

Patients' experiences of unilateral spatial neglect between stroke onset and discharge from inpatient rehabilitation

Citation for published version (APA):

Tobler-Amman, B. C., Weise, A., Knols, R. H., Watson, M. J., Sieben, J. M., de Bie, R. A., & de Bruin, E. D. (2020). Patients' experiences of unilateral spatial neglect between stroke onset and discharge from inpatient rehabilitation: a thematic analysis of qualitative interviews. *Disability and Rehabilitation*, 42(11), 1578-1587. <https://doi.org/10.1080/09638288.2018.1531150>

Document status and date:

Published: 21/05/2020

DOI:

[10.1080/09638288.2018.1531150](https://doi.org/10.1080/09638288.2018.1531150)

Document Version:

Publisher's PDF, also known as Version of record

Document license:

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To cite this article: Bernadette C. Tobler-Ammann, Andrea Weise, Ruud H. Knols, Martin J. Watson, Judith M. Sieben, Rob A. de Bie & Eling D. de Bruin (2020) Patients' experiences of unilateral spatial neglect between stroke onset and discharge from inpatient rehabilitation: a thematic analysis of qualitative interviews, *Disability and Rehabilitation*, 42:11, 1578-1587, DOI: [10.1080/09638288.2018.1531150](https://doi.org/10.1080/09638288.2018.1531150)

To link to this article: <https://doi.org/10.1080/09638288.2018.1531150>



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RESEARCH PAPER



Patients' experiences of unilateral spatial neglect between stroke onset and discharge from inpatient rehabilitation: a thematic analysis of qualitative interviews

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ABSTRACT

Purpose: The purpose of this qualitative study was to explore how stroke patients with unilateral spatial neglect experience; (a) performance in activities of daily living; (b) alterations in bodily perceptions; and (c) personal hopes and expectations, looking at the period between stroke onset and discharge from inpatient rehabilitation.

Materials and methods: We conducted individual semi-structured interviews with 7 (5 men, 2 women, mean age 69 years) consecutively sampled participants. All interviews were transcribed verbatim and analyzed using thematic analysis.

Findings: Participants' experiences were captured in three over-arching themes: *"unawareness of neglect," "emergent awareness for neglect-related difficulties,"* and *"comparing the new life with the old one."* Findings showed that participants progressed from initial unawareness to emergent awareness for their neglect-related difficulties over the course of rehabilitation. Comparing their current life situation with the one before their stroke triggered feelings of uncertainty and regret, with associated decreased pleasure in meaningful activities.

Conclusions: This study informs health professionals regarding personal experiences of orientation in and reorganization of life of stroke patients with unilateral spatial neglect. The findings highlight that being aware of neglect-related deficits is a prerequisite for using coping strategies and incorporating them in daily life. Possible therapeutic strategies that fit the current stage of recovery and level of awareness are discussed.

ARTICLE HISTORY

Received 22 March 2018
Revised 27 September 2018
Accepted 28 September 2018

KEYWORDS

Stroke; unilateral spatial neglect; awareness; rehabilitation; activities of daily living; thematic analysis

► IMPLICATIONS FOR REHABILITATION

- Symptoms of unilateral spatial neglect and anosognosia are most common after right hemispheric stroke, both being predictors of poorer functional outcome during rehabilitation.
- Patients' regaining some awareness of their impairments is a prerequisite for successful treatment and for engagement in neglect-specific interventions.
- Health care providers should carefully examine the "state of awareness" of the patient and adapt their therapeutic approach accordingly.
- This check should frequently be repeated over the course of rehabilitation, as awareness changes at different paces for each patient.

Introduction

Stroke remains the third most common cause of disability and the second most common cause of death worldwide [1,2]. For survivors, post-stroke challenges are multifaceted, typically including motor, sensory, and cognitive deficits of diverse severity [3,4], as well as significant psychosocial difficulties [5]. These consequences may be long lasting and will likely cause alterations in everyday functioning [6], as well as reducing the quality of life [7,8].

Hemispheric specialization within the brain often leads to characteristic symptoms, depending upon the laterality of the cerebral

event. In simple terms, communication problems are more common after left hemisphere lesions while unilateral spatial neglect (USN) and extinction are more frequent after lesions on the right hemisphere [9–11].

USN is the most common cognitive disorder following stroke and is characterized by a multimodal failure to respond to contralesional stimuli [12]. The consequences for rehabilitation are most debilitating in the visual and tactile modalities [13]. Typical problems experienced by patients include difficulties in navigating their environment (e.g., bumping into objects on one side) [14],

and in carrying out activities of daily living (ADL) (e.g., failing to shave both sides of the face equally) [15].

Between 9 to 22% of USN patients additionally suffer from anosognosia, which is a lack of awareness or underestimation of motor impairments (e.g., hemiparesis) [9] and visuospatial deficits [16]. It is well known that USN and anosognosia present a risk for poor stroke rehabilitation outcome, as well as for ADL function at rehabilitation discharge [8,17–20]. In the long-term, many USN patients remain impaired in ADL, as visually guided behavior dominates performance [12,21]. Stroke patients with anosognosia in the acute phase show poorer functional outcome at one year post-stroke than those who are without the problem [18].

