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Exploring sensory changes and social withdrawal among stroke survivors: a qualitative study

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Abstract

Background Sensory changes are common among stroke survivors, significantly impacting their ability to engage in meaningful activities of daily living and participation in social interactions. However, these sensory changes often go unrecognized in clinical settings often resulting into inadequate rehabilitation and reduced quality of life. This study aimed to examine how these sensory changes affect activity participation among stroke survivors.

Methods This qualitative study had a total of 35 participants. These included 20 stroke survivors (12 males and 8 females) and 15 stakeholders (8 females and 7 males) consisting of 8 occupational therapists, 4 physical therapists and 3 caregivers, with at least 2 or more years of professional experience. These were recruited through purposive sampling of regional stroke support groups, stroke outpatient clinics, and online rehabilitation forums in swat district, Pakistan. Data was collected through focus group discussions held via Zoom between January and March 2024 in order to investigate the lived experiences and perspectives on post-stroke sensory changes. Resulting data was thematically analyzed.

Results The main themes identified by all participants (stroke survivors and stake holders) were; (1) sensory changes frequently go unnoticed during clinical assessments, (2) Sensory changes significantly disrupt routine engagement and active participation in activities of daily living, (3) sensory changes lead to social withdrawal and isolation, and (4) limited resources and the absence of standardized sensory assessment tools hinder effective management of these sensory changes.

Conclusion The results highlight an urgent need to incorporate targeted sensory assessments and interventions into stroke rehabilitation programs. Future research should focus on creating standardized sensory changes assessment tools to assist in their mitigation.

Keywords Stroke, Sensory impairments, Social participation, Sensory overload, Stroke rehabilitation



1 Introduction

Stroke is acknowledged as a leading cause of long-term disability worldwide, with around 13.7 million cases reported annually [1]. Sensory health plays a crucial role in functional independence and overall well-being, as the ability to process and respond to visual, tactile, gustatory, olfactory and vestibular sensory information is essential [2]. However, sensory changes, which affect about 47% of stroke survivors in one study [3] and 75% in another study [4] are often under-assessed in clinical settings as literature has shown that post-stroke rehabilitation protocols mainly focus on motor and cognitive evaluations [2, 5]. This oversight fails to consider how sensory changes affect participation in meaningful activities such as social interactions, employment and selfcare, all of which are vital for both mental and physical well-being of post-stroke survivors [6].

For instance, visual impairments may induce anxiety in complex environments, while altered taste or smell can interfere with eating habits and social interactions thus diminishing the quality of life. Health can be conceptualized as the balance between an individual's sensory capabilities, sensory demands of their environment and activities of daily living [7]. The interplay between sensory changes, environmental needs and participation in activities of daily living is not well understood [8, 9]. Post-stroke sensory changes may lead to communication breakdown, feelings of being overwhelmed in stimulus rich environments thus resulting into social isolation and reduced engagement in meaningful activities [7, 10, 11].

Recent studies have underscored the significance of sensory modulation therapies like weighted tools that include; weighted blankets, vests or neck wraps to provide deep pressure stimulation, environmental modifications like dimming lights, creating quiet zones, playing calming music, cognitive behavioral techniques like mindfulness, breathing techniques and many others which are aimed at addressing these sensory changes. These therapies show promise in alleviating sensory changes leading to enhanced activity participation [2, 9, 12].

Factors such as limited access to specialized rehabilitation services in low-income settings may worsen these sensory changes [7]. Furthermore, cross-cultural research has revealed variability in access to sensory changes rehabilitation, with language barrier and cultural attitudes toward disability affecting outcomes in diverse populations [13]. Despite the known undesirable effects of sensory changes among post-stroke survivors, there is still a significant gap in incorporating targeted sensory assessments tools and interventions within stroke rehabilitation protocols especially in resource limited settings [4]. This qualitative study aims to fill this gap by exploring how sensory changes influence engagement in meaningful activities among post-stroke survivors residing in a low resource setting, Swat district, Pakistan.

