



**Karolinska  
Institutet**

**Institutionen för neurobiologi, vårdvetenskap och samhälle**

# Exploring life after stroke; experiences of stroke survivors, their family caregivers, and experts in an Iranian context

**AKADEMISK AVHANDLING**

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## ABSTRACT

The global burden of stroke is immense. Despite the high incidence of stroke, little research has been done on the post stroke recovery process. **Aim;** the overall aim of this research project was to explore life after stroke based on experiences of stroke survivors (I, II), their family care givers (I-III) and expert in field of rehabilitation (IV) in an Iranian context. **Material and Method:** Data for the studies were gathered from knowledgeable participants and followed to figure out the themes by purposeful selection (I- IV) and then by theoretical sampling (II-IV). Data were analyzed by the basic tenets of the grounded theory approach according to Strauss & Corbin, by semi-structured interviews and focus group discussions (II-III-IV) and qualitative content analysis (I). **Results:** In Study (I) the results were categorized into the two main themes that were identified as; (1) challenged by changes in life situations and (2) striving to cope with new conditions. Study (II) identified “functional disturbances” as core concept. Functional disturbances were encompassed by in appropriate strategies in managing and supporting, such as lack of adequate social insurance and access to the few existing rehabilitation services. In study (III) the core concept identified was “lack of continuity of rehabilitation care”. Seven related main categories were extracted including inadequate knowledge and skills, inappropriate accessibility to rehabilitative services, inadequate social insurances, modifying home environment, managing coexisting medical conditions, improving nurses’ roles and, relying on family unity. In study (IV) “non-integrated rehabilitation service” emerged as core concept. The explored concepts were ‘deficiently allocated budget’, ‘inadequate social insurance’, ‘lack of availability of rehabilitative care’, ‘negative public opinions’, ‘lack of consistency of care’, ‘split services and professional separation’. Potential areas for improvements were ‘need for changing policymakers’ attitudes’, ‘needs for refining rehabilitation in health care system’, ‘needs for establishing a registration system’, ‘needs for providing information and skills’ and ‘needs for seeing the family as a whole’. In **conclusion**, the core concept for life after stroke was “functional disturbances”. Non-integrated rehabilitation services within health care system and lack of continuity of rehabilitation care caused stroke survivors and their family caregivers to experience ranges of dysfunctions in terms of physical, emotional, psychological and social aspects. Change of policy makers’ attitude appears to be important in order to allocate adequate budget in this regards. Stroke survivors and their family caregivers experienced everyday life in terms of being challenged by changes in life situation and striving to cope with new conditions. The study results indicate that focusing on multidisciplinary approach and establishing registration system for follow-up of survivor’s rehabilitation are to be recommended.

**Key words:** stroke event, life after stroke, stroke survivor, family care giver, rehabilitation expert, home rehabilitation care, community rehabilitation services, experiences, everyday life, constant comparison method and grounded theory approach.

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