible because self-construction draws on different resources at different times and in different contexts (Hinojosa et al. 2008). The self is tied to the access people have to material and symbolic resources and the way they participate in and have access to diverse social practices (Dreier 2008).

Materials and methods

This study is part of a broader study where the overall aim is to explore (1) essential elements in stroke survivors' and relatives' long-term learning – and change trajectories, and (2) how stroke survivors and relatives see different health services as important contributors in these processes. These questions will, however, be addressed elsewhere. The experience of being part of a rehabilitation setting and reflections about homecoming – the period of time immediately following discharge – were not the main focus while planning the study. These themes emerged as essential issues when analysing the data and led to further developing and specifying the research question. This data-driven qualitative study has a phenomenological-hermeneutical design. The embodied and socially situated approach outlined above represents the study's methodology and has implications for the role of the researchers, how the research process is framed and the understanding of the knowledge that is being produced in this study.

Participants

Six men and three women with moderate stroke and 13 of their close relatives were recruited from one rehabilitation unit and from two different group-based education programmes adapted for both stroke survivors and relatives living at home (see Table 1).

Table 1. Details about the participants.

Name ^a	Age	Stroke (location in the brain)	Impairments and disabilities reported in medical journal the first weeks after stroke	Time since stroke	Status when included in the study	Relatives/ friends included in the study
Agnes	65	Right side	Hemiplegia and reduced sensibility in the left side. Homonym hemianopia, neglect and mild reduced cognitive functions.	12 years	Married and lives in a villa. Works part time. Children and grandchildren.	Husband
Katy	56	Left side	Right side hemiplegia, Broca aphasia. Diminishing concentration. Reduced memory, attention and psychomotor tempo. Emotional changes	9 years	Cohabitant and lives in a flat. Works part time. Children and grandchildren	Daughter, mother, father and friend
George	39	Left side	Hemiplegia and reduced sensibility in the right side, aphasia, reduced memory, attention, psychomotor tempo, diminishing concentration. Apraxia.	8 years	Cohabitant and lives in a house. Works part- time. Small children.	Cohabitant
Steven	42	Right side	Hemiplegia and reduced sensitivity in the left side, neglect, facial paresis, emotional changes	8 years	Lives alone in an apartment. Works part time.	Brother
Sonja	72	Right side	Hemiplegia and reduced sensitivity and proprioceptive sense in the left side. Neglect. Facial paresis, Emotional changes, Wheelchair user, one hand user.	6 months	Lives together with her husband in a villa. Pensioner. Children and grandchildren.	Husband
Oliver	62	Right side	Left hemiplegia, Neglect, dysphasia, facial paresis, reduced sensitivity and proprioceptive sense in the left side. Mild reduced cognitive functions. Wheelchair user, one hand user. Emotional changes	2 years	Divorced, lives alone in a flat. Help from community service in all daily activities. Grown-up children	Daughter and sister
Kurt	49	Right side	Hemiplegia in the left side. Neglect, moderate reduced cognitive functions, One hand user.	7 years	Lives together with his wife in a villa. Receiver of disability benefit. Children and grandchildren.	Wife
Per	66	Right side	Dysarthria identified. Some right side hemiplegia and facial paresis.	2 years	Lives together with his wife in a flat. Pensioner. Children and grandchildren.	Wife
Antony	58	Left side	Mild hemiplegia observed in the right side, reduced sensibility	9 years	Lives together with his wife in a house. Pensioner. Children and grandchildren.	Wife

^aFictitious names.

Both education programmes were part of a specialist health care service aiming to help stroke survivors and their relatives to live with the consequences of stroke. One course was a collaboration between the municipality and a consumer organization and recruited participants through the newspapers. The other programme was part of a long-term follow-up service for previous patients with mainly 'invisible' cognitive difficulties after stroke and their family members. Recruiting from education programmes made it possible to gain access to people with long experience living with stroke and exposure to different health services. Inclusion criteria were that they had to be adults or elderly people who experienced mild or moderate disability caused by a confirmed diagnosis of stroke. Exclusion criteria were that they have major cognitive and communication impairments hindering them from sharing their experience with others. Inclusion criteria for the relatives were that the stroke survivors considered them (one or more) to be close relatives. A convenience sample was taken, which means that the participants were not selected according to age, sex, marital status, functional ability scores and so forth.

Data collection

Retrospective in-depth interview was considered a suitable method for capturing the experience of different periods of the participants' rehabilitation trajectory. The first open-ended interview was conducted from one to three weeks after the education programme or the in-patient stay. The interviewing was conducted at the hospital, at home or at the first author's workplace. To provide an opportunity to ask further questions based on the first interview and for access to experience of the impact of the health services on dealing with their everyday life, a follow-up interview with all participants was conducted after six months. All the in-depth interviews unfolded as a conversation. Both stroke survivors and close relatives were asked to reflect upon their experiences related to different periods of the rehabilitation trajectory. However, different interview guides were designed for interviewing stroke survivors and their relatives about their respective experiences. Opening questions to the stroke survivor could be: 'can you describe a situation somewhere along your rehabilitation trajectory, where you started thinking about yourself, the stroke and your life situation in a new and different manner?' Questions opening the relative interview might be: 'considering the process you and your family have lived through since the onset of stroke what is the first thing that comes to mind?' The interview guide that captures the theme, 'Life before the stroke, experiences of the long-term rehabilitation trajectory and thoughts about the future', was looked over at the end of each interview. With two exceptions, stroke survivors and their relatives were interviewed separately. The interview lasted from half an hour to one hour. After each interview, spontaneous thoughts about the interview situation were noted. Totally 44 interviews were conducted, and half of them were repeat interviews.

