



UPPER-LIMB SENSORY IMPAIRMENTS AFTER STROKE: SELF-REPORTED EXPERIENCES OF DAILY LIFE AND REHABILITATION

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Objective: To describe stroke survivors' experiences of sensory impairment in the upper limb, the influence of such impairment on daily life, coping strategies used, and sensory training for the affected hand.

Design: A qualitative study with a content analysis approach.

Subjects: Fifteen post-stroke patients interviewed individually.

Results: Five categories emerged from the data: "Changed and varied perception of the sensation"; "Affected movement control"; "Problems using the hand in daily life"; "Various strategies to cope with upper limb disability"; and "Lack of sensory training". Numbness and tingling, changes in temperature sensitivity, and increased sensitivity to touch and pain were reported. Many subjects had difficulty adjusting their grip force and performing movements with precision. It was problematic and mentally fatiguing managing personal care and carrying out household and leisure activities. Practical adaptations, compensation with vision, increased concentration, and use of the less affected hand were strategies used to overcome difficulties. Despite their problems very few subjects had received any specific sensory training for the hand.

Conclusion: Stroke survivors perceive that sensory impairment of the upper limb has a highly negative impact on daily life, but specific rehabilitation for the upper limb is lacking. These findings imply that the clinical management of upper limb sensory impairment after stroke requires more attention.

Key words: stroke; upper limb; sensory; qualitative study.

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Up to 85% (1, 2) of persons affected by stroke have sensory impairments of the upper limb (UL), characterized by reduced sense of touch, temperature, pain and proprioception (3). Sensory impairments are associated with stroke severity (3, 4), decreased motor function (5–7), and are a prognostic factor for treatment outcomes (3, 8). Sensory impairment can prolong the duration of hospital stay (9) and negatively affect a person's ability to use the UL in daily life (8,

10–12). A framework that can be used to describe the consequences of sensory impairment on daily life is the International Classification of Functioning, Disability and Health (ICF) (13, 14). The ICF covers aspects of impairments, activity limitations and participation restrictions, as well as personal and environmental factors.

Even though sensory impairment is common after stroke only 2 studies have explored persons' personal experiences of such impairment. Connell et al. (15) interviewed 5 persons post-stroke and found that, although they were aware of the impairment, they had difficulty articulating the impact it had on their daily life. Doyle et al. (16) found that stroke survivors perceived that sensory impairment negatively affected their functional ability in daily activities, social roles and participation. In both studies the participants reported that little attention was paid to their sensory impairment in rehabilitation; instead the focus was on motor recovery, exercises for the lower limbs and mobility (15, 16).

Interventions that may improve UL sensation after stroke are mirror therapy, thermal stimulation, intermittent pneumatic compression (17), and cutaneous electrical stimulation (18). Furthermore, active sensory training, including sensory discrimination for the affected hand, has been shown to be more effective than passive stimuli alone (19). However, despite growing evidence that specific sensory training may be beneficial, the training approach seems to be difficult to implement in clinical practice (20, 21). Therapists report uncertainty about evidence-based interventions (22) and a need for more knowledge regarding the management of sensory impairment after stroke (23). Therapists have also reported the problem of limited access to adequate valid and reliable measures of outcome (20).

Thus, sensory impairment after stroke requires more attention, both in the clinical setting and in research. A more in-depth understanding of how such impairment influences daily life would enable clinicians to address this issue and design better individually targeted rehabilitation interventions. As the number of participants in the previous qualitative studies is low (15) and there may be cultural differences between participants' perspectives, more studies are needed. To the best of our knowledge no study has fully described subjects' own experiences of their UL disability, its impact on daily

life, and which coping strategies they use. In addition, little is known about which interventions patients have received and their perceived effectiveness.

Thus, the aim of this qualitative study was to further describe stroke survivors' experiences of sensory impairment in the UL, the influence of such impairment on daily life, coping strategies used, and sensory training for the affected hand.

METHODS

Research design

A qualitative design with individual interviews and an inductive content analysis approach was used (24). This research design is recommended when the aim is to obtain a rich and broad description of a phenomenon (25).

Participants

A purposive sample of 15 persons with stroke participated in the study, which is suggested to be a sufficient sample size to describe shared perceptions (26). Inclusion criteria were: sensory impairment of the affected UL, but an ability to grasp and release an object; ability to understand verbal and written information and to communicate verbally; age younger than 85 years; and at least 6 months since stroke onset.

