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What aspects of rehabilitation provision contribute to self-reported met needs for rehabilitation one year after stroke – amount, place, operator or timing?

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Abstract

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Background and Objective To a large extent, people who have suffered a stroke report unmet needs for rehabilitation. The purpose of this study was to explore aspects of rehabilitation provision that potentially contribute to self-reported met needs for rehabilitation 12 months after stroke with consideration also to severity of stroke.

Methods The participants ($n = 173$) received care at the stroke units at the Karolinska University Hospital, Sweden. Using a questionnaire, the dependent variable, self-reported met needs for rehabilitation, was collected at 12 months after stroke. The independent variables were four aspects of rehabilitation provision based on data retrieved from registers and structured according to four aspects: *amount of rehabilitation*, *service level* (day care rehabilitation, primary care rehabilitation and home-based rehabilitation), *operator level* (physiotherapist, occupational therapist, speech therapist) and *time* after stroke onset. Multivariate logistic regression analyses regarding the aspects of rehabilitation were performed for the participants who were divided into three groups based on stroke severity at onset.

Results Participants with moderate/severe stroke who had seen a physiotherapist at least once during each of the 1st, 2nd and 3rd–4th quarters of the first year (OR 8.36, CI 1.40–49.88 $P = 0.020$) were more likely to report met rehabilitation needs.

Conclusion For people with moderate/severe stroke, continuity in rehabilitation (preferably physiotherapy) during the first year after stroke seems to be associated with self-reported met needs for rehabilitation.

Background

People who have suffered a stroke report long-term needs, between one and eleven years after their stroke.^{1–10} These needs are related to different aspects of disability and to rehabilitation and are to a large extent unmet. The reasons behind the many unmet needs for rehabilitation have been only slightly explored, but studies indicate that people with more severe disability after stroke are more likely to report unmet needs for rehabilitation.^{7,10}

There is a lack of knowledge about how rehabilitation services should be organized to meet patients' needs after stroke. However, rehabilitation services of different levels of complexity might be considered.¹¹ The *service level* represents a complex package of care provided by more than one health professional, for example, rehabilitation and care in stroke units, which is provided by a multidisciplinary team.¹¹ The *operator level* also represents a complex package of care but is provided by a single therapist.¹¹ Only one study has been found that explores the association between aspects of rehabilitation provision and the meeting of needs for rehabilitation. That study does not find any association between early supported discharge (ESD), or conventional care, and the meeting of needs among people with stroke. However, there was a suggestion of an association between the amount of therapy received and met needs for rehabilitation.¹² To the best of our knowledge, in relation to the meeting of rehabilitation needs, the importance of when in time rehabilitation is provided has not been explored. Most of the evidence and the recommendations in the Swedish national guidelines for stroke care relate to the initial period of rehabilitation after stroke.¹³ Evidence suggests that interventions can, for example, improve independence in activities of daily living (ADL) throughout the first year after stroke and with regard to aspects of walking even after that.^{14,15} Consequently, a number of considerations regarding the amount of rehabilitation provided, at what service level and operator level, and at what time during

the first-year rehabilitation should be provided, might influence whether or not the rehabilitation services meet peoples' needs for rehabilitation after a stroke.

The time period considered in this study is the first year after stroke. During this year, most rehabilitation is provided and there is strong evidence for beneficial results from rehabilitation.^{16,17} The overall goal of the health-care system is to improve health¹⁸ and interventions are to be based on peoples' needs.¹⁹ There is, however, a lack of knowledge regarding ways in which rehabilitation should be provided with the aim of meeting of rehabilitation needs as seen from the perspective of people who have had a stroke. The purpose of the study was to explore aspects of rehabilitation provision (the amount of rehabilitation; service level, operator level and time after stroke) as potential contributors to self-reported met rehabilitation needs at 12 months after stroke – with consideration also given to severity of stroke.

Methods

Patient selection and procedures

The data for this study were collected during the first week and at 12 months after stroke in the context of a prospective observational study named 'Life After Stroke phase 1 (LAS 1)'. The overall purpose of LAS 1 was to increase the knowledge of the rehabilitation process after stroke, for example to identify patients' and relatives' needs for rehabilitation and support during the first year after stroke, and several research questions have been addressed in previous publications.^{20–26} All the patients with stroke who were admitted to the stroke units at Karolinska University Hospital in Huddinge and Solna, Sweden, between 15th of May 2006 and 14th of May 2007 were eligible for the LAS 1; 349 patients were included.