During stroke rehabilitation, therapies include the training of specific motor [22,23], sensory [24], and cognitive [25,26] skills, also focusing on improvements in social participation and occupation [27–30]. Therapies may further address psychosocial difficulties (e.g., sleep disturbances or emotional instability) [5], and symptoms of post-stroke depression [31]. Neglect-specific therapy methods include video feedback [32], visual-scanning training [33–35], right half-field eye-patching [36], and limb activation therapy [13,37]. Promising new tools for the treatment of spatial neglect symptoms include the use of interactive virtual reality training [38], and strategies involving visuomotor imagery [39]. A combination of treatments is commonly recommended [40].

For a truly holistic approach to stroke treatment, not only is it crucial to provide the most effective treatment available, but it is also necessary to have expertise regarding stroke survivors' perceptions of their actual life situation [41]. This perspective may help health care professionals to better comprehend patients' priorities and goals and nurture individualized effective rehabilitation strategies [41]. Previous research investigating stroke patients' experiences during rehabilitation highlights the importance of including these experiences in the rehabilitation process, due to its positive correlations with quality of life and treatment compliance [41–46]. The focus has mostly been on patients' experiences of physical rehabilitation [44], the description of psychosocial processes that influence identity post-stroke [42], or on the resilience of stroke patients [45]. Other research has focused on the impact of dysphagia during stroke recovery [47] or has included stroke patients with aphasia [48].

Few studies have examined the subjective experiences of persons with right hemispheric stroke and USN symptoms during inpatient rehabilitation [49–52]. These studies focused on the impact of the social [51] and physical [50] environment on patients with USN, on neglect experiences adjacent to the first weeks following a stroke [52], and on the adjustment process of discovering and handling USN-related disabilities [49]. Less is known, however, about experiences of stroke patients with USN in relation to their performance of daily activities, their bodily perceptions, and their hopes and expectations between stroke onset and discharge from inpatient rehabilitation. Knowledge of this area is important as patients with USN perceive their body and self differently to how their social environment does. As a consequence, they are oblivious to the contradictions in their own activity performances [53]. Furthermore, a better understanding of USN patients' perceptions may help health professionals to better address patients' needs and concerns during inpatient rehabilitation. The purpose of this study, therefore, was to explore how stroke patients with USN experience their ADL performance, their alterations in bodily perceptions, and their hopes and expectations between stroke onset and rehabilitation discharge.

Methods

Participants

This qualitative study was part of a larger research project investigating the feasibility and usability of a novel game-based exercise intervention aiming to improve neglect symptoms [54,55]. Occupational therapists and neuropsychologists at two-stroke rehabilitation clinics in Switzerland consecutively recruited seven suitable participants between March 2015 and March 2016. These had already participated in the larger feasibility and usability project. Criteria for participation were (a) diagnosed with a first right hemispheric hemorrhagic or ischemic stroke between 2 weeks to 6 months prior to the time point of study inclusion, and (b) USN as measured by the Catherine Bergego Scale (CBS) [56]. The clinic staff adopted the CBS as part of the inclusion screening. We additionally administered the individual level of anosognosia as described by Vossel et al. [15], where negative scores reflect higher self-ratings than external ratings, thereby reflecting anosognosia. This index was calculated based on the results of the Behavioral Inattention Test [57], which participants had completed for the feasibility study [54]. Exclusion criteria were the presence of (a) visual deficits (e.g., hemianopia and optic ataxia) [58], and (b) communication disabilities (e.g., aphasia and dysarthria) [59]. Ethical approval for this study was received. All patients signed written informed consent before study entry.

Data collection

For this qualitative study, we used semi-structured, open-ended interviews [60]. Each interview lasted from 18 to 47 min (mean 32 min), the exact duration was dependent on each patient's levels of fatigue and willingness for disclosure. Interviews were conducted by the first author near or shortly after the end of inpatient rehabilitation (see Table 1 for interview locations). This time point was chosen to include retrospective accounts of patients with USN about their experiences with neglect during inpatient rehabilitation. The "Canadian Occupational Performance Measure" served as a basis to design the interview guide [61]. We chose this assessment for its client-centered design and predefined structure in three occupational performance areas (self-care, productivity, and leisure). Each participant was asked to describe the ADL based on a daily routine post-stroke in the inpatient rehabilitation setting. Subsequently, the course of the interview touched topics such as perceived difficulties and changes in performance of ADL, alterations in bodily perceptions, and their hopes and expectations during the period between stroke onset and discharge from inpatient rehabilitation. The interviews were all audio-recorded and transcribed verbatim. The first author carried out an instant debriefing after each interview, aiming to record immediate observations and impressions [60]. Privacy was ensured during all interviews.

