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Quality of life of stroke survivors and their primary caregivers in Pakistan.

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Quality of life of stroke survivors and their primary caregivers in Pakistan

Dear editor,

Stroke is a global epidemic, and those in lower middle income countries (LMIC) countries register 80% of the total burden of stroke and 87% of disability adjusted life years.¹ LMIC health systems are struggling to respond to the demographic transitional challenge of the presence of infections – like polio prevention, maternal mortality, and the rise of complex disorders like stroke that require a chronic disease approach.² Little is known about the quality of life of stroke survivors from countries that bear the maximum burden of stroke and yet have few resources to deal with these patients. We performed a detailed sequential mixed method study, which was set up in two major private and public tertiary health centers in Karachi which receive the bulk of stroke admissions and interviewed 700 participants. We found that stroke survivors resided in communities in joint family systems, none remained in any dedicated stroke centers, and few had access to even outpatient-based rehabilitation services. Almost everyone paid out of pocket for any kind of health care services.³ Despite all these challenges, survivors reported better quality of life scores assessed by Stroke Specific Quality of Life Scores (SSQOLS) as compared to reported scores from other developing countries.⁴ Qualitative in-depth interviews and focus group discussions exposed the real cost of these scores; they were related to the efforts of stroke caregivers. Caregivers revealed disappointment with the existing health services. They felt alone and isolated. Almost all of them reported major financial crises.^{5,6} Our observations and caregiver input suggest a community centered, centralized, supportive, integrated treatment program for stroke patients that supports primary caregivers. Using IT-based technologies to support primary caregivers, given Pakistan's 92% mobile land coverage, may be an avenue for further research.⁷

Declaration of Conflicting Interests

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