Data analysis

Being the main subject of research stroke survivors' interviews play a more significant role and were analysed more closely than the interviews with relatives. The relative interviews function as supplementary data, providing important insight and helping to contextualize and differentiate the stroke survivors' experiences. The process of structuring and further analysing the stroke survivors' interview data was inspired by Lindseth and Norberg's (2004) phenomenological hermeneutical method which can be described as three methodological steps (see Table 2). The first step is called 'naive

Table 2. The steps in the methodological analysis.

Naive reading and structural analysis		Comprehensive understanding
Meaning units	Code	Theme and subthemes
		<i>The in-patient experience</i>
'I was taken under the wings' (Kurt)	A good place	A good place to be in a
'I was vulnerable in the acute phase and was well taken care of' (George)	Feeling of being shielded	vulnerable situation
'It was very good being there'(George)	Training the physical body	Shield from everything
'... in a hospital (...) you are very much shielded from everything'(George)	Focus on the physical body	Hope of recovering the physical body is all-absorbing
'I become very attached to it (the body)'(Sonja) 'I was so eager to train all the time' (George)	Be like before	Being absorbed into culture of the rehabilitation practice
'It was easy for the physical therapist to know which "buttons he had to press" to get back my gait function...but there was so much more I needed help to sort out' (George)		The Body 'detached' from self and real life participation.
'I wanted to be the way I used to be' (Katy)		
'Back to work, I will just be absent for a week. I just needed a rest.'(Katy)		
		<i>Discharge home experience</i>
'It was a very abrupt transition from being very safe to kind of wondering if this is a life I feel like living...when I was done with the rehabilitation I realized very quickly that something was missing, because there was such a tremendous follow-up for four-five months.' (George)	Feeling of being safe to a feeling that something is missing	Transfer from the safe to the uncertain
'...it was very difficult (laughs) to get the button in the buttonhole! And to wipe one's behind and everything... and to wash your hair and to put on mascara! Things I never considered before!' (Katy)	Trouble doing things they never considered before	Unexpected and problematic bodily responses to everyday activities
'When I saw him suffer...I jumped. He never asked for help. It was like that for a year and a half!' (Kurt's wife)	Doing things for the other	Negotiated and changed participation in everyday life context
'Well I was laying here on the couch... What else should I be doing? I needed help with everything. If I was going to bed I had to be supported over to the bed. It was really tough, yes, bloody hell!'(Kurt)	Who am I now?	The sense of self fragments
'He was always in the forefront, and then suddenly he was...nothing. That was the worst part.'(Kurt's wife)		

reading' in order to grasp the overall meaning of the texts. Regarding the first step, all the recorded interviews were listened to twice before they were transcribed verbatim. Periods of silence, laughing, crying, etc. were noted. The next step, the 'structural analyses', first identified meaning units – groups of statements relating to the same meaning – in the transcribed text from each participant, and then labelled them with a code that summarized what the meaning unit was about, in terms close to those transcribed. While ordering the coded interview data one significant theme appeared which helped specify the research question. Then a second and more focused analysis was developed, tracing experience during in-patient stay and the early experience of transition home, in and between all participants. All the coded units relevant for the research question were considered against the background of the naive understanding and then grouped across the participants and abstracted into themes and sub themes. A 'comprehensive understanding' is the third and last step in the process of analysis described by Lindseth and Norberg (2004). In this study, themes and sub themes were further developed when a theoretical abstraction took place tracing the tensions between bodily perception, participation in everyday life and sense of self as expressed by the stroke survivors in all the coded units and in and across the interview texts as a whole. The theme and sub theme represent the findings of the study. After identifying themes and sub themes in the stroke survivors interviews, a systematic inspection of interviews with relatives was conducted searching for patterns, contrasts and supplementary descriptions in the already identified themes and sub themes.

Trustworthiness and transferability

Trustworthiness in this kind of research relies on systematic work, insight and integrity throughout the research process (Guba and Lincoln 1998). The first author aimed at thoroughness and accuracy in data collection and transcription and worked systematically in the interpretation of the data. All transcripts were coded by the first author. Another author has read selected transcriptions, and all the authors have had regular meetings discussing data collection, analysis and interpretation.

