

Developing culturally responsive strategies to support emotional recovery and continuity of care for South Asian Stroke Survivors: Interim Findings.

Exploring Emotional Experiences among South Asian Stroke Survivors : A Qualitative Study

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Background

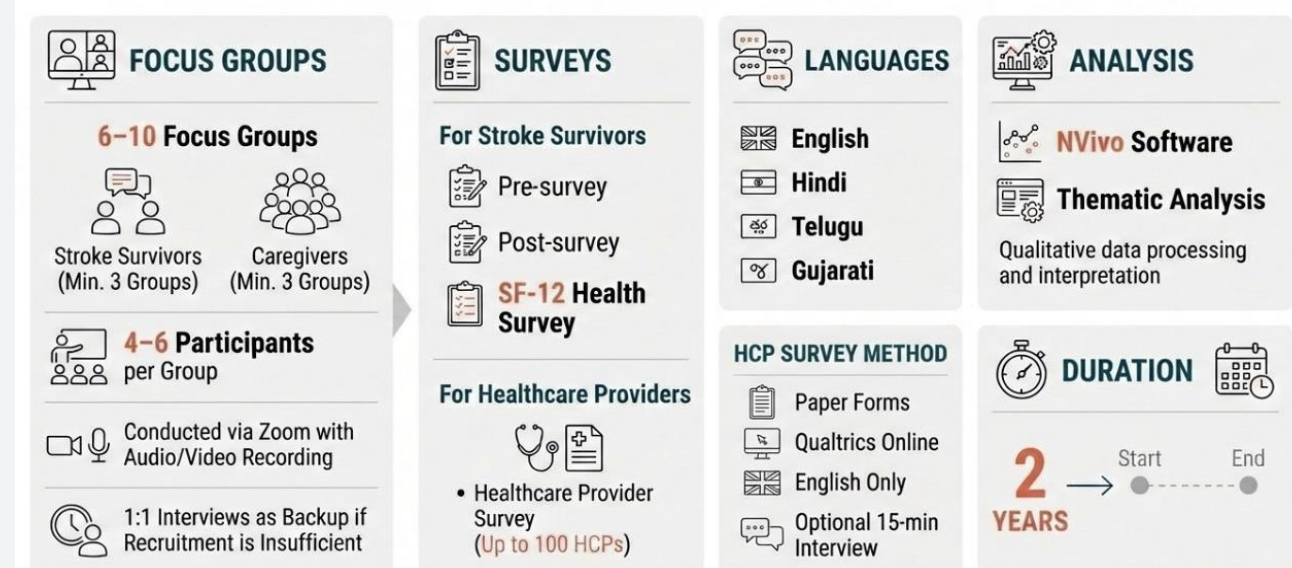
South Asians comprise nearly 25% of the global population yet account for approximately 40% of stroke-related deaths worldwide, often occurring at younger ages than in other populations^[1]. **This study focuses on South Asian stroke survivors living in the United States**, who experience a substantial stroke burden but remain underrepresented in research on post-stroke emotional recovery and mental health support. Existing post-stroke care models in the U.S. frequently fail to account for culturally and linguistically specific factors—such as family-centered caregiving practices, language discordance, and culturally rooted coping mechanisms—resulting in significant unmet emotional and psychosocial needs.

Study will be guided by thematic analysis using Braun and Clarke’s six-phase framework^[2], with grounded theory elements to inductively derive concepts from narratives.

Objective(s)

1. To characterize the emotional experiences of South Asian stroke survivors and caregivers following stroke.
2. To inform culturally responsive strategies to improve emotional recovery and continuity of care.
3. To identify healthcare system gaps in post-stroke care using healthcare provider perspectives.

Methods & Study Design



A combined framework helps capture both individual emotional journeys and shared cultural patterns, providing a more holistic understanding of post-stroke emotional well-being.

Findings

- To date, **six participants (3 dyads)** have been recruited, reflecting the difficulty of engaging South Asian stroke survivors and their caregivers in community-based research.
- The project is led by a community principal investigator with many years of sustained engagement in South Asian health-related outreach.
- Despite an established trust and prior success, enrollment in the current study has been substantially more challenging.
- Many caregivers reported limited availability due to intensive caregiving responsibilities and competing family and household demands.
- Stigma surrounding stroke, disability, and mental health may have reduced willingness to engage in research discussions.
- Additionally, logistical barriers—such as QR code-based registration and online consent—may have limited participation due to digital, cognitive, motor, or visual challenges, as well as post-stroke fatigue difficulties.

Collectively, these findings suggest that recruiting South Asian stroke survivors and caregivers presents distinct challenges compared to prior community-based health education or chronic disease management studies, highlighting the need for stroke-specific, culturally responsive recruitment approaches.



HCP Survey Interim Analysis: A total of 36 HCPs involved in post-stroke care of South Asians completed the survey to date. The following gaps were identified:

Clinical Gaps:

- Inconsistent post-acute coordination across care settings
- Gaps in structured post-discharge follow-up
- Limited visibility into long-term survivor outcomes
- Variable interdisciplinary communication across care teams – post discharge

Non-clinical gaps: Challenges in care navigation and patient education

It is unclear whether post-stroke care gaps disproportionately impact South Asian survivors due to language barriers, cultural factors, and family-mediated care practices.

Conclusions

Challenges

- Slow enrollment despite broad outreach
- Minimal success through neurology clinics (initial hope didn't materialize)
- No recruitment from temples (2-3 attempted)
- No recruitment from NJ health screenings (4-5 events)

Adaptive Solutions

- Senior day care centers with high SA attendance showing some success
- Naveena and Varsha conducting site visits
- Willingness to pivot to 1:1 interviews if focus group recruitment insufficient

- Recruitment of SA stroke survivors and caregivers is currently ongoing, reflecting both the importance and challenges of engaging this community in research.
- Preliminary findings from the HCP survey have identified potential system-level gaps in post-stroke care that may disproportionately affect SA stroke survivors.
- The study is actively integrating perspectives from stroke survivors, caregivers, and HCPs to inform ongoing analyses – strengthening the validity.
- Next steps will focus on the co-development and iterative refinement of culturally responsive strategies, designed to improve:
 - Emotional recovery and psychosocial support for SA stroke survivors
 - Care continuity and communication across care settings
 - Family-centered approaches that reflect SA caregiving practices

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References:

- 1 Wasay, M., Khatri, I. & Kaul, S. Stroke in South Asian countries. *Nat Rev Neurol* 10, 135–143 (2014).
- 2 Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.