2 Methods

2.1 Design

This was a qualitative study that aimed to explore the impact of sensory changes on activity participation among post-stroke survivors.

2.2 Participants and setting

Thirty-five participants (20 stroke survivors and 15 stakeholders consisting of 8 occupational therapists, 4 physical therapists, and 3 caregivers) were recruited through

purposive sampling of regional stroke support groups, stroke outpatient clinics, and online rehabilitation forums in swat district, Pakistan. The participants were placed in seven cohorts of five participants each. With four cohorts consisting of five stroke survivors, per cohort and three cohorts consisting of five stakeholders, per cohort.

Stakeholders needed at least 2 or more years of experience working with stroke survivors.

Inclusion criteria for the stroke survivors; (i) aged 18 years and above; (ii) a diagnosis of ischemic or hemorrhagic stroke in the last 24 months; (iii) Fluent in Urdu, Pushto, English, or Arabic and capable of participating in video conference calls and lastly, (iv) a resident of Swat District, Pakistan. The sample size was determined through the principle of data saturation to the point at which no new themes emerged from the newly collected data.

Exclusion criteria for the stroke survivors; (is) Those who are mentally unstable with conditions such as depression or schizophrenia, (ii) those with significant motor or speech issues, (iii) stroke survivors with pre-existing neuropathies like those with diabetes, (iv) Those with pre-existing neurological conditions like Parkinson's, Alzheimer's disease, Huntington disease, amyotrophic lateral sclerosis, and lastly, (v) those with cognitive difficulties and therefore unable to follow instructions or participate in a video conference call for at least 45–60 min.

2.3 Data collection

Data was collected through focus group discussions conducted via a secure video-conferencing platform (Zoom) with a total of two sessions per cohort. Each session lasted approximately 45–60 min and was moderated by two trained researchers using a semi-structured interview guide. The semi-structured interview guide was developed with insights from the adolescent/adult Sensory Profile [14] ensuring that the questions effectively covered sensory changes in the visual, auditory, gustatory, olfactory, and tactile domains. Stroke survivors and stake holders interview guides are included as supplementary materials (SM 1).

Sessions were audio-recorded and transcribed verbatim using automated transcription software followed by manual verification for accuracy. The participants provided written informed consent, and all data were anonymized to ensure confidentiality and were provided with guidelines to ensure a safe, comfortable environment. Moderators were trained in qualitative techniques (e.g. managing group dynamics and probing for depth) using a standardized semi-structured interview guide to maintain consistency.

To ensure data quality, environmental factors such as internet connectivity issues reported by 10% of participants were addressed through technical support and rescheduling.

2.4 Data analysis

All focus group discussion transcripts were included in the thematic analysis to ensure a comprehensive evaluation of participant perspectives. A hybrid approach combining inductive and deductive coding was employed. Initial codes were derived from research questions of a similar study [15] while new codes were added as they emerged from the data. Themes were identified by grouping related codes and refined through team discussions. Multiple researchers agreed upon final themes to ensure consistency and

Table 1 Baseline characteristics of participants

Characteristic	Stroke survivors	Stakeholders	Notes
Age (mean, SD)	58 years (SD 8.2)	42 years (SD 6.5)	
Sex (% male)	60%	47%	
Time since stroke (range)	6–24 months	N/A	
Stroke severity (NIHSS, mean)	7.5 (SD 2.1)	N/A	NIHSS = National Institutes of Health Stroke Scale; estimated from records
Comorbidities (% with ≥ 1)	65%	N/A	
Professional experience (years, mean)	N/A	5.2 (SD 2.8)	

validity. Data was analyzed using NVivo 14 software through a two-stage coding process: open coding to identify initial patterns and focused coding to refine themes. A codebook was developed based on a literature review [9, 15] and iteratively refined after the initial coding to incorporate emergent themes. Three researchers independently coded the transcripts, meeting after each round to discuss discrepancies and reach a consensus. To enhance rigor, we conducted member checking with five participants to validate the themes.