The first author's professional background as an occupational therapist working in stroke rehabilitation constitutes a basis for understanding and entrance into the field of investigation. It influenced what caught the first author's attention, and probably also what was overlooked. Discussing the empirical material and findings with the other authors, reading specific philosophical, sociological and psychological texts and relevant research literature helped to generate a necessary analytical distance throughout the research process. It helped the first author to develop new questions and to see new perspectives. As a phenomenological hermeneutical inquiry, this study does not offer the reader conclusive arguments or a determinate set of ideas. But by using specific theoretical concepts analysing participants' experience of their long-term trajectory, this study aims at theoretical generalization (Fangen 2004; Kvale and Brinkmann 2009). This analytical goal aims at making the findings transferable beyond the study participants.

The topic of the broader study was the reason for recruiting persons with long experience of living with stroke and for including relatives. The choice of sample and design of the present study must be seen within the framework of the broader study. The stroke survivors' and relatives' experience during and immediately after homecoming are based on how they now, retrospectively (1–13 years later), describe this period. The retrospective data relies on the participants' memory and the interpretation they provide of the early events today, which can represent a shortcoming of the study. Clearly, many

episodes and situations had been engraved on their memories and were told in great detail; the stroke survivors were getting quite emotional in the process. Most of these stories were brought up by participants themselves. Thus, questions to the participants initiated by the first author concerning other, less significant aspects of the early period were harder to remember due to the passage of time since the onset of stroke.

Most of the participants' with stroke experienced physical progress during the in-patient stay and discovered more cognitive, diffuse impairments after discharge. Because consequences of stroke and recovery paths vary a lot and the sample is small, it is important to further explore whether the findings resonate with other comparable studies.

Ethical considerations

The study has been approved by Regional Committees for Medical and Health Research Ethics (REK). There has been a continual focus on ethics throughout the project. It has been important to establish good and confident relationships with the participants, ensuring that participation in the study did not become an extra burden. The participants said they were glad to contribute to developing knowledge that might help themselves and others. The participants are given fictitious names in the text.

Findings and discussion

The study shows that stroke influences the participant's perception of his/her own body, participation in everyday life and sense of self, and that these interrelated dynamic phenomena may transform in specific ways during people's participation in in-patient rehabilitation stay. The specific manner of negotiating the body and self during the in-patient stay can influence the early experience of discharge to their home environment. These findings will now be outlined and discussed below.

In-patient experience

A good place to be in a vulnerable situation

All stroke survivors experienced different degrees of bodily limitations and disabilities (see Table 1). For seven of the nine participants, the body changes were so comprehensive that they were offered intensive institutional rehabilitation stays. Their stays lasted from a few months to half a year. Each of them attended several rehabilitation departments before they were discharged to their homes. All seven participants recalled the rehabilitative stay as a safe and good place. Kurt says 'I was taken under the wings', George remembers 'I was vulnerable in the acute phase and was well taken care of', while Katy recalls that she 'as a patient was doing very well, considering the circumstances.' Many of them described the period as an 'unreal' situation. George says that 'he stood on the side of himself' and Katy experienced 'not to be part of this world', saying she 'was strapped in' and became part of a plan she still cannot fully conceptualize:

I was obtained by a physical therapist and an occupational therapist and you name it –... I was just floating. In a way I was not part of this world, I just heard what they said... So I just... went with the flow...It was not real in a way. It is not about you.

The feeling of being ‘taken under the wings’ in their exposed situation can be interpreted in the light of the rehabilitation practice they became a member of, for it offered care and treatment that they were in need of. The stroke survivors relate the ‘feeling of not being a part of this world’ to the stroke, but this feeling might also derive from the unfamiliar environment which the stroke survivors had come to, one where everything was planned by others before they arrived and only limited and specific participation was expected – a place totally different from their familiar everyday life environment.

Shield from everything

Agnes says ‘It was very good being there’, and George expresses the same thing when he says: ‘In a period of rehabilitation at an institution, or in a hospital, when you are very much shielded from everything, as I said, I was doing very well. I thrived at the hospital.’ George also explains how heavy thoughts come to the surface, but are pushed to the background at the break of dawn when the professionals lead him through the rehabilitative contexts and procedures:

At the same time there was nothing wrong with me, I had a strange feeling...early in the morning I use to wake around four or five...and then, it was very tough. It was perhaps then I started thinking about ending it all...these were parallel thoughts. But when the physical... the nurses came along and we had breakfast and the day started, then it was nothing...

The description of ‘parallel thoughts’ is striking. Dual thoughts and shifting emotions are closely connected to a body which at this point is perceived in a very fragmented manner. The gap between being ‘very satisfied’ to wondering if ‘this is the life I want to live’ can be seen in connection to a body which is perceived as more scattered than unified. This could partly be due to brain injury that results from stroke causing different degrees of perceptual, motor and cognitive disturbance, but is also probably linked to bodily experiences which are new, unexpected and completely alien. The body as an ambiguous phenomenon is especially evident in this situation, as Merleau-Ponty (2002) also points out.