Data analysis

We used a data-driven inductive thematic analysis to gain insight into the ways in which life events and experiences are described within a social context [62]. Braun and Clarke's six-phase guide to thematic analysis was followed (Figure 1) [62]. During data analysis, each step was discussed with due consideration of all previous ones between the authors. This allowed us to check if the condensed data units still represented the meaning of the whole data set. Additionally, we checked the instant debriefing notes to complement the interview data, integrating those notes as

Table 1. Demographic data of participants.

	P1	P2	P3	P4	P5	P6	P7
Age	64	74	64	70	53	78	77
Sex	m	m	m	m	m	f	f
Weeks of inpatient rehabilitation	6	8	14	11	10	9	8
CBS ^a	7	17	5	6	5	10	16
Neglect awareness ^b	0	0	-0.07	0	0.27	0.18	-0.92
Weeks post-stroke	9	12	22	12	14	13	11
At time point of interview							
Interview place	clinic	home	clinic	clinic	clinic	home	nursing home
Stroke type	ischemic	ischemic	ischemic	ischemic	ischemic	hemorrhagic	hemorrhagic
Hand function of Affected left hand	none	full	none	full	clenching fingers	full	full
Locomotion	WC	W	WC	WC	W	W	WC
Profession	farmer	divisional bank director	catering service holder	blue-collar worker	newspaper editor	secretary	bookseller
Family status	married/2 adult children	widowed/no children	married/2 adult children	domestic partner/no children	married/2 children	married/2 adult children	widowed/3 adult children
Leisure time activities	dog caring/ riding a bike/ timbering	gardening/ visiting relatives	skiing/ biking/ sailing/ playing music	singing in a choir/ playing cards and bowls	gardening/cooking/hiking	visiting friends/ reading/ listening to music	reading/ knitting/ sewing/ traveling

Note. CBS: Catherine-Bergego-Scale; f: female; m: male; P: participant; WC: wheelchair; W: walker.

^aCBS: maximum score = 30 (severe neglect); 0 points = no neglect/^blevel of neglect awareness; anosognosia index ≥ 0 : no anosognosia; < 0 : patient suffers from anosognosia.

memos to the corresponding data extract. Only after consensus was reached between the authors data analysis moved forward to its next phase. An example of how we conducted our data analysis is given in Figure 2. We used MS Word to structure the data analysis phases 1–3 and 5–6, and PowerPoint to generate thematic maps (phase 4). We exchanged all documents in an anonymized format through a secured email-address and stored them in a password-protected computer.

Findings

In total, 5 men and 2 women (mean age 69 years, range 53–78 years) were interviewed. They had USN of varying severity (CBS score range 5–17 points). Five out of seven participants had regained partial awareness of deficits during task performance at the time point of the interview. All participants were independent and living at home prior to the stroke event. Additional demographic data are presented in Table 1.

The data analysis revealed three main themes in the participants' discourses about how they experienced everyday life post-stroke with USN in relation to their performance of ADL, alterations in bodily perceptions, and their hopes and expectations between stroke onset and discharge from inpatient rehabilitation. Each theme incorporated specific sub-themes (Figure 3).

Theme 1: Unawareness of neglect

Early after stroke, all participants reflected on an unawareness of many of the behavioral deficits caused by USN. This unawareness had caused incomprehensible situations, where mismatches between their personal capabilities and external demands became evident. We identified three sub-themes indicating areas where those mismatches were manifest: in (a) being unaware of the paralyzed side of the body; (b) perceiving incomprehensible mismatches between personal capabilities in (i) results of actions, (ii) content of therapy; and (c) trusting themselves to do more than they were able to.

Being unaware of the paralyzed side of the body

Whilst USN was evident to external observers, most participants described early frustrations at being unaware of their own sensorimotor deficits. P4, for example, told his wife not to call the ambulance after the stroke event, because he perceived that his hands worked perfectly: "She nevertheless called [the ambulance]. I told them to go: Nothing happened, you see, I can walk again and the arm functions well, too. But it was the right arm that functioned well and that still works fine today." During acute care, P6 recounted not realizing that he had a paralyzed leg: "I simply couldn't walk – not a single step. This was very clear to me. But I didn't realize I was paralyzed, and even less so my hand." P5 wanted to get out of bed in the hospital without having the capacity of doing so: "I always kept the nurses busy. As soon as I woke up at night [after the stroke event], I wanted to get up. I somehow had the feeling that I was able to walk."