A third round of analysis confirmed four thematic legends. Inter-rater reliability was determined based on the code given to each participant response and was assessed using Cohen's kappa which yielded a value of 0.82, indicating strong agreement.

3 Results

The study had a total of 35 participants. These included 20 stroke survivors (12 males and 8 females) and 15 stakeholders (8 females and 7 males). The stakeholders consisted of 8 occupational therapists, 4 physical therapists, 3 caregivers who had at least 2 or more years of professional experience. The age range of the therapists (Physical therapists and Occupational therapists) was 35–46 years while that of the caregivers was 50–60 years (Table 1).

3.1 Thematic findings

The four primary themes identified were; (1) sensory changes frequently go unnoticed during clinical assessments (2), Sensory changes significantly disrupt routine engagement and active participation in activities of daily living (3), sensory overload leads to social withdrawal and isolation, and (4) limited resources and the absence of standardized sensory assessment tools hinder effective management of these impairments.

Theme 1: Sensory changes frequently go unnoticed during clinical assessments

Sensory issues were seldom assessed and often went unnoticed until after discharge. For example: “...I did not realize I could not smell until I burned something while cooking...” (Participant 12, Stroke survivor), “...No one checked my senses in rehab...” (Participant 1, Stroke survivor), “...I didn't know I lost my sense of smell until my wife pointed it out...” (Participant 6, Stroke survivor), “...Rehab focused on walking not hearing...” (Participant 8, stroke survivor), “...I didn't notice my smell loss until later...” (Participant 14, Stroke survivor), “...Rehab didn't address this...” (Participant 16, Stroke survivor), “...No one checked this in hospital...” (Participant 18, stroke survivor). “We test strength and coordination, but sensory deficits? They are easy to miss.” (Participant 22, Physical therapist), “...Patients often mention light sensitivity but it's not assessed...” (Participant

21, Occupational therapist), "...Taste changes affect diet, but we don't test for it..." (Participant 23, Occupational therapist), "...Sensory assessments aren't standardized in treatment protocols..." (Participant 27, Physical therapist), "...Smell loss is overlooked, risking safety..." (Participant 28, Occupational therapist), "...Touch deficits slow recovery, but we don't assess for them..." (Participant 32, Physical therapist). Caregivers noted sensory impairments were not addressed until they affected daily tasks, such as detecting spoiled food (Participant 33, Caregiver), "...She can't smell, which I noticed first..." (Participant 34, Caregiver).

Theme 2: Sensory changes significantly disrupt routine engagement and active participation in activities of daily living

Sensory changes profoundly impacted participation in everyday tasks for example, visual impairments created challenges navigating crowded spaces: "...Bright lights make me dizzy, so I avoid stores..." (Participant 1, Stroke survivor), "...Food tastes bland, so I don't cook anymore..." (Participant 2, Stroke survivor), "...Blurry vision makes crowded places scary..." (Participant 3, Stroke survivor), "...Food doesn't taste right, so I eat less..." (Participant 4, Stroke survivor), "...My hands feel numb, making chores tough..." (Participant 7, Stroke survivor), "...I can't taste spices, so cooking isn't fun..." (Participant 9, Stroke survivors), "...I can't smell gas leaks, which worries me..." (Participant 10, Stroke survivor), "...Blurry vision makes driving impossible..." (Participant 13, Stroke survivor), "...I can't feel textures, so I avoid crafts..." (Participant 16, Stroke survivor). Changes in taste diminished enjoyment of cooking and dining: "She stopped cooking because she could not taste the spices, and it upset her kids." (Participant 34, Caregiver), "...Light sensitivity limits community outings, taste issues disrupt eating habits..." (Participant 26, Occupational therapist), "...A patient stopped cooking due to taste loss, numb hands affect therapy progress..." (Participant 29, Physical therapist), "...Tactile deficits impeded fine motor tasks like buttoning clothes, restricting independence..." (Participant 25, Occupational therapist).