The example above also shows how the sense of safety is threatened when the bustle of the day calms down and patients are lying there pondering more existential questions. But at dawn, when a new day begins and they once again are taken ‘under the wings’ and become part of the rhythms and practices of rehabilitation, the sense of safety returns. The sense of safety and confidence can be interpreted in light of how the perception of one’s own body and sense of self are being constructed through action and interaction between participants in this specific context. A dawning renegotiation in the tension between perception of one’s own body and the sense of self appears but is muted in the professional context in which the stroke survivors participate. The context seems to protect from and reduce the feeling of one’s own body as unfamiliar, fragmented and fluid. At the same time, the unambiguous attention to one’s own body discourages any focus on life as it progresses in the other contexts the person used to participate in. This finding is further examined by looking closely at specific ways of how the body is perceived and the sense of self is being transformed through stroke survivors’ participation in the rehabilitation unit.

Hope of recovering the physical body is all-absorbing

The body receives a lot of attention. Sonja says: ‘I became very attached to it (the body)’. There is also much talk about the body. It fuels the ability to persevere, to mobilize, to

find hidden sources of energy and to focus on regaining body functions. Sonja was in despair the first days after her acute stroke and explains: 'I was thinking about everything I couldn't do and thought I did not have the ability to recover'. The despair at losing bodily functions and life opportunities was gradually replaced by a partial focus on bodily progress and small improvements that were proof of change. A strong feeling of hope emerges, and at the same time a belief that things will work out. The professionals' focus on the physical body, partial functions, descriptions of progress and milestones, resounds loudly in the ears of the stroke survivors and nurtures hope, which most of the stroke survivors describe as crucial. Sonja says it is 'a shot of vitamins, it means everything!' Agnes's husband talks about something similar when he says: 'I never thought there would be progress, but after six-seven days they got her up, and they had made her truly believe in herself'. This particular road towards progress is built through the efforts of the professionals. However, this means that when the training one day is cancelled or delayed it is perceived as a real threat in terms of the possibility of and hope for bodily change.

In such institutional contexts, stroke survivors develop a belief that the outcome is undecided and that the only way to recover is to train in order to optimize one's opportunities. As Katy says: 'I got a strong belief that things would go well.' It is a common trait of the participants' experience that they do not give up. They mobilize and show immense willingness and are eager to train. This applied especially to George and Katy who wanted to train all the time and had to be restrained. George says:

I knew that I was not supposed to train too much and too hard over a long period of time, I had to relax, but I was so eager to train all the time. I did not consider that I had to take it easy and relax.

Being absorbed into the culture of the rehabilitation practice

Many of the stroke survivors describe how their changed bodies were approached by the professionals in a rather narrow way. George reflects: 'It was easy for the physical therapist to know which "buttons he had to press" to get back my gait function...but there was so much more I needed help to sort out.' This reconstruction of the body described by George contributes to his perception of time and understanding of the process of recovery in the early stage. When asking George if he had any perception of time during the in-patient stay, he says 'none at all'. Staying in the rehabilitation institution he perceived his body to be in a sort of vacuum divorced from the rest of his life. He says:

eh... right now, this hand is not supposed to function. It will require help from the left hand...so there were many such things that – That you in some way became used to... strangely enough. And it probably led to that I felt that—that things worked well.

He and the other interviewed stroke survivors explain that during the rehabilitation stay they had a more instrumental relationship with their own body; the body had to be 'repaired'. They learned to anchor their body in the context of the hospital or the training context and outside the continuum of the biographical time of the lived body. Therefore, they did not experience their own body to be overwhelmingly problematic or as something that produced hopelessness and strong negative feelings. Certain thoughts, for instance, how to continue participation in everyday life outside the institution were almost non-existent during the in-patient stay, according to the stroke survivors.

The participants' description also reveals other elements that connect the perception of their own body with the way time and space are being enacted and transformed in the institutionalized practice. The stroke survivors' experiences in rehabilitation are about the

now, hours and days organized around procedures such as caring for oneself, training, visiting hours, surveys, appointments with therapists, etc. Time to reflect on oneself 'dwindles' to nothing. The stroke survivors fit into and become part of the established practices of the department, and the institutional time rhythms and schedules. The body of the stroke survivor that has changed suddenly and dramatically is not in conflict with the physical environment and practice they are being absorbed into. As seen, the past and the future is pushed back or muted for the participants. This particular condition helps keep at a distance the stroke survivors' reflection on the sense of self and other life contexts that they used to be part of.

Many of the interviewed persons become involved in 'the rehabilitation community' and explain how they developed good relationships with certain professionals and close ties to fellow patients. In addition, confidence seems to grow from the community and the experience of belonging, being part of a common project. The 'new' body is also recognized through the bodies of other patients, creating confidence and assisting to a certain extent in the management of the body. While the stroke survivor experiences being part of the rehabilitation community, their relatives experience being somewhat excluded. Some relatives were well-informed and felt included in what takes place at the rehabilitation department, while others did not. No-one gave examples of being actively a part of the therapy, receiving in-depth training to cope with the patient or guidance on how to facilitate, help or stimulate the stroke survivor to actively participate after discharge, etc. Relatives were not given full access, an active role or any key position in the process of rehabilitation.