Perceiving incomprehensible mismatches between personal capabilities and

(i) results of actions. All participants described how, on the day that their stroke occurred, they had experienced discrepancies between their personal expectations and the actual achieved results. Some participants, for example, expressed how they got exasperated with their confusing arm, because it did not do what they wanted. For example, while taking a shower at home

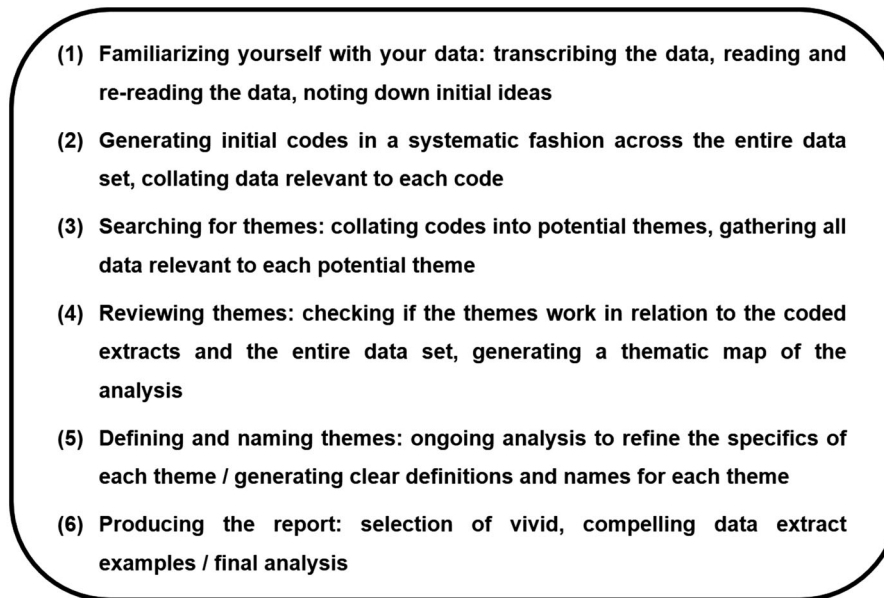


Figure 1. Braun and Clarke's six-phase guide to thematic analysis [62].

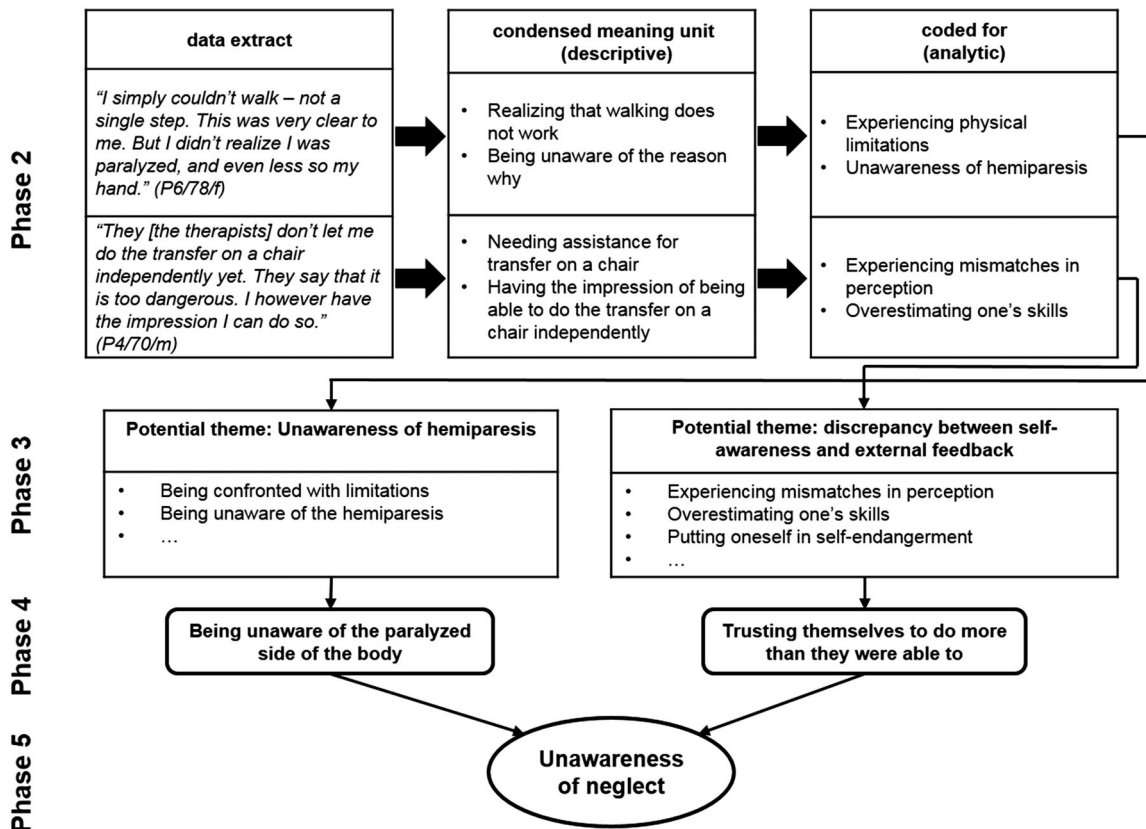


Figure 2. Example of thematic data analysis.

immediately after his stroke, P5 realized that "everything I tried to hold in my left hand fell on the floor, which extremely upset me." He did not understand that his left arm was paralyzed and expected it to function as usual. P5 mentioned having the same feeling when he unsuccessfully tried to place his rucksack on his back prior to leaving home to meet a friend for lunch: "I was extremely upset because I could not thread in my left arm through the strap of my rucksack. This didn't work out." P5 did not realize he had had a stroke until his friend told him that something was

wrong with his left arm and face when they finally met later that day.