A total of 47 persons with mild to moderate impairment of the UL were identified from a database at the Department of Neurology and Rehabilitation, Skåne University Hospital. Of these, 21 persons were chosen to reflect diversity regarding gender, age, time since stroke, hand dominance and degree of sensory impairment. An additional 3 persons were identified by colleagues in a daycare setting. Information about the study was sent to these 24 persons by post. After 1–2 weeks they were contacted by phone by the first author, who provided further information about the study, confirmed that they met the inclusion criteria, and asked if they were interested in participating in the study. They were also given the opportunity to ask questions and obtain more detailed information. Three persons were not contactable, and 6 declined to participate due to having no perception of sensory impairment, inability to be away from work, or for other reasons that were unclear. A final total of 15 persons (8 men, age range 35–78 years, time since stroke 6 months to 11 years) agreed to participate.

Ethics

Prior to inclusion both verbal and written informed consent was obtained from all the participants. The study was approved by the Regional Ethical Review Board in Lund Sweden (Dnr 2015/296).

Data collection

Interviews were conducted by the first author at the Department of Neurology and Rehabilitation Medicine, Skåne University Hospital between May and December 2015. All participants had received primary rehabilitation at the department and 5 had had professional contact with the first author 2.5–7.5 years prior to the study. Before the interview, each participant was informed about the purpose of the study and encouraged to be as truthful as possible. A semi-structured interview guide based on the domains of the ICF model was used (14). The questions

covered the following areas: perception of the impaired sensation of the UL; how it affects daily life; how to cope with UL disability; and experiences of sensory training for the affected hand. Follow-up questions, such as: "Can you give an example?" and "Please, describe" were used to encourage the participants to give a rich description of their experiences. Interviews lasted between 15 and 70 min, with a mean of 38 min.

Data analysis

All interviews were recorded and transcribed verbatim by the first author. Analysis was performed according to Graneheim & Lundman (24). First, all interviews were read several times to gain a sense of the whole material. Meaningful units in the text that answered each research question were then identified. The meaningful units were condensed and labelled with preliminary codes. The third author took part in the analysis process and had access to the raw data. The first and third authors (physiotherapists) discussed and refined the findings, which were validated by the second author (a physiotherapist and psychologist) throughout the process. The codes were discussed between all authors until consensus was obtained. Then the authors discussed and reached agreement on how to organize the codes into subcategories based on their similarities and differences. Finally, the subcategories were grouped into categories.

RESULTS

The 5 categories that emerged from the analysis were: "Changed and varied perception of the sensation"; "Affected movement control"; "Problems using the upper limb in daily life"; "Various strategies to cope with upper limb disability"; and "Lack of sensory training". The 5 categories comprised 8 subcategories (see Table I), which are presented below with illustrating quotes.

Changed and varied perception of the sensation

Numbness and tingling. Several participants reported a strange feeling in their hand, such as numbness or tingling, whereas others felt a burning sensation. Another common feeling was that the fingertips were asleep, comparable with dental anaesthesia. These sensations often became worse when they tried to use the hand in activities. Some participants perceived that the UL was not alive, whereas others reported a feeling of heaviness.

Table I. An overview of the categories and subcategories

Categories	Subcategories
Changed and varied perception of the sensation	Numbness and tingling Changes in temperature sensitivity Increased sensitivity to touch and pain
Affected movement control	Difficulty adjusting the grip force Proprioceptive and perceptual difficulties
Problems using the upper limb in daily life	Personal care and dressing difficulties Difficulty with cooking and eating Difficulty performing leisure activities
Various strategies to cope with the upper limb disability	
Lack of sensory training	

My hand feels like it, how do I say this, it doesn't feel alive (Participant P7)

Changes in temperature sensitivity. Many reported that the affected UL was more sensitive to cold and that the hand was often perceived as cold even if they wore gloves. Some reported that this sensitivity increased the risk of cramp and muscle stiffness.

I experience cold a lot, then it [the arm and the hand] gets completely stiff (P7)

Participants also reported difficulty judging temperature and detecting the difference between warm and cold water. Some experienced a delay in the perception of heat; for example, when holding a hot beverage or taking something out of the oven.