The participants experienced going home on leave differently. George is an example of how it can be less threatening to relate to the body than to the coming broader life situation. Others believe that the body will function much better at home in familiar circumstances. Katy 'forces' herself to go home to try things out in a familiar environment, but is surprised when things do not turn out exactly the way she had anticipated:

And so I was home alone one weekend. I got permission to leave after much discussion. I lay there one night but had to call (the hospital) so that I could return. It did not work but I had tried. It was not as I expected and I did not like it! Here, everything is facilitated, you can go to bed when you please and you participate in physical therapy. If something is unclear you can always ask. It is very different to be home all by yourself.

For participants in this specific context, the possibilities and potential of the body are maximized through professionals' treatment, adaptation and gradation of tasks. The professional ongoing practice and bodily adaptation become a buffer and 'protect' them from the overwhelming experience of defeat and bodily failure. This helps the stroke survivor feel he is in control and able to manage the situation. His sense of mastery increases. But at the same time thoughts concerning the new bodily condition, participation in contexts outside the rehabilitation unit and reflection on the sense of self, are not considered.

The body 'detached' from self and real life participation

The particular way of understanding the body that George and the others give examples of is a sense of a body 'detached' from its own biography, former sense of self and from the familiar activities, contexts and relationships established earlier. The changed body, participation in everyday life outside the institution and the sense of self are being treated

as different aspects of life. Only the physical body seems to be of relevance in this context. Many imagine that they will continue their 'old life' when they are discharged – continue where they left off. Katy says that she did not think she was so badly off and that she probably had a different experience of her own situation than that of the professionals: 'I wanted to be the way I used to be, I was very concerned about that...I asked a lot, will I be like before?'

The initiatives towards recovery point unambiguously towards physical improvement, and the activities the stroke survivors are struggling to re-engage in this phase are not reminiscent of the complex activities that previously caught their attention. Their days are spent repeating sequential actions in an attempt to recapture partial functions. The focus is on the everyday practical 'pieces of the puzzle' that were previously so internalized in the bodily repertoire of action that they were barely offered a thought. To turn over before you get out of bed, to grip and guide the knife properly so the toast can be buttered, etc. Plans for the future are not related to the body in the 'here and now'. Katy had a plan ready: 'back to work, I will just be absent for a week. I just needed a rest.' For various reasons the problematic relationship between changed body, everyday life participation and the sense of self is excluded from the current stage. The role as a patient seems safe and manageable, and is thought of, by most, as temporary. The institutional context may frame their existence in ways that are not threatening to their sense of self. As we have seen in this study, the rehabilitation context may delay the process of reconnection to former life contexts and re-orientation of the sense of self in relation to the changed body and life circumstances

The in-patient experience and previous research

Findings outlined above do not support previous studies' descriptions of sudden and overwhelming catastrophic experiences for those suffering from acute stroke (Becker 1997; Borg 2002; Burton 2000, 32:301–309). This study does not support Becker's (1993) conclusion that the patients' first weeks were dominated by an overwhelming feeling of uncertainty and awareness of their change in role, which might lead them into crises. Becker writes that the known self is thrown into disarray which interrupts the sense of continuity in life (Becker 1993). Shock, grief or paralysed despair when confronted with profound bodily changes does not seem to dominate the stroke survivors' thoughts and being during the in-patient stay. As we have shown, terrifying feelings threaten, but are being held at bay by, in various ways, constructing a sense of safety in the context of rehabilitation. Ellis-Hill, Payne, and Word (2000) describe stroke patients' experience as a 'split' between body and self during a hospital stay. The researchers describe the sudden experience of separation of self and body, as the body became 'separate', 'precarious' and 'perplexing'. In contrast, this present study shows that professional culture and specific social arrangements in the context of the rehabilitation institution may prevent such an experience. The interrelated dynamics between the lived body, participation in everyday life and self during in-patient stay can be framed in ways that uphold a sense of continuity seemingly without any 'split'. Because the dramatically changed body seemed to 'fit in' with the institutional rehabilitation context, the sense of self is not questioned. It appears as a former or 'the up to now not questioned self', rather than a 'split'.

When the unclear and unsettled situation prevails for the stroke survivors, the context of rehabilitation obviously has the potential, not only to provide a sense of safety, as other studies also points out (Ellis-Hill et al. 2009; Pound, Bury, Gompertz, and Ebrahim

1995), but also to establish ways of acting and thinking that prevent the stroke survivors from getting lost in grief and helps them stay focused using all their energy on physical progress and maintaining hope of change. The stroke survivors enter into specific professional practices and social arrangements where they learn the need to work hard and maximize the physical body's potential and not to surrender. Economic and professional resources are mobilized and the stroke survivors are encouraged to be dedicated to working on physical progress.

