

Stroke Survivors' Experiences of Upper Limb Somatosensory Retraining

An Interpretative Phenomenological Analysis

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Upper Limb Somatosensory Impairment Following Stroke

- 👉 Approximately 50% of people cannot detect or interpret bodily sensations in the upper limb after stroke.
- 👉 Stroke survivors report somatosensory loss impacts negatively on their performance, roles, and participation in life situations.
- 👉 Stroke survivors typically receive minimal rehabilitation to treat sensory impairment.
- 👉 Quantitative evidence shows upper limb somatosensory discrimination retraining can help people improve their sensation after stroke.

Aim

- We aimed to investigate stroke survivors' experiences of participating in a program of somatosensory discrimination retraining that is based on principles of neural plasticity and learning and designed to help the person to regain a sense of touch and use it in daily activities.



Helping stroke survivors regain a sense of touch

Research Questions

- a) How do stroke survivors perceive and describe their experience of sensory retraining?
- b) What motivates people to participate in sensory retraining?
- c) What variables do stroke survivors perceive and describe as impacting on their ability to learn and/or perform during somatosensory discrimination retraining?
- d) What changes do people experience following upper limb somatosensory retraining?

Recruitment and Participants

- 👉 We recruited participants who had participated in a randomised control trial of upper limb sensory retraining.
- 👉 We purposively selected a sample of 14 (out of 36 participants) stratified for age and treating therapist.
- 👉 A total of 8 participants replied to the invitation and participated between August 2016 and January 2017.
- 👉 All received SENSE training of texture, proprioception, and object recognition and application of principles to 2 personally-important tasks.



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Method

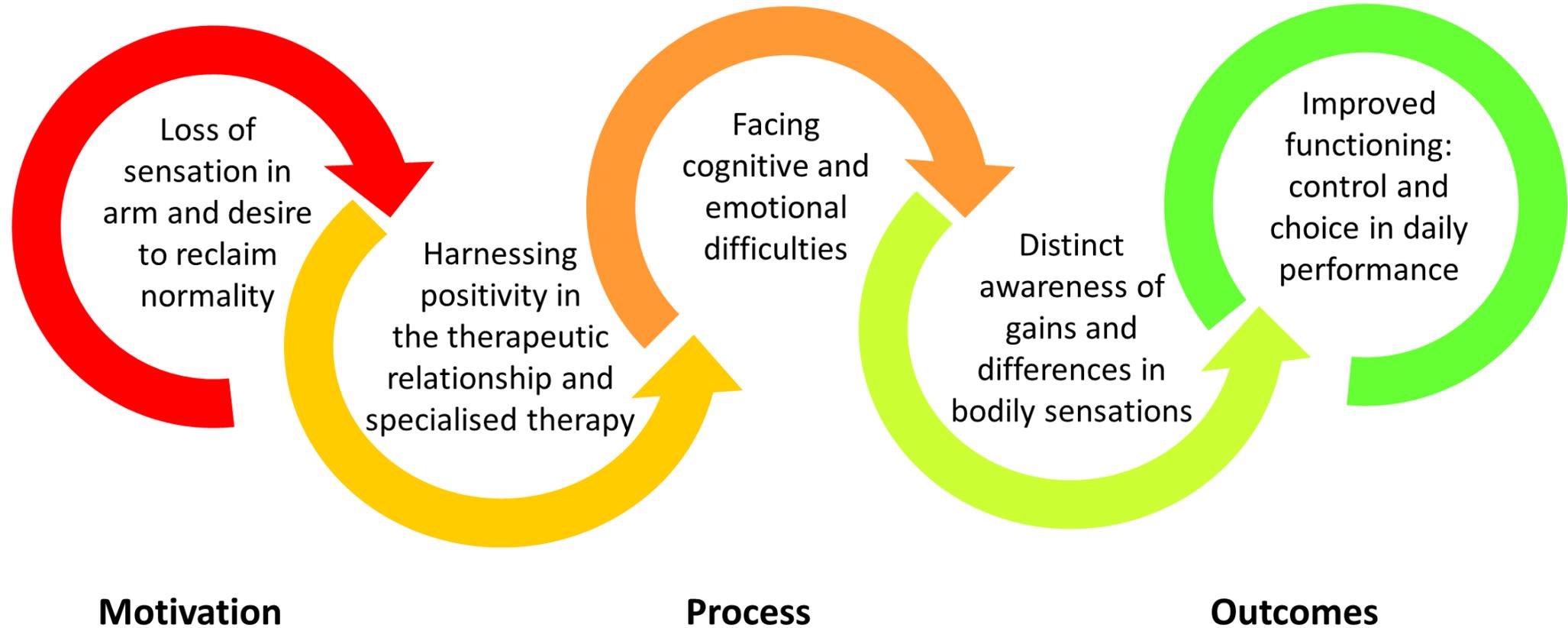
- Qualitative: Interpretative Phenomenological Analysis (IPA) was used to understand, in detail, each person's unique view of somatosensory retraining after stroke.
- Semi-structured interviews were used to obtain qualitative data.
- The interviewer had no prior relationship with the participant, but had experience delivering sensory retraining
- Data analysis involved an iterative process following recommendations from leaders in the field of IPA. Themes reflected the psychological essence of the experience.

