



**Karolinska  
Institutet**

**Institutionen för Neurobiologi, vårdvetenskap och samhälle  
Sektionen för arbetsterapi**

## Needs for, use of and satisfaction with health care services in the course of the first year after stroke – the perspective of people with stroke

AKADEMISK AVHANDLING

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av

**Malin Tistad**

Leg sjukgymnast

*Huvudhandledare:*

Med Dr Charlotte Ytterberg  
Karolinska Institutet

*Bihandledare:*

Professor Lena von Koch  
Karolinska Institutet

Professor Kerstin Tham  
Karolinska Institutet

Med Dr Christina Sjöstrand  
Karolinska Institutet

*Fakultetsopponent:*

Professor Jan Lexell  
Lunds universitet

*Betygsnämnd:*

Docent Ingvar Krakau  
Karolinska Institutet

Professor Inger Knutsson Holmström  
Örebro universitet

Docent Britta Lindström  
Umeå universitet

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## ABSTRACT

**Background** Many people who have had a stroke report unmet needs for rehabilitation. There is, however, a lack of knowledge about what issues underlie the many unmet needs. Assessment tools are used in the health care services to identify the presence of disabilities, but it is not known to what extent patient expressed disabilities are identified in the assessment tools. There is also a lack of knowledge regarding changes over time in length of stay (LOS) at stroke units and subsequent rehabilitation after stroke.

**The general aim** of this thesis was to generate new knowledge about needs for rehabilitation, use of and satisfaction with health care services in the course of the first year after stroke from the perspective of people with stroke.

**Method** Data was derived from an observational prospective longitudinal study of people diagnosed with a stroke who received care at the stroke units of Karolinska University Hospital 2006/2007 (n=349). Data was also taken from the control-group in a randomized controlled trial of people who received care at the same stroke unit during 1993/1996 (n=40). Data collection comprised baseline assessment and follow-ups at 3, 6 and 12 months. Data was collected using an open question, established assessment tools, medical records and the Stockholm County Council's computerized registers for use of health care services. Analyses applied in the thesis were: in paper I a comparison of the perspective of people who have had a stroke (categories of self-reported problems in daily life) and the health care services' perspective (results from three established assessment tools); in paper II and III multivariate logistic regression analyses, and in paper IV comparisons regarding LOS, recovery in activities of daily living (ADL) and patient satisfaction.

**Results** Fatigue was the most common self-reported problem that people experienced in daily life after stroke. Items/domains in three standardized assessment tools corresponded to only 15 of 24 categories of self-reported problems. Furthermore, the assessment tools failed to identify 0-57% of the self-reported problems in the 15 categories that had corresponding items/domains (paper I). Unmet needs for rehabilitation at 12 months were predicted by high impact on strength (on the affected side) at 3 months, and associated with high impact on hand function (on the affected side) and poor self-rated recovery at 12 months (paper II). Among participants with moderate/severe stroke, met needs for rehabilitation was associated with having seen a physiotherapist at least once during each of the 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup>-4<sup>th</sup> quarters of the first year (paper III). Dissatisfaction with care at 12 months was predicted by poor coping capacity and restrictions in participation at three months, and associated with poor coping capacity and strength (on the affected side) at 12 months (paper II). The LOS at the stroke unit was shorter for patients who received care during 2006/2007 compared to 1993/1996 (median 8 versus 13 days), but no difference in LOS was found regarding the total LOS (stroke unit and subsequent in-patient rehabilitation). The participants from 2006/07 were to larger extent independent in ADL at 3 months after stroke, but no difference at 12 months was revealed and both groups were equally satisfied with health care services received (paper IV).

**Conclusion** There is poor concurrence between the perspective of the people who have had a stroke and the perspective of the health care services regarding problems experienced in daily life after a stroke. If health care services are to be based on problems experienced by the people who have had a stroke, the use of assessment tools should be complemented by a dialogue. Extra attention should be paid to the rehabilitation needs of people with high impact on strength and hand function and poor recovery since these are more likely to experience unmet needs for rehabilitation. For people with moderate/severe stroke, continuity in rehabilitation and particularly physiotherapy during the first year after stroke seems to contribute to meeting their needs for rehabilitation. It seems possible to reduce the number of days a patient spends in the stroke unit after mild to moderate stroke and for them to spend these days in a rehabilitation unit instead, and yet achieve a faster recovery in ADL.

**Key words:** activities of daily living, assessment tools, disability, health care services, long-term, length of stay, mixed methods, needs, need assessment, patient satisfaction, rehabilitation, stroke, stroke unit