In line with Kaufman's (1988) findings, the stroke survivors and professionals seem to have a congruent focus; their centre of attention is on medical stabilization and physical progress and only focusing on just a few aspects of everyday activities. Also other authors have stressed how rehabilitation units focus on improving physical functions and basic daily activities rather than enabling people to regain valued role performances in their different everyday life contexts (Borg 2002; Cott, Wiles, and Devitt 2007). Ellis-Hill et al. (2009) also highlight that the hospital environment is designed to be as patient-friendly as possible, and that stroke patients' perception of progress is being judged against this situation or standard. The stroke survivors learn to become 'skilled' stroke patients. All this may sound unambiguously appropriate. However, it does not necessarily prepare them or their families to cope with changed life conditions.

Discharge – home-experience

Four central elements seem to threaten the acquired sense of safety after being discharged home. This will be outlined and discussed below.

Transfer from the safe to the uncertain

George exemplifies the transition from the safe institutional context of rehabilitation and out into the 'real world':

The experience you have from that place (the hospital) is just as a patient, with your current handicap. But then you should return to the real world, where you lived before, where you functioned well, and then you are not functioning at all...

He elaborates further saying:

It was a very abrupt transition from being very safe to kind of wondering if this is a life I feel like living...when I was done with the rehabilitation I realized very quickly that something was missing, because there was such a tremendous follow-up for four-five months, and then I returned and lived at (the place) and then it was like no one...I got physical therapy and probably had occupational therapy and...I also had a speech therapist ...but it was not the same way as at the hospital. I did know I had to return to normal life. But the transition was sort of like bang! I became very depressed and started taking anti-depressants, but I received no other follow-up in conjunction with that.

While Steven experienced the transition to home as 'abrupt and brutal', Kurt felt it as a betrayal: '...I had nine weeks all together at the rehabilitation department, and then I was discharged...and forgotten!' The stroke survivors are confronted by 'normal life' and the new experience is described as 'a slap in the face'. George thinks the crisis he describes was reinforced; he clearly remembers the surgeon at the hospital explaining that he could not expect much improvement after six months. Discharge occurred at the end of this

six-month period leaving him deprived of all hope of improvement just at the point, when he started to realize the scope of his illness.

Two things happen simultaneously, and most likely contribute to the fact that the stroke survivors describe the transition home as a painful and difficult time. At the same time as they become aware of the consequences of the stroke, the professionals, the fellow patients and the safe rehabilitative context are gone. Despite the fact that many are offered interdisciplinary follow-up locally, they experience being left to themselves. Steven reflects on the great frustration he felt after being discharged and says: 'I think it was a great transition needing so much help, and that's why there was so much frustration. Perhaps it was aimed at the municipality. They were blamed for everything.'

The energy, intensity and selective attention that were maintained by themselves, the professionals and their fellow patients in the 'rehabilitative fellowship' are suddenly gone. Expertise, plans, goals, initiatives and the 'sense of community' which, during the stay, mainly safeguarded the physical body, and its progress marking new milestones, take on a different value and meaning when they come home. They are now back to familiar everyday life, but a life in which they are not able to function as before. The stroke survivors come to realize that this everyday life reality is quite different to the institutional context with all its facets, constellations and intersecting needs. After discharge, the stroke survivors' bodily improvements are no longer the centre of attention in the way they were at the institution. Now the focus is on living an everyday life.

The confidence given by the professionals who provided hope for and faith in the future is no longer there. 'The redeemers' they were surrounded by at the hospital and who 'saved' them from tricky situations, those who organized them and gave them ability to cope, are no longer close by or a part of their lives. George touches on this when he says,

'It got a bit hard for me when I came out, because I had become accustomed to the security and comfort, you know... You become the centre of attention in every way'. The 'cheerleaders' are gone and the physical progress experienced during rehabilitation is insufficient to cope with the complexity of everyday life.

The municipality, which is responsible for follow-up after discharge, does not replace the expertise that took responsibility, initiated and functioned as the 'driving force' in the process of rehabilitation. Many describe a feeling of emptiness and of being abandoned. The need to have someone to consult with, whether it is about symptoms, bodily discomfort, uncertainty or thoughts about the drastic changes in one's life, etc. can be a more intrusive need once the patient returns home. As there is a lack of professionals and fellow patients, these conversations are now often conducted with relatives. Both the stroke survivor and the relative admit it is difficult. George's partner says: 'It is a grieving process that he has not completed. He needs help to do that... I cannot help him (...) He needs tools to function and to learn how to live with it...'

The transition home can be considered a significant break in the continuity of the process of rehabilitation. Considering the fact that the participants in this process move between contexts that stand in stark contrast to each other, returning home and the time thereafter represents a critical, vulnerable and incomplete facet. The transfer from the rehabilitation stay to home brutally disturbs the sense of safety both at a level of self, body and as a participator in the nexus of everyday life contexts.