Theme 3: Sensory overload leads to social withdrawal and isolation

Many participants experienced increased sensitivity to stimuli like noise or light, leading to social withdrawal: "...I cannot handle loud restaurants anymore; it is too overwhelming..." (Participant 15, Stroke survivor). "...Patients avoid social events because background noise makes them anxious..." (Participant 27, Physical therapist), "...Background noise makes conversations hard..." (Participant 5, Stroke survivor), "...Noise sensitivity keeps me from social events..." (Participant 11, Stroke survivor), "...Bright lights make me dizzy..." (Participant 15, Stroke survivor), "...Light sensitivity stops me from socializing..." (Participant 17, Stroke survivor), "...Background noise makes me to avoid gatherings..." (Participant 20, Stroke survivor), "...Noise issues lead to withdrawal..." (Participant 21, Occupational therapist), "...Noise overwhelms patients..." (Participant 31, Physical therapist), "...Withdrawal was associated with feelings of frustration and loneliness, loud noises upset my wife, so we stay at home..." (Participant 34, Caregiver).

Theme 4: Limited resources and the absence of standardized sensory assessment tools

Both stroke survivors and stakeholders (physical therapists, occupational therapists and caregivers) emphasized the scarcity of resources, absence of standardized sensory assessment tools to detect and manage sensory changes and a lack of education on post-stroke sensory changes. Stroke survivors voiced frustration over lack of access

to personalized interventions and technology to overcome these sensory changes; "... No one told me how to deal with not tasting food properly..." (Participant 10, Stroke survivor), "...I drop things because I can't feel them properly, nobody told me how to handle this..." (Participant 4, Stroke survivor), "...Food tastes metallic, so I stopped dining out, no resources were offered for this..." (Participant 12, Stroke survivors). Therapists (Physical therapists and Occupational therapists) advocated for standardized assessment tools and training: "...We need better protocols to identify these issues early." (Participant 29, Physical therapist), "...Touch deficits hinder tasks, but we lack adequate training..." (Participant 25, Occupational therapist), "...No protocols exist to manage these sensory changes..." (Participant 22, Occupational therapist). Caregivers noted absence of guidance in supporting survivors with sensory changes at home, "...He struggles to hold things, no help was offered..." (Participant 35, Caregiver).

4 Discussion

The finding that sensory changes across visual, tactile, gustatory, olfactory and vestibular sensory, frequently went unnoticed during clinical assessments highlights a serious assessment gap. A study by Thielen et al. reported that sensory changes are not always noticeable in the sub-acute phase and only become more apparent when participation demands increase in the chronic phase after stroke for example when returning to work, participation in social gatherings, shopping for groceries in a supermarket and many others. This is because in the acute and sub-acute phases of stroke, focus is usually put on life saving interventions and gross motor recovery outcomes [11]. However, this often leads to the unintended neglect of the invisible sensory changes as reported by the stroke survivors and stake holders. According to a study by Ölmestig et al. 2025, it was noted that clinicians often lacked standardized frameworks for detecting sensory hypersensitivity and misattributed sensory changes for cognitive decline or post stroke depression [16]. Furthermore, Passier et al. 2013, reported that clinicians often focused on motor neurological deficits like hemiplegia, neglecting the integrative sensory functions that enable patients to make meaningful understanding of their everyday environments [17]. This is consistent with a study by Duncan et al. 2005, who highlighted that stroke survivors often struggled to articulate sensory changes they encountered post stroke which made it difficult for clinicians to identify and manage them before discharge from hospital [18].

Our study findings revealed that sensory changes significantly disrupted routine engagements and participation in meaningful activities which is consistent with what was reported by Thielen et al. [11, 19], and Alwawi et al. [2]. For instance, one stroke survivor reported to have lost the ability to taste spices thereby making cooking and dining less interesting. This inability to participate increases the cognitive load required to ably engage in meaningful activities of daily living making it more exhausting than usual [2]. A study by Schmid et al. 2009, described this as a loss of occupational flow where the environment becomes a physical barrier to functional independence [20].