The participants in this study were a subset of the patients included in LAS 1 who also fulfilled the following criteria; living in the community during the first year after stroke and

having completed the data collection at 12 months after stroke themselves or with assistance from someone else, that is, participants with only proxy answers were not included.

The study was approved by the Regional Ethical Review Board in Stockholm, Sweden.

Data collection

Data were collected by an occupational therapist or a physiotherapist trained for the purpose. Following upon informed consent by the patient, the baseline assessment was carried out at the stroke unit during the first week after stroke. Information about the participants' current health condition and impairments was extracted from their medical records. The data collection at 12 months post-stroke was carried out in the participants' homes.

Data regarding met rehabilitation needs were collected at 12 months after stroke in the form of a structured interview using a questionnaire previously employed in research that explored needs for and satisfaction with health-care services among people with neurological disabilities.^{27–29} Based on a taxonomy developed by Ware,³⁰ the questionnaire was originally developed by Bendtsen *et al.*³¹ and later modified by Widen Holmqvist *et al.*²⁷ and covers 14 statements relating to different dimensions that are thought to influence patients' satisfaction with care. Levels of agreement concerning the statements were rated by the patients on a 1-to-5 response scale with 'agree' and 'do not agree at all' as the endpoints. The dependent variable in this study, 'met needs for rehabilitation', was represented by the statement 'I have received too little rehabilitation after my stroke'. Cognitive interviews regarding this statement have been reported elsewhere.³² The scores on the statements were dichotomized into needs met (4–5 on the response scale) or unmet needs (1–3).

Data on the Barthel Index (BI),³³ were collected in the form of a structured face-to-face interview at baseline and at 12 months after stroke. The BI assesses independence in essen-

tial activities of daily living (ADL); feeding, mobility, grooming, toilet use, bathing, transfer, ascending and descending stairs, dressing, bowel and bladder control. The BI, collected at baseline, was used to categorize stroke severity. Inspired by Govan *et al.*,³⁴ we categorized a BI score on 100 (maximum score) as very mild stroke, 50–99 as mild stroke and 0–49 as moderate/severe stroke.

Data on use of in-patient and out-patient rehabilitation services during the first 12 months after stroke were collected from the Stockholm County Council's computerized register. The days/visits were dichotomized into 'has received the service'/'has not received the service', structured according to service level and operator level and divided into three periods in time: the 1st quarter (0–3 months after stroke), the 2nd quarter (4–6 months after stroke) and the 3rd–4th quarter (7–12 months after stroke). These time periods correspond to the phases in the trajectory of illness during the first year after stroke suggested by Kirkevold³⁵ (the first very acute phase excluded). Rehabilitation usually started within the first 24 h after arrival to the stroke unit (within 2–3 days for those who arrived during weekends since physiotherapists and occupational therapists did not work during weekends). Participants who stayed at the stroke unit longer than 7 days (the median of the sample) were considered as: 'has received in-patient rehabilitation'.

Analyses

Descriptive statistics were used to present socio-demographic data, medical information, results from the BI and the frequency of participants with met/unmet needs and the use of rehabilitation services.

Using met need of rehabilitation as dependent variable and proceeded by univariate analyses, logistic regression analyses were performed. In an initial logistic regression analysis including all participants, the independent variables represented socio-demographic factors (sex, age, civil status, personal finances and

education) and stroke severity. Subsequent logistic regression analyses with separate models for the amount of rehabilitation, service level, operator level and time were performed for each stroke severity group separately. As the number of variables that can be entered in a multiple logistic regression analysis is 1 variable per 10 participants, the number of variables in each multiple regression analysis, with the exception of the initial analysis, was limited to three.

Categorization/dichotomization of the independent variables regarding provision of rehabilitation is described in Table 1.

Amount of rehabilitation

In the model for the amount of therapy received, the independent variables represented the total number of days spent at in-patient rehabilitation as well as the number of visits to outpatient rehabilitation during the first year after stroke divided into four classes (0–14, 15–28, 29–63 and >63 days and/or visits). The same classes for the amount of rehabilitation have previously been used by Pound *et al.*,¹² representing daily rehabilitation for approximately 2 weeks, 2–4 weeks, 1–2 months or more than 2 months.

