Self-Perceived Participation and Autonomy at 1-Year Post Stroke: A Part of the Stroke Arm Longitudinal Study at the University of Gothenburg (SALGOT Study)

Karin Törnbom, MSSc,*,† Kristin Hadartz, MD,* and
Katharina S. Sunnerhagen, MD, PhD*,†

Background: Identifying factors predicting the long-term outcome of participation and autonomy after stroke is essential for developing individualized rehabilitation interventions. The aim was to describe self-assessed participation and autonomy and to explore factors associated with the same at 1 year post stroke. *Methods:* Participants consisted of 79 persons (mean age = 67) with a first-time stroke at the 1-year follow-up. To investigate perceived participation and autonomy at 1 year, a self-assessment questionnaire, the Impact on Participation and Autonomy—English version (IPA-E) was used. Multivariate logistic regression models were performed using age, gender, stroke severity, and functional dependency at discharge as potential contributors to the perceived level of participation and autonomy. *Results:* A high percentage (70%-88%) evaluated their functions as *fair* to *very good* within all domains of the IPA-E at 1 year post stroke. However, around a fifth experienced their Family role as *poor* to *very poor*. Participants' functional dependency at discharge significantly influenced the outcome for the domains of Family role (odds ratio [OR] = 5.66, $P < .01$), Social relations (OR = 3.23, $P < .03$), and Autonomy indoors (OR = 3.44, $P < .04$) at 1 year post stroke. *Conclusion and Implications:* Aspects of the Family role domain deserve further attention in interventions aimed at improving participation and autonomy at 1 year post stroke. The results also indicate that supporting indoor autonomy and social relations of persons with stroke during the acute rehabilitation is important to enhance participation and autonomy at 1 year post stroke. **Key Words:** Stroke—rehabilitation—participation—autonomy—functional dependency—neurological outcome.

From the *Research Group for Rehabilitation Medicine, Institute of Neuroscience and Physiology, Sahlgrenska Academy; and †Centre for Person-Centred Care (GPCC), University of Gothenburg, Gothenburg, Sweden.

Received August 25, 2017; revision received October 11, 2017; accepted November 21, 2017.

Author contributions: K.T., K.H., and K.S. contributed to the study design. K.T., K.H., and K.S. analyzed the data and interpreted the results. K.H. and K.T. wrote the first draft of the manuscript. K.T. and K.S. made revisions to the first draft. All authors have read and approved the final manuscript.

Grant support: This study was supported by The Norrbacka-Eugenia Foundation and the Swedish Stroke Foundation, and in part by the Swedish Research Council (VRK 2012-70X-22122-01-3), the Swedish Brain Foundation, the Swedish Heart and Lung Foundation, the Foundation of the Swedish National Stroke Association, Promobilia (an unconditional grant from Allergan), the Greta and Einar Askers Foundation, and Hjalmar Svensson's Research Foundation.

Address correspondence to Karin Törnbom, Rehabilitation Medicine, Section of Clinical Neuroscience, Sahlgrenska University Hospital, Per Dubbsgatan 14, 413 45 Göteborg, Sweden. E-mail: Karin.Tornbom@neuro.gu.se.

1052-3057/$ - see front matter

https://doi.org/10.1016/j.jstrokecerebrovasdis.2017.11.028

Introduction

Stroke is one of the most common causes of long-term disability worldwide. It is a global health-care problem that affects about 16 million people, leaving around 5 million with neurological disabilities each year.[1] Despite a falling incidence rate in Western countries,[2] an aging population combined with better survival rates[3] is expected to create an increased need of efficient rehabilitation for persons after stroke.[4]

The physical, cognitive and psychological impacts from stroke can lead to a wide range of activity limitations and participation restrictions, even in a long-term perspective.[5] Consequently, stroke survivors are often disposed to a sedentary lifestyle that affects performance in activities of daily living (ADLs), increases the risk of falls, and may contribute to a heightened risk of recurrent stroke or other cardiovascular events.[6] Resuming prestroke activities is therefore of great importance for life satisfaction and is often seen as a main goal for rehabilitation.[7,8]

