April 2016

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

Wardah Khalid
Aga Khan University, wardah.khalid@aku.edu

Shafquat Rozi
Aga Khan University, shafquat.rozi@aku.edu

Tazeen S. Ali
Aga Khan University, tazeen.ali@aku.edu

Iqbal Azam Syed
Aga Khan University, iqbal.azam@aku.edu

Michael T. Mullen
Perelman School of Medicine at the University of Pennsylvania, Pennsylvania, PA, USA.

Follow this and additional works at: http://ecommons.aku.edu/pakistan_fhs_mc_med_med

Part of the Neurology Commons

Recommended Citation
Available at: http://ecommons.aku.edu/pakistan_fhs_mc_med_med/336
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

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article: The funders had no role in study design, data collection, analysis, decision to publish, or preparation of the manuscript. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Fogarty International Center, National Institute of Neurologic Disorders and Stroke or the National Institute of Health.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The study is funded by Award Number 5D43TW008660-04 from the Fogarty International Center and the National Institute of Neurologic Disorders and Stroke of the National Institutes of Health, USA.

References


Wardah Khalid

The International Cerebrovascular Translational Clinical Research Training Program (Fogarty International Center, National Institutes of Health), Aga Khan University Hospital, Karachi, Pakistan
Letter to the Editor

NP35

Shafquat Rozi
Department of Community Health Sciences,
Aga Khan University Hospital, Karachi, Pakistan

Tazeen S Ali
School of Nursing and Midwifery (SONAM),
Department of Community Health Sciences,
Aga Khan University Hospital Karachi, Pakistan

Iqbal Azam
Department of Community Health Sciences,
Aga Khan University Hospital, Karachi Pakistan

Michael T Mullen
Department of Neurology, Perelman School of Medicine
at the University of Pennsylvania, Pennsylvania, PA, USA

Saleem Illyas
Department of Neurology, Professional Development Centre,
DOW University of Health Sciences, Karachi, Pakistan

Qamar-un-Nisa
Department of Neurology, DOW University of Health Sciences,
Karachi, Pakistan;
Section of Neurology, Department of Medicine, Aga Khan
University Hospital, Karachi, Pakistan

Nabila Soomro
Institute of Physical Medicine and Rehabilitation, DOW
University of Health Sciences, Karachi, Pakistan

Ayeesha K Kamal
The International Cerebrovascular Translational Clinical
Research Training Program (Fogarty International Center,
National Institutes of Health), Department of Medicine, Aga
Khan University Hospital, Karachi, Pakistan

Corresponding author:
Ayeesha K. Kamal, Aga Khan University, Stadium Road, Faculty
Office Building, Karachi, 74800, Pakistan.
Email: ayeesha.kamal@aku.edu