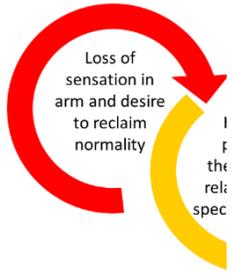
Results

Participant Characteristics

- 8 participants with stroke and upper limb somatosensory impairment
- 3 females and 5 males
- Average age was 46 years (range: 31 to 61 years)
- Mean time post stroke was 2.5 years (range: 5.5 mths to 4.6 years)
- 6/8 participants with their dominant hand (right) affected
- Varying severity of somatosensory impairment and most had some degree of motor ability

Themes





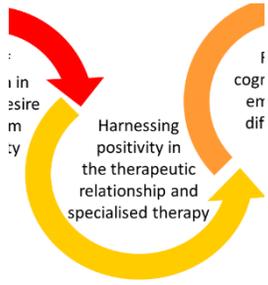
Loss of Sensation in Arm and Desire to Reclaim Normality

“I don’t feeling nothing, nothing at all [...] no sensation at all” (Carlos)

“...I couldn’t really do daily stuff [...] I couldn’t hold anything, things were just dropping, yeah so I had nothing, there was nothing there” (Maria)

“It is very difficult for people to understand the experience that you are having when you can move your hand but you can’t feel [...] and no-one around you will accept that it is real, you are kind of fighting on both fronts” (Veronica)

“You just want to get as good as you think you’re going to and that is hard. I mean I was 58 and that for me is too young” (Julie)



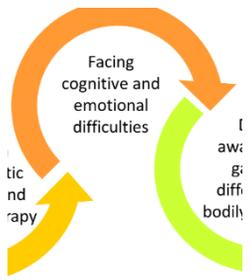
Harnessing Positivity in the Therapeutic Relationship and Specialised Therapy

Collaborative effort: “We both worked so hard, so, so, so hard. Like we really both gave it our all” (Veronica).

Shared knowledge: “Not only, was doing the activities as important but also from my point of view was understanding, and the therapist was really good at explaining why we were doing certain things [...] and that was fantastic” (Simon).

Goal focused and Problem solving resources: “Asking her where she got that from and she would say ‘oh yeah I walk around thinking oh yeah that would be good’ and you just don’t think about that” (Julie).

Encouragement and Emotional support: “Positive, positive. There was always an element where I was really asked how I was feeling in the training and that was fantastic [...]” (Simon).

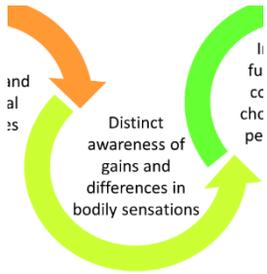


Facing Cognitive and Emotional Challenges

“It was from a completely different type of thinking and processing than I had ever been used to [...] It was always a positive thing, it was challenging but I wouldn’t have changed it, I knew it was working then.” (Maria).

“When I first started, ... as we went on each session I get very tired [...] I don’t think I realised how much the change had occurred and it is ongoing. That something is gone but then something else is on.” (Julie).

“I’m going there [sensory retraining] and I sure nothing going to happen. I just think to myself what am I doing here you know [...] The therapists explained things very well just the way I feeling cos I never had a stoke before. I don’t know the way things work you know” (Carlos).



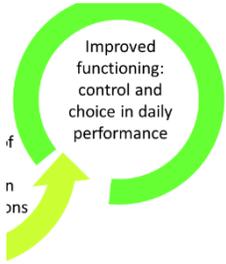
Distinct Awareness of Gains and Differences in Bodily Sensations

“When I started I had no clue they were different and by the end I was picking everything up [...] Um, so, so, so the changes that I experienced in terms of my sensing were pretty remarkable”
(James).

Yeah, 100%. It just like when I didn't have the retraining to when I done it, it's like chalk and cheese, just, chalk and cheese [...] It done wonders for me, like, um, in sensation. [...] (Michael).

The difference that it made for me is indescribable. Um, it is like for a blind person their eyes move but they don't see, it is that, your hand moves but it doesn't see. And the difference in what you can do when you can feel something as opposed to not feel something just is indescribably different in life [...] (Veronica).

“It has become part of my routine, especially things like transferring what I feel on my good side and critically thinking about that and trying to understand what feels like on my good side and then transferring that to my affected side and trying to feel the same ridges on a piece of clothing, or top, or whatever [...] (Simon).



Improved Functioning: Control and Choice in Daily Performance

“I always use my right (affected) hand. In our daily life, sensory retraining does a lot of things for me [...] I can do all the things at work, at home, the driving” (Kevin).

“It helped me like getting dressed, cos like you have to use both hands to pull up your pants and just day to day stuff like driving, just feeling the steering wheel, like cutting up food” (Michael).

“It gave me skills for everything I need in my job, my daily work [...] I felt so proud and so grateful [...] (Maria).

Much easier, everything is different, unbelievable. It's like a glass of water and a glass of wine, but its true [...] and now I go for walk and if I see a coin I pick it up (laughter) (Carlos).

Conclusion

- 👉 People change with somatosensory retraining; they know joy and pride in their sensory and functional gains.
- 👉 Sensation may still feel less than perfect after retraining, yet people can connect with and use their arm in ways that provide control, confidence, and choice in daily performance and participation.

Implications for Rehabilitation

👉 People experience meaningful somatosensory and functional gains with a perceptual learning, neuroscience based approach to upper limb sensory discrimination retraining after stroke.

👉 Stroke survivors report a desire to improve their sensation and reclaim normality, and thus should be offered the opportunity in rehabilitation to remediate somatosensory deficits, such as with somatosensory discrimination retraining.

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Declaration of Interest Statement: L. M. Carey was the original developer of the sensory retraining program investigated in this study. For this reason, M. Turville and J. Walker were involved in data collection and analysis.



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