When I'm sitting with a cup of coffee in my hand, the coffee feels usually hot if I hold it with my right hand. But if I hold it with my sick hand, the left one, it can be pleasant (P11)

Increased sensitivity to touch and pain. Some subjects reported increased sensitivity or a different sensation when somebody touched the affected UL or when they explored different textures and objects in the hand. These situations were described as unpleasant and painful experiences.

... when my husband touched my arm... he couldn't touch it; I was hurting because then it was like... don't touch me... (P3)

Affected movement control

Difficulty adjusting the grip force. Difficulty adjusting grip force in different daily situations was also reported. Many participants used too much pressure when holding or manipulating an object, because they were afraid of dropping it. Some said that they had lost their automatic movements and had to increase their concentration when holding or carrying an object, which led to increased mental fatigue. Inability to adjust the grip force when shaking hands or holding on to another person was also perceived as problematic by a few participants.

I can't adjust it... portion that force... it becomes firm, don't drop it, hold it firmly (P2)

Proprioceptive and perceptual difficulties. Many participants had difficulty feeling the position of their UL and performing smooth movements with precision. They reported difficulty recognizing small objects with their hand without vision, for example identifying an object in their pocket by touch alone. Others reported a continuing feeling of having something left in their hand even after they had put it away.

I have difficulty controlling my hand because I don't really know where it is in space (P12)

Problems using the upper limb in daily life

Personal care and dressing difficulties. Difficulty personal care performing activities, such as showering and using a towel afterwards, cutting nails, applying make-up, brushing teeth, combing the hair while simultaneously using a hair-dryer, were described as a huge problem by most of the participants. Putting on earrings and styling the hair with gel were also perceived as difficult by some.

And then combing my hair and drying and curling it, it's difficult for me, it doesn't really turn out well (P15)

Many participants also reported difficulty dressing themselves, particularly in tasks that require dexterity, such as tying shoelaces, pulling up zips and buttoning trousers and shirts. Others mentioned that the sensory impairments became worse when they were stressed and in a rush.

I don't feel the button hole so [that] I can hold it with my left hand and take the button with my right, but I don't feel it (P7)

Difficulties with cooking and eating. Many reported difficulty peeling potatoes, slicing bread, and cracking an egg, due to problems with holding the wrist in the correct position and controlling grip force. Grasping objects, such as a milk carton, or lifting a plastic cup were also perceived as problematic, as was increasing the speed of movement when chopping or whipping food.

I have the power, but in some kind of way I don't really know it... maybe I'm not holding the potato enough... I think I have it but when I pull back the peeler it jumps out of my grasp (P8)

To coordinate the knife and fork when cutting and eating was another common problem and the participants reported that they often had a feeling of being observed in restaurants when eating.

I do think it's a little hard not being able to eat with a knife and fork like others do (P5)

Difficulty performing leisure activities. The sensory impairment also influenced the participants' ability to perform leisure activities, such as gardening, playing the piano, boules, tennis, and applying the brakes on a bicycle. Driving a car was also challenging, for example finding the safety belt or the gear-lever without vision, or managing the cruise control and indicators. Fatigue in the arm while holding the steering wheel was also reported.

It's a lot worse, I used to be able to play the piano but I can't do that now (P1)

Now I can't find the gear stick, the hand lands to the side of it.... or if it's just that the sense is not there so you can't feel it (P6)

Handling technical products and tools was also reported as problematic; for example, writing on the computer, handling the TV remote control, and taking pictures with a camera. Using a mobile phone was perceived as difficult, especially phones with a touch screen.

The remote control for the TV is more difficult, because then you have to hold it, search with the thumb and then I have to look (P8)

Another common problem was writing with a pen; feeling the pen in the hand, using the proper grip and forming letters. Difficulty using a screwdriver or holding a nail or a screw with the affected hand was also perceived as problematic by some participants.

I can't get to it [writing], the letters get quadratic as the pen slips away (P14)

Various strategies to cope with upper limb disability

Participants used a variety of strategies to cope with everyday difficulties. Some had accepted that recovery of their affected UL would no longer occur, and made less effort to use the impaired hand in daily life. Others had relearned how much force they should use when holding and manipulating different objects, or had learned to carry fewer things simultaneously.

