

**Survey and Focus Group study to Identify Unmet Needs and Avenues for Enhancing Therapist Support to Stroke Survivors and their Caregivers in India**

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**Introduction**

Stroke a cerebrovascular, neurological incident often causes motor, speech, cognitive and psychological sequelae. In India, access to rehabilitation resources are limited, hence burden of care often falls on family members <sup>(1)</sup>. This study explores stroke caregiver's challenges and potential avenues for added therapist support to caregivers of stroke survivors.

**Aims:**

- To explore stroke survivors' & caregivers' experience with managing stroke sequelae via online survey.
- To identify avenues to aid stroke caregivers in addressing challenges via focus group.

**Methods**

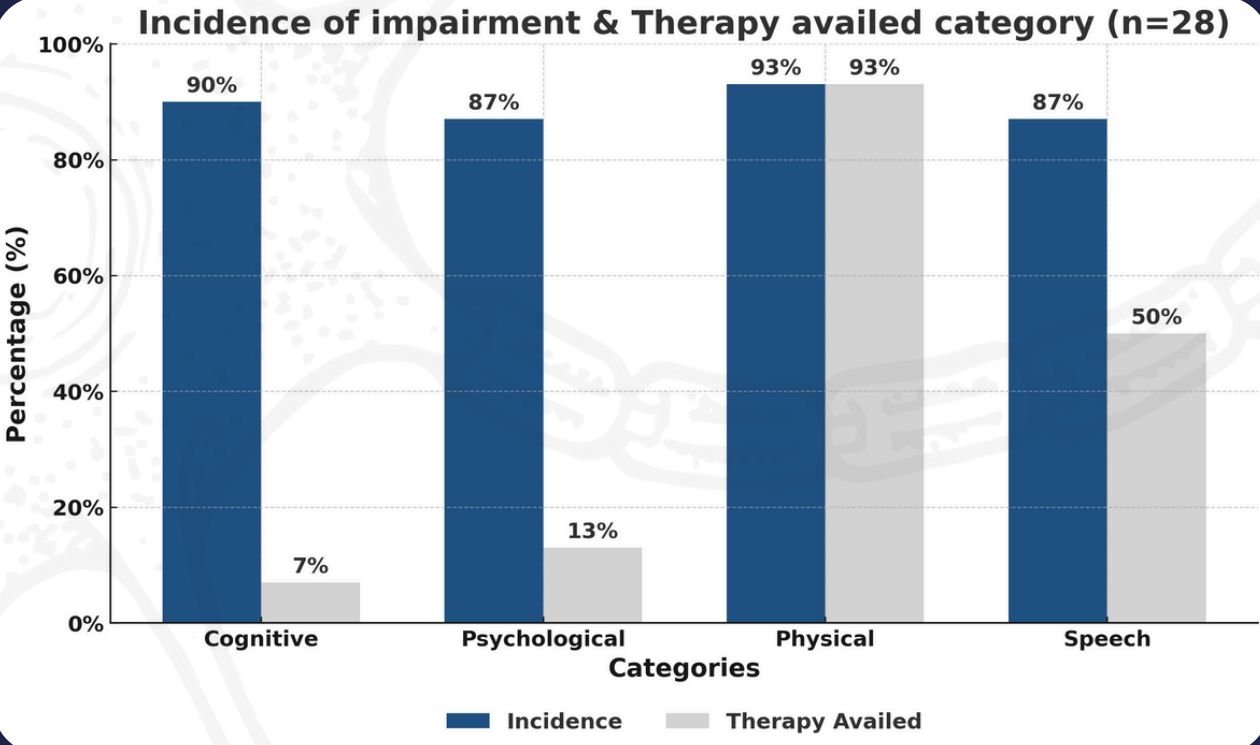
**Online Survey**

- **Sample:** 22 stroke patients and 6 stroke caregivers
- **Procedure:** Google form circulated via Stroke Support India <https://strokesupport.in> & Team Physiotherapy and Rehabilitation services, Pune.
- **Content:** Questions were asked related to incidence of sequelae, awareness of services and barriers to access of services in India.
- **Data analysis:** Descriptive analysis

**Focus Group**

- **Sample:** 8 Stroke caregivers
- **Procedure:** Online Meeting via Google Meet. Moderated by a multidisciplinary team including a neuropsychologist, physiotherapist & speech therapist.
- **Content:** Questions related to identifying gaps, caregiver needs and possible solutions
- **Data analysis:** Thematic analysis

**Results**



**Results: Online Survey**

- Cognitive & Psychological sequelae were reported as frequently as Physical & Speech sequelae post-stroke.
- Despite high incidence of cognitive and psychological sequelae, therapy for these deficits were substantially less frequently availed as compared to the physical and speech sequelae.
- Most common reason (88% responders) cited lack of awareness about Neuropsychological services.

**Focus Group Results**

**Gaps identified**

- Stroke survivors commonly experienced challenges related to **cognitive, behavioural, motor and speech functions**.
- Caregiver burden was prominent, stemming from **role changes, increased responsibilities, and lack of stroke survivor's insight into their impairments**.
- Participants highlighted a **lack of knowledge regarding the nature of stroke, prognosis, available resources**.

**Solutions discussed**

- **Need for therapist-led educational programs**
- **Training in individualised strategies for home-based caregiving**
- **Development of resource booklets**
- **Establishment of support groups for stroke survivor and caregiver support**

**Conclusion**

- *Cognitive and psychological issues are as common as physical and speech difficulties* after stroke. While physiotherapy and speech therapy are widely used, *neuropsychological services remain underutilised*, mainly due to *lack of awareness (88%)*. This highlights the need to improve awareness and access to holistic post-stroke care.
- To support stroke caregivers in managing stroke-related challenges, there is a *need for therapist-led education, accessible resource booklets, and support groups*. These interventions can empower caregivers with practical knowledge and emotional support, ultimately improving patient outcomes.

**Next steps**

- **Development of a Stroke Caregiver Education Program.** To facilitate stroke caregivers with the appropriate information they need concerning diagnosis, prognosis and outcomes, followed by tailored management strategies.
- **Formulation of resource booklet** for relevant information for the stroke survivor and their caregivers.
- **Formulation and Facilitation of Support groups** to alleviate stroke caregiver stress with trained professionals.

**References/ Resources**

1. Pandian, J. D., & Sudhan, P. (2013). Stroke epidemiology and stroke care services in India. Journal of stroke, 15(3), 128–134. <https://doi.org/10.5853/jos.2013.15.3.128>
2. <https://strokesupport.in>

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