(ii) *content of therapy*. For most participants, the neglect-specific therapy made no sense in the early stage of recovery: "Initially I didn't understand what this was all about [the computer-based visual scanning therapy]. For what purpose it was meant to be useful. I've always seen all objects to the left and to the right. But she [the therapist] kept telling me that I have a 'left-handicap'." (P2).

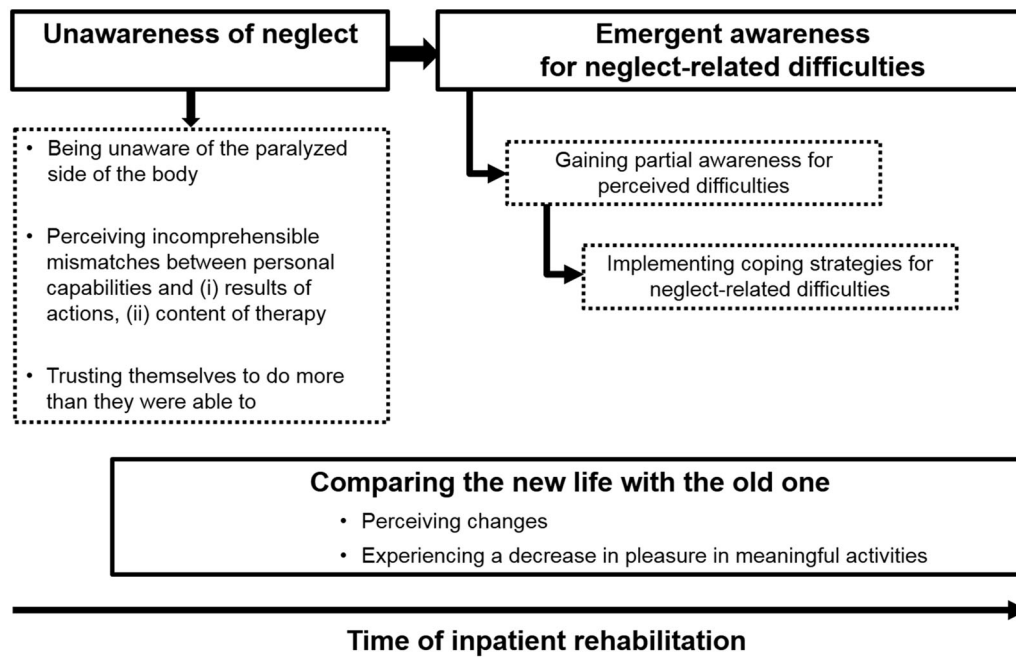


Figure 3. Overview of main themes and sub-themes of the thematic data analysis in relation to the time of inpatient rehabilitation.

Another example was provided by P6, who had to attend an “arm-group” without understanding why: “Because I can do everything with my arm, no problem. But they told me that it was paralyzed, too, which I didn’t realize.” Despite experiencing such mismatches between the external feedback they received from clinic staff and their self-awareness, all participants were nonetheless compliant with therapy. “Well, I thought: As I’m here anyway [at the rehabilitation clinic], I might just as well improve ‘this thing’ [neglect] with those therapists.” (P2).

Trusting themselves to do more than they were able to

During inpatient rehabilitation, most participants talked about having trusted themselves to do more than they were actually capable of doing. This experience was described in terms of having to deal with constraints imposed by clinic staff for safety reasons that they did not understand. P2, for example, explained: “Throughout my life I’ve always read a lot. That’s why it initially bothered me not being allowed to go to the cafeteria independently [to read the newspaper]. And well, on the second-to-last day, he [the neurologist] told me: ‘We simply had to thwart you a bit [to avoid accidents]. I don’t like having people in casts in the clinic [due to a broken limb].’”

Statements made by clinicians, which the participants did not agree with further described this sub-theme. P4, who was in a wheelchair at the time of the interview, stated: “They [the therapists] don’t let me do the transfer on a chair independently yet. They say that it’s too dangerous. However, I’ve got the impression I can do so.” As a farmer, P1 used to cut his fruit trees alone in the past. “I then asked my therapist: ‘Will I be able to climb those trees, use the ladder next year to cut them?’ I should forget about that and hand it over to someone else, she replied. Well, I nevertheless thought I would be able to do it. I considered trying it.” Driving was one activity most participants wanted to resume in the near future, but the doctors kept telling them that they were not allowed to do so due to their current situation. Despite his anosognosia, P3, for example, was nonetheless convinced that: “I’m able to drive, I know that. [...] I see everything. I’m not restricted in my field of view. I don’t have all those limitations. My

responsiveness is still good.” As he owned a catering service, driving a car was a prerequisite for earning his living: “If I can’t drive again, I can forget about my job. [...] If not [being able to drive again] I will have to join the breadline, [...] if I don’t earn anything at all, can’t do anything at all.”