I've learned how much to hold for different objects in order not to drop them (P3)

Some participants reported that they often used the non-affected hand instead, especially for activities that required precision (e.g. eating). Others used the non-affected hand in situations when the effort was too great to use the affected hand and when they could not rely on it. However, participants with their dominant hand affected reported that it was sometimes impossible to use the non-dominant hand for activities that required precision, such as tooth-brushing and applying make-up.

Usually you grasp with the wrong hand, you become so lazy, or well lazy isn't the right word, it's more of a natural reaction because you don't want to sit and use the bad hand when you know you have a good hand (P6)

Some participants compensated their sensory impairments with vision to improve eye-hand coordination and to be able to confirm what they had in their hand. Increased concentration when using the affected hand in daily activities was another strategy.

If I have to concentrate so much on things I'm going to do, holding neatly or firmly, I get tired, it becomes tough... (P13)

Practical adaptations were also used to make everyday life easier. One participant reported how he used to place his keys in a pocket on the non-affected side. Other strategies were using shoes with elastic shoelaces, clothes without buttons, a string attached to the zip, safety gloves at work, and an adjusted keyboard when

writing on the computer. Some used extra household utensils to be able to chop onions and unscrew corks.

I can help a little bit to hold, zip up my jacket, I have a string that I pull to manage it (P4)

Lack of sensory training

Very few participants reported that they had received any specific sensory training for their affected UL. One participant had trained the hand by touching various surfaces and textures, but was uncertain if this was related to the impaired sensation. Another person had received electrical stimulation and acupuncture. One woman reported that she manipulated different rings in her hand as a training exercise at home.

... and then that I have to touch different surfaces... but that doesn't have to do with the touch, or does it...? (P15)

Instead, most reported that the focus was on other types of training, such as gross and fine motor skills, as well as strength and mobility training for the UL. Some participants had received constraint induced movement therapy, but were uncertain if the aim of the therapy was to improve the sensation. Instructions to use the UL as much as possible in daily life or a home training programme from an occupational therapist or physical therapist were other training strategies mentioned.

I didn't think about it so it was probably more focus on fine motor skills and gross motor skills (P5)

Many reported a desire to receive more task-specific training for the UL, during both inpatient and outpatient rehabilitation periods. Instead of having a more general training programme after discharge some said that they would have liked a more specific training programme for the UL, focusing on activities related to daily life.

I was interested in my daily life starting again. A lot of the exercises I received were nothing I could make use of in daily life (P10)

DISCUSSION

This qualitative study shows that persons with sensory impairment of the UL after stroke experience a changed and varied perception of the sensation, leading to affected movement control and problems using their hand in many daily situations. A variety of strategies were used to overcome these difficulties. However, despite their problems very few participants had received any specific sensory training.

Changed and varied perception of the sensation

Numbness and tingling, changes in temperature sensitivity, as well as increased sensitivity to touch and pain, were reported among participants. The percep-

tion of increased cold sensitivity increased the muscle tone and thereby augmented the perception of a stiff and clumsy arm, which further negatively affected movement control. Reduced ability to judge temperature increased the risk of receiving a burn and thereby impacted on safety in many daily activities.

Some participants experienced mild sensory impairment of the skin, whereas others had a feeling of dental-like anaesthesia, or almost complete loss of touch, as if the arm was not alive. These experiences are in agreement with another qualitative study in persons with sensory impairment after stroke (16), in which participants perceived that the UL felt as if it was dead or was not part of the body. Moreover, in the current study some participants reported an increased and unpleasant sensitivity to touch from another person. These experiences of hypersensitivity may limit the person's intimate relationships. In a study by Sjögren & Fugl-Meyer (12) it was reported that impaired cutaneous sensation could be a major negative factor for sexual intercourse.

Affected movement control and problems using the upper limb in daily life

The impaired sensation also affected proprioception and movement control of the hand. Difficulty performing smooth movements with precision and adjusting the grip force when lifting, holding and carrying objects were situations that many participants perceived as problematic, especially when they had to concentrate on 2 things simultaneously. Many participants reported difficulty using the UL for bimanual activities that required dexterity, for example in personal care and household activities, and that this became even more problematic in stressful situations. Similar problems in personal care and meal situations were reported in a study by Doyle et al. (16). However, the participants in the current study gave richer examples of everyday difficulties, leading to a more in-depth understanding of their problems.