Unexpected and problematic bodily responses to everyday activities

Returning home was not what the stroke survivors' had expected. The new recognition shatters their expectations. Katy describes the new experience as a slap in the face. It is only after returning home that it becomes obvious that everyday actions have been changed by the illness. Katy says;

Things like buttoning; it was very difficult (laughs) to get the button in the buttonhole! And to wipe one's behind and everything... and to wash your hair and to put on mascara! Things I never considered before! I got shaky; I did not have the strength to hold the mascara brush that weighed absolutely nothing! Those are the things you don't think about, those girly things!

As a general pattern among those who experienced improved mobility during rehabilitation now discussed more diffuse and indeterminate bodily struggles when faced with everyday tasks. George says:

In one way it was not so great to appear as normal as I did because in my head I was far from normal! ... It was terribly difficult, both to be easily exhausted and also feeling that you did not cope well with meeting people you knew... And also doing things on your own, everything from cooking, buying food...it was very different from what I had...or how I remember it before I got ill. In the beginning it felt impossible... I couldn't...I did not know what to take hold of to make it work.

The paradox that becomes apparent is that the body does not act as expected in familiar situations. The body, surprisingly, appears in a new light. Due to the fact that the body in everyday practices does not, as Merleau-Ponty (2002, 64) describes, 'respond with certain types of solution to a situation', the participants are moving into new negotiations between body, participation and self. The attention rotates from classification of different body parts, partial functions and improved mobility to a more overriding recognition that it is their lived body (which 'rotates around the axis of habits') that has been afflicted. Patients realize what costly implications for everyday life are involved. For many, the body is now perceived as something overshadowing, ambiguous and elusive. The stroke survivors talk about overwhelming everyday challenges and the lack of tools to handle the situation.

Increasing conflict between perception of the body, participation in everyday life and the sense of self evolves. It is impetuous, partly related to a new stage of recognition, and also a feeling of being deceived. Many must deal with the intangible and prohibitive bodily challenges they now experience alone and without support, information or care from any professionals. At this point, the stroke survivor must be the 'driving force' of his/her own recovery process.

Negotiated and changed participation in everyday life context

The description above shows how the stroke survivors arrive home to a familiar but at the same time very different everyday life. They describe that the contexts which take centre stage upon their return are the home, family, and, for some, leisure time and relationships with friends. When this membership resumes, the stroke survivors quickly experience that family members or friends are not necessarily as focused on their needs, goals, personal struggles and projects as themselves. What is quickly evident in the complexity of everyday life is that there are further intersecting needs, projects and goals at stake, some coincide and complement each other, and others conflict and create tension. The relatives

describe how they, in the absence of their partner, have to tackle the everyday routines as best as they can; kids have to go to school and their job and other daily routines do not wait. The stroke survivor knows this life well, but the familiar everyday life has been pushed aside during the intense period of training. The first few weeks after returning home are experienced as an 'initial phase', where they are figuring out the new situation. This situation is characterized by ambiguity and is dominated by frustration, negotiations and strong emotions. The interviews highlight how both the stroke survivor and relatives at this stage have very little idea what the new everyday life will look like. What this situation means for the family in terms of changed positions, obligations, roles, new routines and division of labour is not clear. Uncertainty, experimentation, trying and failing dominate. The stroke survivor has learned to be a dedicated patient, but neither they nor the relatives have learned how the changed conditions in everyday life should be dealt with.

Oliver, Steven, Kurt and Sonja still have extensive paralysis at the time of discharge; they are all one-handed users and two of them are in a wheelchair. They still need a lot of assistance with practical tasks. Kurt and Sonja have partners who assist them at home, while Steven and Oliver, who live alone, are offered home care. The help they receive appears to be quite, even too, comprehensive, and it can seem that the help provided and the re-establishment of routines reduces partial functions that they have trained and rehearsed at the hospital. As relatives were neither actively involved in the training at the hospital nor received guidance, it is hard for them to know how they can assist in supporting, optimizing and further developing remaining functions. The practice that develops does not seem to facilitate a more active involvement. Some relatives truly enter the role as a helper, such as Kurt's wife: 'When I saw him suffer...I jumped. He never asked for help. It was like that for a year and a half!'

Visible physical changes seem to generate help, and perhaps inappropriately in terms of progression and independence. Many relatives talk about the dilemma of helping too much or not knowing exactly what the best way of helping is. Some provide a lot of help taking over bodily functions unnecessarily, while others do not help enough or paying little attention to bodily limitations. The renegotiations and the shaping of everyday life in this phase are largely dependent on how the stroke survivors and those close to them understand and interpret the stroke survivors' situation, and their abilities. We must also take into consideration the expectations the stroke survivors have of themselves, how they consider their bodily potential and what thoughts they have regarding participation within the contexts they were a part of before. What also becomes obvious is that the potential for opportunity is not just about the stroke survivors' experience of 'empowerment' or how they see themselves as 'agents'. It is also a question of how others interpret their bodies and their abilities. The interpretations of those close relatives form the basis for their actions, involvement, facilitation and help; and either help increase or decrease the stroke survivors' ability to participate in the tasks of everyday life. The issue is what others perceive as a challenge and how they facilitate their knowledge, initiative and support. The visibility of the illness is also relevant, how 'subtle' the consequences of the stroke appear at this point.