Theme 2: Emergent awareness for neglect-related difficulties

Most participants recounted how, as rehabilitation had progressed, they had (a) gained partial awareness for their neglect-related difficulties through doing, and (b) gradually started to implement coping strategies for mastering those difficulties during daily life.

Gaining partial awareness for perceived difficulties

With time, four men and one woman (see Table 1) narrated that they started becoming aware of difficulties. P5, for example, became aware of having problems with calculating and reading the time: “I have a problem with reading the time. Often I don’t look properly. I’m then sometimes too early and wait for the therapists. [...] The same story with calculating. I do have problems there, too. Adding and subtracting [figures].” Discovering those neglect-related difficulties caused feelings of uncertainty and confusion. P6 described her dismay when she tried for the first time to type in her name: “I felt as if struck by a hammer when I sat at a computer for the first time and realized that I wasn’t able to write my name. Awful! This was terribly awful. Really.”

At this stage of rehabilitation, all participants searched for a reason behind experienced difficulties with familiar activities. P6, for example, equated her deficits with having mental health problems: “You’ve now become a basket case’ I thought.” Furthermore, having difficulties when reading the newspaper, or when working on a computer, were believed as being due to “poor eyesight” (P7), forcing them to “look two to three times” (P6) until they were able to read something. At this stage of recovery, the participants did not yet relate these difficulties to their having USN.

Implementing coping strategies for neglect-related difficulties

Toward the end of rehabilitation, most participants had started implementing coping strategies for perceived neglect-related barriers to mastering daily activities. Strategies used ranged from delegating tasks to others, to doing them together with other people, to adopting an increased level of awareness toward their left side. P6, for example, explained how she now organized tasks with her husband, whereas she had previously completed these independently prior to the stroke incidence. *"We now do quite a lot of things together."* Besides cooking, they now shared doing some computer work, too: *"I cannot pay our bills [on the computer] at the moment, because I can't properly read the figures. Well, this would result in very funny bills if I did pay (laughs). No, my husband simply has to type them now. Yes - teamwork."* Besides the positive aspect of doing things together, P6 also described herself as *"being much more sensitive"* than before the stroke event: *"If my husband says something twice I do not agree with, I'm immediately grumpy. [...] He's a poor man with me now, and I feel sorry for him, but it's not that simple."*

P5 expressed experiencing a raised awareness toward his environment, which *"happened unknowingly"*: *"I take more care of what is on the left. This was already a problem from the beginning in the hospital. Because of the neglect, you know. That I don't always bump into the door frame. My awareness for that got raised. This doesn't happen to me anymore. [...] You simply take much more care of that."*

Theme 3: Comparing the new life with the old one

During the interviews, the participants often compared their current life situation with the one before their stroke. For P2, it was *"no better or worse than before"*, as he was able to cook, dress, and shower again independently, plus was able to work at the computer on his own once more. Most participants, however, perceived that changes had occurred, with associated decreases in pleasure and feelings of uncertainty and regret in some instances.

Perceiving changes

The participants talked about perceived changes. For P7, *"the whole of life has changed. It's simply not the same as it used to be. I'm not as fit and adventurous as I used to be. The body isn't the same anymore."* This change was not easy to accept for her, as she liked traveling to visit friends. P6 perceived herself being slower than before the stroke, which was difficult for her: *"When I have to be somewhere at 10 a.m. [...] I then check 100 times - well no, I am exaggerating now, but 20 times if it adds up what I have calculated to get up at the right time to be ready on time."*

Another example was given by P3, who used to be very active before his stroke: *"I always did something from morning till evening. I've been working 12 to 14 h a day and additionally did lots of things during my leisure time. I always used to be active - and now all of a sudden you're just a couch potato."* This change in identity triggered feelings of uncertainty and fear about his future employment.

Feeling tired was another issue most participants talked about. P6, for example, explained: *"I was tuckered out in the evenings. From 6 p.m. onwards, I would have been able to fall asleep standing up. [...] So many sensations bombarded me each day - they frazzled me out. It is getting better now with every week."* To cope with this tiredness, she started to take a nap after lunch to rest.

Experiencing a decrease in pleasure in meaningful activities

Both women expressed a decrease in pleasure in reading, one of their leisure time activities before the stroke: *"Then you try to read the newspaper. I don't like reading that much anymore, because I have much more difficulty reading. [...] I then think: 'is it worth reading it?' (laughs). This effort, you know. [...] No - reading isn't as nice as it used to be."* (P6). This change was perceived as *"difficult for someone who likes reading"* (P7). Another activity P6 did not like doing that much anymore was her computer work, *"because I have so much bother now doing my computer work"*.

