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# Participation after stroke in a short- and long-term perspective

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Akademisk Avhandling

som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs Universitet kommer att offentligens försvaras i Hörsal Arvid Carlsson, Academicum, Medicinargatan 3.

Fredagen den 15 november 2019, kl. 9:00

Fakultetsopponent: Professor Audny Anke, Institutionen för Klinisk Medicin, Universitetet i Tromsø.

## **Avhandlingen baseras på följande delarbeten**

- I Törnbom K, Persson HC, Lundälv J, Sunnerhagen KS. Self-Assessed Physical, Cognitive, and Emotional Impact of Stroke at 1 Month: The Importance of Stroke Severity and Participation. *Journal of stroke and cerebrovascular diseases*. 2017 Jan; 26(1):57-63. Epub 2016 Sep 9
- II Törnbom K, Persson HC, Lundälv J, Sunnerhagen KS. The impact of physical function on participation in the first year post-stroke. *Acta Neurologica Scandinavica*. 2017 Jun;135(6):649-655. Epub 2016 Aug 11
- III Törnbom K, Lundälv J, Sunnerhagen KS. Long-term participation 7-8 years after stroke: Experiences of people in working-age. *Plos One* 2019 Mar 13;14(3)
- IV Törnbom K, Lundälv J, Palstam A, Sunnerhagen KS. "My life after stroke through a camera lens"- A Photovoice study on participation in Sweden. *Plos One* 2019 Sep 11;14(9)

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# Participation after stroke in a short- and long-term perspective

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## ABSTRACT

The main scope of this thesis was to study and describe perceived participation among persons with stroke. In doing so, different timepoints were chosen to make a more complete picture of participation after stroke. The two first studies were performed using quantitative methods. The results of study I demonstrated that emotional health, communication skills, and the ability to remember were perceived as quite good one month after stroke. The findings of study II showed that participation scores were widely distributed during the first year after stroke. Associations between perceived physical capacity and participation were found at 1, 6, and 12 months. Findings of study I and II indicate that physical functioning was important for perceived participation during all timepoints that were investigated in the first year after stroke. A continuous focus on physical functioning in rehabilitation should therefore also be beneficial for perceived participation.

Study III and IV had qualitative designs and aimed to exemplify, describe and to deepen our understanding of how participation, and life in general, may be experienced in a long term perspective after stroke. Results of study III showed that participants most often emphasized work and social life when describing their participation. They had adapted to a somewhat altered way of living and the importance of consequences after stroke in everyday life had decreased. This result was partly confirmed by the results of study IV, which showed that participants had found new ways to approach difficult situations in everyday life. However, the more multi-dimensional result of study IV showed that several participants still felt depressed many years after onset, and were not content with how life had turned out at all. Findings of both qualitative studies showed a need for more knowledge about how participation can be promoted many years after stroke, so that more persons after stroke may achieve a positive identity and a life which they consider meaningful.

Keywords: stroke, rehabilitation, physical functioning, participation, interview study, photovoice.