The increased concentration required in dexterity-related activities was perceived as exhausting. These experiences are in agreement with earlier studies, which have reported that stroke survivors with impaired sensation experience increased effort during UL movements and while grasping (27) and have increased consciousness of how to handle the problems (16). This indicates that sensory impairments after stroke require a lot of patience, time and effort, which may further add to the fatigue experienced following stroke.

Impaired sensation of the UL also restricted perceived participation and the ability to perform leisure activities. The feeling of being observed in restaurants

because of problems using cutlery efficiently affected participation and hindered socializing with others. Similarly, difficulty handling smartphones and tablets to purchase tickets, manage personal banking and maintain contact with friends via social media also restricted participation. These findings emphasize the need to develop technical products that are better tailored for persons with UL disabilities. Moreover, many participants in our study perceived problems when bicycling, gardening, participating in sports, or driving a car. It has been shown that driving is a significant factor in the frequency of social and leisure activities after stroke (28) and that involvement in leisure activities is related to how content persons are with their lives (29). Not being able to continue meaningful leisure activities because of sensory impairment of the UL could have a negative impact on a person's well-being and should be considered in rehabilitation.

Coping with upper limb disability

To overcome perceived difficulties the participants used a variety of strategies, such as vision compensation, increased attention and avoidance of using the affected hand, in line with previous studies (16, 27). Another common strategy among participants in the current study was to use technical aids to compensate for impaired sensation. However, although activities may be easier to perform with the use of technical aids, current brain research shows that recovery and long-term improvement of the UL is facilitated by active movements and task-specific training (30). Not using the affected hand may lead to "a learned non-use phenomenon", i.e. a condition in which the person does not use the affected arm and hand as much as they can (31). Therefore, it is important to support persons with sensory impairments of the UL to use their affected hand in daily life in order to prevent further decline in functioning.

Different experiences of sensory training

Only one participant had received specific sensory training for the hand, i.e. similar to the sensory re-learning training, as reported by Carey et al. (19), but they were not aware of the purpose of the training. The reasons why clinicians pay little attention to sensory training in stroke rehabilitation vary. Pumpa et al. (20) have shown that therapists report barriers, such as lack of time and resources, but also report having a limited knowledge of evidence-based interventions (23). The lack of sensory training was also evident in our study. Instead, focus during the training was on motor function, as has been reported previously by Connell et al. (15) and Doyle et al. (16). Altogether, this implies that the management

of sensory impairment of the UL after stroke needs to be improved. Education for therapists should focus on assessment of the sensory impairment, meaningful goal-setting related to the UL sensory impairment, as well as providing specific sensory training (23).

Clinical implications and methodological considerations

This study has contributed to a deeper knowledge of how stroke survivors experience the influence on daily life caused by sensory impairment of the UL, and which strategies they use to cope with the disability. The findings partly confirm previous studies (15, 16), but further illuminate that sensory impairment of the UL after stroke is complex and deserves more attention in clinical settings. There is growing evidence to support the need for specific sensory-focused interventions worldwide, not only in Australia and the USA, but also in Scandinavia, as suggested by Pumpa et al. (20) and Doyle et al. (21).

In order to achieve rigour and trustworthiness in the present study, credibility, dependability, confirmability and transferability were considered (24, 32). Participants were purposively selected regarding gender, age, time since stroke, hand dominance and degree of sensory impairment. A semi-structured interview guide was used with follow-up questions to provide a variety of aspects of participants' experiences. To further enhance the credibility of the results the authors continuously discussed the subcategories and categories until a consensus was reached and quotations from different participants were inserted to verify the results (24). All authors were flexible and changed perspective in accordance with the analysis process, thus ensuring dependability. Concerning confirmability, all authors tried to stay neutral to the data. The first author had had professional contact with 5 participants several years prior to the study, but this was not thought to influence the present results. The first author's experience of stroke rehabilitation may have deepened the understanding of the data collection, but the pre-understanding was considered carefully during the analysis. The study population was a selected group of persons with mild to moderate sensorimotor impairment of the UL after stroke and somewhat younger than the mean age of first-ever stroke patients. Therefore, the results cannot be transferred to all persons with stroke, but may be relevant for persons with similar disability of the UL after stroke and for persons with other neurological disorders.

In conclusion, stroke survivors perceive that sensory impairment of the UL has a highly negative impact on daily life, but specific rehabilitation for the UL is lack-

ing. These findings imply that more attention should be given to the clinical management of UL sensory impairment after stroke.

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