Most men regretted not being able to resume certain leisure time activities that required physical effort. P4, for example, stated: *"I used to play bowls... well, if I'll ever be able to resume it is doubtful."* P2 liked gardening: *"You see the garden out there. I had lots to do which I now have to drop. The doctor said I shouldn't do anything in the garden - because of exhaustion."* P3 was especially desperate, as almost all of his hobbies were sport-related: *"I went skiing during winter time. I went sailing and biking during summer. I played music. None of that's possible anymore."* He considered learning to play the trumpet instead, which can be done single-handedly.

Discussion

This study identified three themes that described everyday life experiences of seven persons with right hemispheric stroke and USN, based on their recollections at or shortly after discharge from inpatient rehabilitation. The findings supplement existing literature by providing evidence of rehabilitation experiences from an insider's perspective, which might help to reduce barriers to providing the best possible care for USN patients [63]. They might enhance the rehabilitation process by, for example, enhancing the planning and implementation of therapy in accordance with the patient's stage of recovery, needs, and preferences [37,64].

Some of the findings in the present study are of particular interest for health professionals working with stroke patients and USN symptoms in an inpatient rehabilitation setting, which we would like to discuss below.

Unawareness of neglect

The initial unawareness of hemiparesis described in this paper triggered perceptions of mismatch between personal capabilities and results of actions, causing feelings of confusion and exasperation in some participants. Other patient groups, such as the traumatically brain injured, have also described similar feelings of loss of control over one side of the body [65,66]. Like our participants, they also experienced their body as 'something that can't be trusted', thus hampering their emotional response to their suddenly disabled selves.

According to the "pyramid model of awareness," restoration of this faculty occurs on three levels [67-69]: (1) intellectual awareness, where patients are aware of the types of deficits following stroke; (2) emergent awareness, where patients have regained partial awareness of deficits during task performance; and (3) anticipatory awareness, where patients are able to predict their task performance. Adopting this model in clinical practice might assist therapists in choosing the right intervention that fits the current stage of awareness recovery. Therefore, at this early stage, the study findings suggest implementing an educational approach for the patients to learn about the types of impairments following stroke to gain intellectual awareness [68].

The findings revealed that a lack of understanding for neglect-specific therapy by patients at an early stage of recovery might further aggravate their confusion. In order to diminish confusion, experts recommend choosing specific treatments by recovery phase and, thus, waiting with neglect-specific therapy interventions until the relevant level of awareness has been established [37]. For example, some participants described how they were convinced of being able to do more than the clinic staff allowed to, thus potentially increasing their risk of injury. Therefore, structuring the environment and providing greater levels of supervision to enhance neglect patients' safety during the acute stage of recovery are effective interventions [69], as was the case for P2's visits to the cafeteria.

Emergent awareness for neglect-related difficulties

During the course of rehabilitation, the participants described an emergent awareness for their neglect-related difficulties experienced during performance of everyday tasks such as reading and computer work. The more they engaged in doing daily activities, the more aware of their disabilities and the effects of these on their lives they became. This stage of recovery has been variously described as "fostering autonomy [44]," "adjustment," [45] and "constant strife for mastery" [50] over the problematic physical world and body. It is described as a process of adjustment often marked by setbacks [45], which triggers new modifications and simplifications of daily activities whenever possible. During this process, provision of an appropriately timed and measured therapeutic input can be challenging for health professionals. Examples of strategies designed to meet their specific needs during this adjustment process might be to (i) allow patients to practice daily activities on their own and – thus – experience setbacks, and (ii) provide sufficient time and support to gain familiarity with new therapeutic appliances [43,46].

Only after having recovered to a level of emergent awareness is the patient ready for a multicontextual approach to neglect-specific interventions [69]. Then, the combination of active learning of new skills to compensate for impairments with receipt of passive stimulation training seems to be most effective [69–71]. Examples for passive stimulation training include sensory cueing [72,73], prism adaptation [74,75], and virtual reality [54,76]. Evidence also supports the benefits of providing video and observer feedback [77]. For feedback to be successful, it is important to know patients' actual level of awareness in order to adjust both feedback and support accordingly [51]. Furthermore, adopting a feedback culture that is concordant among different health professionals (e.g., nurses, therapists, clinicians), might reduce the described perceptions of mismatches and, thus, enhance patient's comfort.

Toward the end of inpatient rehabilitation, some participants were able to predict their task performance and implement appropriate coping strategies to accomplish those activities successfully. These participants had regained a certain level of anticipatory awareness [67–69]. For example, doing tasks together that have been done independently prior to the stroke event, such as paying bills on the computer for P6, was a coping strategy that worked well for her and her husband. This creation of a "shared life-world" has previously been described [51], where family members have learned how best to assist their relative during task performance. For health professionals, it is therefore important to integrate families within the rehabilitation process to increase an understanding of what it means to live with a stroke and unilateral neglect [78]. Embracing an increased awareness for the

neglected environment is another example of a coping strategy, as for example adopted by P5 in order not to "bump into objects." This finding is in line with previous neglect studies [49,51], where participants increasingly screened the left side of the body and environment as a compensatory strategy. Learning from mistakes made in the "left-world" encouraged this searching process. Evidence suggests that health professionals should support patients in using their own strategies in a more structured way, rather than teaching new strategies. Additionally, the provision of external feedback, also from other patients in the clinic, might facilitate encountering the "left-world" [49,51].