The sense of self fragments

The lack of habitual activities especially those most appreciated, changed level of participation or limited access to established contexts is threatening to the stroke survivors' sense of self. Thoughts about who I am and who I can be are forced to the

surface. Changing some activities is not so harmful and can easily be left to others, while removing activities that previously nourished and confirmed the notion of the sense of self has a strong effect and can be experienced as a 'smack in the face.' Katy says: 'I was like a beginner, and barely that.'

To come back like that in the context where one has one's own routines, interests, unique competencies and positions is testing for the notion of sense of self. Kurt, who in the beginning needed a lot of practical help from his wife, describes the transition home the following way:

Well I was laying here on the couch... What else should I be doing? I needed help with everything. If I was going to bed I had to be supported over to the bed. It was really tough, yes, bloody hell!

His wife who is sitting at the end of the table by the kitchen can hear the interview and adds: 'He was always in the forefront, and then suddenly he was...nothing. That was the worst part.' Kurt says, 'I was so angry in the beginning... God I was so angry...about everything...so she (the wife) had to clearly warn me.' Katy also talked about the anger that had to come out and how she hit her fist against the wall, cursed and swore when she was bothered. Many begin taking antidepressants. Agnes refers to the doctors and says: 'It was only to choose what I wanted.' George says that he wished he had gotten something more than just pills. He lacked professionals who could have given him tools to handle the enormous sense of grief he felt for a lost 'body' and a lost sense of self.

Discharge-home-experience and previous research

As shown, the crises, the profound grief, discontinuity and deep conflicts between self and body appear to be delayed. The experience of 'biographical disruption' described by Bury (1982), becomes more applicable to the participants later in this study, especially after discharge. Our analysis agrees with Ellis-Hill et al. (2009) which says that coming home to the familiar environment has become unfamiliar presenting many obstacles for the stroke survivor so that the sense of momentum built up in hospital was seen to be challenged and reduced. The stroke survivors in our study describe how the feeling of being protected disappears abruptly after discharge. In life at home, other preferences, focuses, needs, social arrangements and projects are at stake. Such challenges 'strike' immediately and unexpectedly and draw stroke survivors into life crises so intense that the feeling of safety is threatened. At home, they become dependent, as people they feel 'less than' they once were; if they cannot get back to normal, they yearn for the structure and interaction at hospital where they were important contributors to everyday life in the institutional world. The transition between institution and home constitutes a vulnerable phase in the course of rehabilitation, where the health care system is seen to fail. These findings are largely congruent with those of Ellis-Hills et al. (2009). They describe stroke survivors' discharge experience as a feeling of being left in the dark. Similarly, Cott, Wiles, and Devitt (2007) describe the lack of continuity and of overlap between the in-patient and out-patient service and Rittman et al. (2004) describe the transition home as a critical period. Borg (2002) points out the same problems and stresses and also that the stroke survivors in the following period are at risk of developing a long list of additional problems, both personal and relational problems with close relatives.

According to the described conditions it is not until homecoming that the patient feels the full weight of his/her situation. The new experience 'hit' both the stroke survivors and their families unexpectedly and hard. Medication is seen as the solution when problems

accumulate. The stroke survivors lack tools to handle their difficulties when the professionals that might have assisted them are absent.

Clinical implications

Summarizing; the study shows that the institutional rehabilitation context constructs specific ways of negotiating the body, participation and self which have implications for the stroke survivors' immediate experience of discharge home. The promotion of physical recovery by means of intensive training is of great value for the stroke survivors, but the consequences of ignoring the sense of self and the coming contexts of everyday life outside the rehabilitation institution lead towards a crisis after discharge.

Proot et al. (2000) also stress the important role professionals have supervising and stimulating self-confidence and gradually preparing stroke patients for discharge home. Our findings stress that professionals, during in-patient stays, have the potential to prepare the stroke survivor and carer's homecoming by improving family members involvement, facilitating stroke survivors' agency, and initiating dialogue about aims, plans, strategies and challenges regarding their return home to changed living conditions. This study highlights the professionals' crucial role of empowering the patients and their families in the process of change and learning beyond the 'safe' rehabilitation context, just as other authors have reported (Borg 2002; Cott, Wiles, and Devitt 2007; Gustafsson and Bootle 2013).

In order to minimize the described crises this study indicates the need to broaden professional initiatives and culture by bringing the coming context of everyday life into focus during in-patient stay. Knowledge about how stroke survivors reflect on their own lived body, their participation in everyday life and the sense of self and how the phenomena interact, creating tensions and change through the unfolding trajectory will be of vital importance in supporting patients and relatives in the early process of rehabilitation. Broadening professional initiatives will furthermore require professional availability, change of culture in the institutional rehabilitation context and access to committed, specialized expertise. The crises stroke survivors and relatives described shortly after homecoming can be reduced by increasing professional support in their own homes. An important focus must be on enabling the stroke survivors to become embodied agents in their socially situated recovery processes.

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