Our study finding that social environments are inherently unpredictable and overwhelming making them high risk settings for stroke survivors to ably engage in meaningful activities. For example a stroke survivor reported that noise sensitivity deterred them from attending social events while a caregiver reported that withdrawal was associated with feelings of frustration and loneliness which is consistent with finding by Marzolla

et al. [21], Thielen et al. [11], and Ben-Sasson et al. [22]. A study by White et al. reports that this environmental fear was the primary reason for social withdrawal and isolation from community re-integration and often stroke survivors chose controlled home environments where they felt safe [23]. This is consistent with Pryor et al. which reports that the “social self” is often sacrificed for the sake of the “physical self” during the recovery period [24]. Furthermore, Cosbey et al., emphasizes that this withdrawal is not merely a psychological choice but a physiological necessity. When post-stroke survivors lack the ability to regulate sensory changes in high stimulus environments like busy supermarkets, large gathering, busy offices and many others, this however makes social interactions to become very overwhelming leading to social withdrawal and isolation [25].

Finally, the lack of access to standardized assessment tools to detect these sensory changes reported by the stroke survivors and stake holders represents a major limitation in the mitigation of these sensory changes. For instance, one of the occupational therapists reported an absence of protocols to manage these sensory changes while one caregiver noted the absence of guidance in supporting survivors with sensory changes at home. This is consistent with findings by Thielen et al., which reported that a lack of psychometrically sound assessment tools hindered the development of targeted intervention programs to help mitigate sensory changes experienced by post-stroke survivors [4]. Furthermore, Bailliard et al., argues that while motor assessments are rigorous and frequent, sensory changes assessments are rarely integrated into routine assessment and discharge planning. This necessitates a timely need to be incorporated into routine clinical assessments [15]. And lastly, the lack of data as reported by Winstein et al. 2016, limits the development of context specific sensory changes assessment and treatment guidelines especially for low resource settings that often lack comprehensive rehabilitation services [1].

4.1 Study limitations

Selection bias may have influenced the sample composition due to the purposive sampling method we employed. This limits the generalizability of these findings to broader stroke populations and lastly, participants who volunteered for the study may have been experiencing more severe sensory changes or those with a high level of self-awareness. Consequently, the perspectives of stroke survivors with severe cognitive impairments including those who are aphasic and are unable to communicate the different sensory changes they could be experiencing may be underrepresented.

5 Conclusion

The study demonstrates that sensory changes across visual, tactile, gustatory, olfactory and vestibular sensory, serve as a major barrier to functional independence and social re-integration among post-stroke survivors. These findings reveal a significant gap in the rehabilitation clinical pathway of stroke survivors undergoing neuro-rehabilitation necessitating an urgent need for the integration of standardized sensory assessment tools and protocols to address the seemingly “invisible” sensory changes thus bridging the existing gap.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1007/s44202-026-00761-0>.

Supplementary Material 1. SM 1 Stroke survivors and Stakeholders interview guide.

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Author contributions

All authors approve submission and contributed as follows: M.K, A.I.A.K, N.B (conceptualization, writing); M.A, H.A, S.M. A, O.A (data curation, analysis); H.A, E.M (review, editing).

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Data availability

The minimal dataset required to replicate our study findings is available at figshare: [https://figshare.com/articles/dataset/_b_Exploring_Sensory_Health_Changes_Post-Stroke_and_Their_Impact_on_Activity_Participation_b_/29430596](https://figshare.com/articles/dataset/_b_Exploring_Sensory_Health_Changes_Post-Stroke_and_Their_Impact_on_Activity_Participation_b_/29430596).

Declarations

Ethics approval and consent to participate

The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the institutional review board of IQRA National University with reference number (IRB# HM2024-057). Informed written consent was obtained from all participants.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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