Comparing the new life with the old one

During the interviews, participants often compared their current life situation with the one before their stroke. This experience of change, transition and transformation challenged the participants' sense of self by being confronted with a new post-stroke self. Participant P3, for example, perceived himself as a "couch potato" early after stroke, with inherent feelings both of anger and frustration. This challenge has been previously described as an ongoing process of re-interpretation of the post-stroke self [41,42]. Professional and family support are crucial at this time to assist patients to rebuild their lives through this experience. For health professionals, it is important to acknowledge that the present self of stroke survivors is not a desired self, which can cause tensions between the past and present self [66]. Engagement in meaningful occupations in familiar environments can facilitate this self-adaptation process [51]. In our study, the opportunity to go home over the weekend during inpatient rehabilitation supported this process.

Needing more time to perform ADL and being more tired thereafter were experiences reported by all participants. The stroke event creating effort where there had previously been none is a well-known phenomenon [44]. There is evidence that stroke-related fatigue can overwhelm participants' ambitions to be more active or independent [44]. For health professionals, it is important to recognize that recreational activities (e.g., reading, crafts, sleep, and electronic games) also form part of rehabilitation in order to reduce fatigue and, thus, improve the patient's capability to participate in therapy.

The study findings also emphasized how some patients experienced a decrease in pleasure in meaningful activities, as for example P6's comments about reading the newspaper. Experiencing difficulties in reading were also described by Lampinen et al. [50] and Klinke et al. [79], who recount resultant feelings of powerlessness. Interestingly, our participants talked mainly about leisure time activities that were important and meaningful to them, as they associated joy and pleasure during the performance. Therefore, addressing and integrating such meaningful activities during rehabilitation is deemed crucial to meet the patients' priorities, expectations, and goals.

Limitations and future research

The rather disproportionate number of men in our sample might have biased our results. It is likely that men and women differently respond to and deal with USN and its associated consequences, feelings, etc. Therefore, future studies should strive for a more homogenous sample regarding gender, neglect severity and presence of anosognosia.

During thematic analysis, distinguishing neglect-specific experiences from other depicted impairments - for example, those due

to the hemiparesis - was quite challenging, as those experiences are always intertwined. Therefore, a constant dialog between the co-authors of this study was a prerequisite for the selected chunks of data and related codes to match. A mix of data collection methods (triangulation), such as for example conducting interviews together with participation observation, might facilitate this process in future studies and increase validity of the findings. This approach has been taken in other studies [50–53].

We considered data saturation as reached when further coding relevant for the scope of our study was no longer feasible [80,81]. However, one might argue that a sample of seven participants with but one interview per person is insufficient for data saturation to be reached. This might be true in terms of reaching “meaning saturation” to “understand it all”, where 16 to 24 interviews are recommended [81]. However, potential participants, who were both well enough and willing to participate in this study, were hard to find. We were, therefore, pleased having reached at least “code saturation”, indicating that researchers have “heard it all” after seven interviews [81].

Future studies with this target group should consider applying a longitudinal design by conducting at least two interviews per participant. Follow-up interviews might give insight into how participants’ lives have developed over time and if anosognosia still persists [82], and how they reason about their inpatient rehabilitation from a more distant point of view. If adopting a longitudinal design, a narrative approach might be a suitable method of data analysis, focusing on change over time [83].

Conclusion

This study presents everyday life experiences of seven persons with right hemispheric stroke and USN symptoms near or shortly after the end of inpatient rehabilitation. The findings showed that all participants initially suffered from unawareness of USN during the early stage post-stroke. During the course of rehabilitation, most participants experienced an emerging awareness for their neglect symptoms, while comparing their current life situation with the one before their stroke. Only after having recovered to this level of “emerging awareness” is the patient ready for a multi-contextual approach to neglect-specific interventions. The study findings further highlight that being aware of neglect-related deficits is a prerequisite for using coping strategies and incorporating them in daily life. They inform health professionals regarding personal experiences of orientation in and reorganization of life in stroke patients with USN during inpatient rehabilitation. Based on the findings, health professionals should provide a multimodal, client-centered treatment approach fitting the current stage of recovery, while maintaining a collaborative relationship and open communication style with patients and their relatives.

Acknowledgments

We would like to thank the two collaborating clinics who made recruitment of potential participants possible, namely the Klinik Bethesda Tschugg and the Zürcher Höhenklinik Wald in Switzerland. Many thanks go to the seven participants for sharing their time and experiences with the first author. Final thanks go to Anina Röthlisberger for help in transcribing the interviews.

Disclosure statement

No potential conflict of interest was reported by the authors.

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