Self-Assessed Physical, Cognitive, and Emotional Impact of Stroke at 1 Month: The Importance of Stroke Severity and Participation

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Objectives: The aims of this study were to describe the self-assessed physical, emotional, and cognitive impact of stroke and to investigate associations with participation and stroke severity in early stage (1 month) poststroke. *Methods:* Participants (n = 104, mean age = 68) with reduced upper extremity function assessed at day 3 were included from a Swedish stroke unit. Participants were evaluated with *The National Institutes of Health Stroke Scale* at arrival, median 7.9 (0-24). The cohort was assessed for their perceived impact of stroke with the *Stroke Impact Scale* at 1 month poststroke. *Results:* The perceptions of emotional health, communication skills, and ability to remember were perceived as quite good, with a mean score of 83-86. However, nearly 60% reported limitations in participation. This group also evaluated their physical function to be significantly lower compared to participants who did not report limitations in participation. *Conclusions:* One month poststroke, a lower score on self-assessed physical function was associated with both a perceived restriction in participation and a more severe stroke. The association of physical function and perceived participation at 1 month poststroke needs to be taken into account when planning the early rehabilitation. **Key Words:** Stroke—social participation—rehabilitation—physical function.

Introduction

Stroke impacts an individual's ability to participate in everyday life, and is a barrier to living a normal life when compared to peers.[1] Stroke is a global healthcare burden that is common, serious, and disabling.[2,3] It is currently the second largest contributor to a life with disabilities in developing countries and the third largest contributor in developed countries.[4] The absolute numbers of people who have a stroke every year and live with the consequences of stroke are increasing, and without a widely applicable new medical treatment, most poststroke care will continue to rely on rehabilitation interventions.[4-6]

The International Classification of Functioning, Disability and Health defines participation as "involvement in a life situation" that includes the following: taking part in activities, being engaged in different life areas, being accepted by others, and having access to necessary resources.[7,8] In an early poststroke stage, when many are still hospitalized, personal opportunities for choice and control are particularly relevant to participation, because these areas can help to retain a person's sense of integrity and autonomy.[9]

To capture meaningful individual experiences after stroke, a questionnaire has to reflect priorities held by persons

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with stroke.[10,11] The Stroke Impact Scale (SIS 3.0)[12] is a questionnaire developed with input from persons with stroke, caregivers, and healthcare professionals. The SIS encompasses questions about participation, as well as the physical, cognitive, and emotional aspects of health-related quality of life.[13] Previous research[14] showed that almost 50% of the participants had a meaningful positive or negative change between 3 and 12 months in the SIS Participation domain. This sensitivity to change supports the clinical use of the Participation domain, both to be used in the planning of rehabilitation interventions and to understand the individual impact of stroke.[14] In addition, the SIS Participation domain has shown to be a broad-based indicator of perceived participation after stroke.[15]

A person's ability to look after himself or herself and live independently are areas that clinicians evaluate shortly after stroke.[16,17] The early impact and experiences of poststroke are less understood than those in a later stage.[11] With better understanding of a person's typical experiences in the early poststroke stage, healthcare professionals can learn more about how to tailor-make early interventions. The aims of this study were to describe the self-assessed physical, emotional, and cognitive impact of stroke. and to investigate associations with participation and stroke severity at 1 month poststroke.

Materials and Methods

Participants

Over a period of 18 months (2009-2010), 117 patients were consecutively included from the largest of three stroke units at the Sahlgrenska University Hospital in Gothenburg, Sweden, to the Stroke Arm Longitudinal Study at the University of Gothenburg, (the SALGOT study).[18] The cohort for the present study was extracted from the SALGOT study.[18]

Eligible for inclusion were persons with a first ever clinical stroke[19] who were ≥18 years with an impaired upper extremity function and admitted to the stroke unit within 72 hours of the stroke event.[18] Exclusion criteria were the following: (1) an upper-extremity impairment that limited the functional use of the affected arm and/or hand prior to the stroke; (2) severe multi-impairment or diminished physical condition that had effect on the arm-hand function before the stroke; (3) life expectancy less than 12 months; and (4) non-Swedish speaking. For more detailed information, please see the SALGOT protocol.[18] The minimum level of participation required for inclusion in the present study was completion of the SIS[13] at 1 month, which included 104 participants from the original SALGOT population (n = 117).

Procedure and Measurements

The SIS is a self-assessment questionnaire that estimates how stroke affects health and quality of life.[12] It comprises 59 items divided into 8 domains: Strength, Memory and Thinking, Emotion, Communication, Activities of Daily Living (ADL), Mobility, Hand function, and Participation.[12] Possible scores range from 1 to 5, and a higher score indicates a lower self-evaluated disability, better participation, or overall mood. In the SIS, overall recovery is measured with a *Visual analog scale*, from 0 (no recovery) to 100 (full recovery). The SIS has been proven valid, reliable, and useful when assessing the impact of stroke.[13]

The SIS was assessed at 4 weeks poststroke. The Physical domain, identified by the developer of the SIS,[12] comprises the domains of Strength, Hand function, Mobility, and ADL. When Physical functions are mentioned, it is in reference to these domains.

To assess stroke severity, participants were evaluated with the *National Institutes of Health Stroke Scale* (NIHSS)[20] upon arrival at hospital. The scores range from 0 = *no deficit* to 46 = *severe deficit*. Additional background data were assessed at day 3 and included the following: home care prestroke, occupation, shared household, age, and sex. Three physiotherapists, trained together on how to perform the assessments and not involved in the care of the participants, performed the tests and gathered data following a standardized protocol.[18] Most of the evaluations were performed in the hospital; however, if someone was unable to travel at 1 month, the assessment was completed in the participant's home, nursing home, or rehabilitation unit.

Ethics

The project was approved by the Regional Ethical Review Board in Gothenburg, registration number 225-08. Written informed consent was obtained from the participants or from a close relative, and the Helsinki Declaration[21] was followed. The SALGOT study is registered on ClinicalTrials.gov (NCT01115348).

Data and Statistical Analysis

Baseline characteristics are presented as number, mean, and percent. The SIS and NIHSS are presented as median, quartiles 1 and 3 (Q1, Q3), mean score, and standard deviation. Mann–Whitney *U* tests were performed, due to ordinal data, to test for differences between levels of participation and SIS domain scores. Chi-square tests were used when data were dichotomized. When calculating differences between participants at a group level, two means of dividing groups have been used: (1) according to the level of participation SIS domain 8, as in previous research[22] classified as follows: a score below 50 indicated a limitation in perceived participation and ≥50 corresponded to participating partly or fully[22]; and (2) according to initial NIHSS score: a score of >5 indicates mild impairment, 5-14 moderate impairment, and <14 severe impairment.