



Karolinska Institutet

**Institutionen för neurobiologi, vårdvetenskap och samhälle,
sektionen för sjukgymnastik**

Long-term effects of stroke seen in young individuals living in the community

AKADEMISK AVHANDLING

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ABSTRACT

Background: Suffering a stroke in the midst of life may lead to half a life-time to be lived with disability. Thus, to meet the needs of long-term measures by health care among young individuals of working age, it is essential that the occurrence of long-term effects of stroke is thoroughly explored and mapped. Although improvements in functioning can be seen over time the young individuals of working age may still perceive that they are disabled in comparison with their pre-stroke functioning. Therefore, studies are needed that focus on self-perceived effects of stroke experienced in an everyday life context.

Aims: To explore self-perceived long-term effects of stroke seen in young individuals of working age living in the community.

Methods: Among individuals living in the community, differences between younger individuals of working age (<65 years) and older regarding use of health care during the first 12 months after stroke were explored by means of data from the Stockholm County Council. In addition, differences between the same younger and older individuals, regarding self-perceived disability and recovery at 12 months after stroke were explored using the Stroke Impact Scale in structured interviews. Further, to map effects of stroke relevant to individuals of working age, a postal questionnaire (the MYS-questionnaire) was developed and tested by an expert group and the individuals in target. By means of the posted MYS-questionnaire, long-term effects seen up to 6 years after stroke onset were then mapped among young individuals of working age living in the community in Stockholm. Medical data were retrieved from medical records. Further, the generic EQ-5D questionnaire was used to assess differences in terms of self-rated disability and global health between the same individuals with stroke and a matched general population. In addition, among the individuals with stroke, the associations between self-rated disability and self-rated global health were explored.

Results: Compared to the older group (n=129), the younger group (n=63) received more care and rehabilitation and at 12 months after stroke the younger group reported less impact on self-perceived disability in terms of strength, mobility, self-care and domestic life. However, ratings of self-perceived global recovery did not differ between the groups. Factors explaining the variance in self-perceived recovery in the younger group were limitations in activities requiring hand function and aspects of self-rated depression. The developed and tested MYS-questionnaire was found to cover relevant aspects of long-term effects of stroke. The posted MYS-questionnaire was responded by 68% (n=158). Of the respondents, 78% had suffered a mild stroke. Irrespective of time elapsed since stroke onset, tiredness was the most commonly reported mental impairment experienced by 44%, and each individual reported a median of 7 concurrent mental impairments. In addition, restrictions in returning to leisure activities and work were reported by 58% and 52% respectively. These factors could not be sufficiently predicted by means of factors known at stroke onset. Further, among the same young individuals with stroke 45% rated a low global health. Among the young individuals with stroke, limitations and restrictions in leisure activities, work, reading, low level of physical activity, utilizing personal care provider or personal assistance and tiredness were negatively associated with self-rated global health (R square 0.60).

Conclusion: This thesis presents long-term, multi factorial and substantial effects of stroke that affected global health negatively in young individuals of working age, living in the community. A majority had suffered a mild stroke but experienced long-term disability that could not be sufficiently predicted by factors known at stroke onset. Therefore, regular long-term assessments by health care services irrespective of initial stroke severity are warranted. It is of particular importance to implement regular assessments of mental impairments and future studies are needed to establish evidence based interventions.