Participation is defined in the International Classification of Functioning (ICF) as "involvement in a life situation" or "the lived experience" of people in the actual context in which they live.[9] Participation is a subjective experience of interactions between health conditions, environmental factors, and interactions with others. The concept of full participation has been suggested as one of the most important outcomes for persons with stroke.[10]

Autonomy has been found to be a fundamental precondition for effective participation.[11] Previous research has described autonomy as the ability to make choices, to feel in control of which activities to engage in, and in what manner these activities are performed.[11,12] Therefore, it is important to consider this concept as the aim was to capture the quality in participation rather than just the frequency in activities.[13]

To reach a better understanding about the consequences of stroke, a self-assessment questionnaire, the Impact on Participation and Autonomy—English version (IPA-E), was used in the present study. The IPA-E is designed to assess different aspects of autonomy and participation in chronic conditions.[11,12] The main focus is to capture self-perceived participation and autonomy, as well as restrictions of participation within common life situations.[14]

With more knowledge about individual experiences at 1 year post stroke, health-care professionals can tailor-make interventions in later stages for this group more efficiently. The objectives of the current study were to describe self-perceived participation and autonomy and to investigate associations with background data at 1 year post stroke. As far as we know, this is the first study to examine these issues at 1 year post stroke in a longitudinal perspective.

Methods

Participants

This cross-sectional study was a part of the Stroke Arm Longitudinal Study at the University of Gothenburg (SALGOT study), Sweden.[15] All patients admitted to the stroke unit at Sahlgrenska University Hospital with a first-ever stroke between February 4, 2009, and December 2, 2010, were considered for inclusion.

Inclusion criteria to the SALGOT study were as follows: (1) age over 18 years old, (2) first-ever clinical stroke,[15,16] (3) impaired upper-extremity function at day 3, (4) admission to the stroke unit within 72 hours of the stroke incidence, and (5) residency in the Gothenburg urban area (within 35 km). Exclusion criteria were (1) an upper-extremity impairment that limited the functional use of the affected arm or hand before the stroke, (2) severe multi-impairment or diminished physical condition that had an effect on the arm–hand function before the stroke, (3) a life expectancy of less than 12 months, and (4) non-Swedish speaking. The SALGOT study resulted in 117 consecutively recruited persons (for more details, the study protocol is referred to).[15] An additional inclusion criterion for the present study was completion of the IPA-E questionnaire at the 1-year follow-up. This criterion resulted in 79 participants being eligible for inclusion (see Fig 1).

The IPA-E questionnaire was administered by 3 experienced physical therapists undergoing a training period together for the assessment battery before the start of the study. Participants could get support when answering the questionnaire. For example, some questions were clarified,

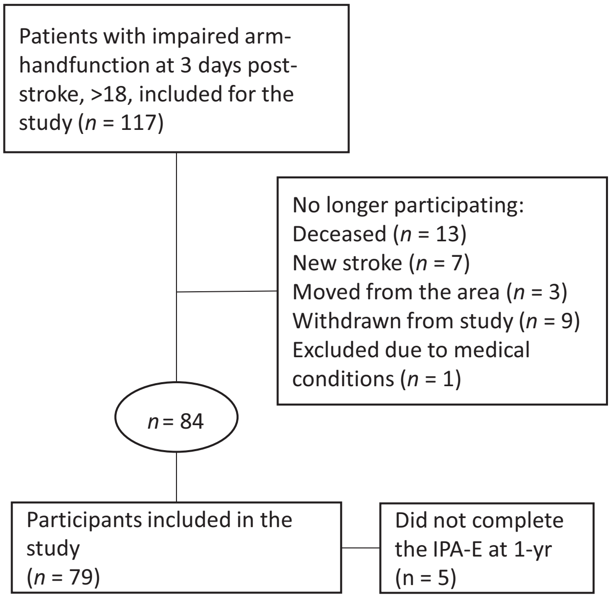

Figure 1. *Flowchart of reasons for not participating and the number of participants included in this study. Abbreviation: IPA-E, Impact on Participation and Autonomy—English version.*