Table 1 Description and categorization of rehabilitation services

Variable	Description	Categorization/dichotomization
Amount of rehabilitation		
Class 1	Days at acute stroke unit exceeding 7 days/days at in-patient rehabilitation/visits to out-patient rehabilitation facilities	0–14 days/visits
Class 2		15–28 days/visits
Class 3		29–63 days/visits
Class 4		>63 days/visits
Time periods		
1st quarter	0–3 months after stroke	≥1 visit of the specified service within the time period/0 visits
2nd quarter	4–6 months after stroke	
3rd–4th quarters	7–12 months after stroke	
1st and 2nd quarters	0–3 and 4–6 months after stroke	≥1 visit of the specified service within each time period/<1 visit in at least one time period
1st quarter, 2nd quarter and 3rd–4th quarter	0–3, 4–6 and 7–12 months after stroke	
Service level¹		
In-patient rehabilitation ¹	More than 7 days at acute stroke unit/rehabilitation ward/geriatric rehabilitation ward with physiotherapist (PT), occupational therapist (OT) and speech therapist (ST) available	≥1 day/0 days
Day care rehabilitation ¹	Specialized day care rehabilitation with PT, OT and ST available	≥1 visit/0 visits
Primary care rehabilitation ¹	Visits to PT, OT or ST in primary care facilities	≥1 visit/0 visits
Home-based rehabilitation ¹	Visits by PT, OT or ST in a stroke team/home rehabilitation team	≥1 visit/0 visits
Operator level²		
Physiotherapist (PT) ²	The patient has seen PT in primary care or home-based rehabilitation. Alternatively, patient has received in-patient or day care rehabilitation	≥1 visit/0 visits
Occupational therapist (OT) ²	The patient has seen OT in primary care or home-based rehabilitation. Alternatively, patient has received in-patient or day care rehabilitation	≥1 visit/0 visits
Speech therapist (ST) ²	The patient has seen ST in primary care or home-based rehabilitation. Alternatively, patient has received in-patient or day care rehabilitation	≥1 visit/0 visits

¹Day care rehabilitation, primary care rehabilitation and home-based rehabilitation are in analysis combined with the different periods in time.

²PT, OT and ST are in analysis combined with the different periods in time.

Service level

In the model for service level, the independent variables represented rehabilitation services provided from different facilities (*day care rehabilitation during the 1st, 2nd and 3rd–4th quarters, primary care rehabilitation during the 1st, 2nd and 3rd–4th quarters, home-based rehabilitation during the 1st, 2nd and 3rd–4th quarters*) (Table 1). To mirror all the common service combinations during the first quarter after stroke in the analysis, in-patient rehabilitation was considered as equivalent to hospital-based, home-based or primary care rehabilitation.

Operator level

In the model for operator level, the independent variables represented different professionals who had provided rehabilitation (*a physiotherapist during the 1st, 2nd and 3rd–4th quarters, an occupational therapist during the 1st, 2nd and 3rd–4th quarters, a speech and language therapist during the 1st, 2nd and 3rd–4th quarters*).

Time

If a model regarding service level or operator level was found to be statistically significant, a model was applied that explored the importance of having used rehabilitation services at that significant operator or service level during three different time periods during the first year after stroke. The time periods used in the analysis were as follows: *during the 1st and 2nd quarters; during the 3rd–4th quarters and during the 1st, 2nd and 3rd–4th quarters* (Table 1).

The significance level was specified at 0.05, and all the statistical analyses were performed using the Statistica (version 10; StatSoft Inc., Tulsa, OK, USA) software.

Results

Participants and characteristics

A total of 173 participants from the LAS-1 met the inclusion criteria for this study. Rea-

sons for people not being eligible for inclusion were as follows: living in nursing homes ($n = 33$), answering by proxy ($n = 17$), missing data on the dependent variable ($n = 2$), living in another county where data on health-care use were not available ($n = 1$) or deceased ($n = 55$). Sixty-eight participants were lost to follow up because they could not be reached ($n = 9$); declined to participate ($n = 44$) or were lost to follow up for unspecified reasons ($n = 15$). A comparison between those included in the study and those lost to follow up showed that among those lost to follow up, the number of men/women was 35/35, mean age 70 and number of people with very mild/mild/moderate or severe stroke was 15/27/20.

Baseline characteristics, socio-demographic factors, the number of days spent in the stroke unit and further met needs for rehabilitation and score on the BI at 12 months after stroke are displayed in Table 2. Fifty-nine of the participants had very mild stroke, 83 had mild stroke and 31 had moderate or severe stroke. The total number of participants with met needs for rehabilitation was 116 (67%) and by stroke severity very mild 50 (85%), mild 50 (60%) and moderate/severe stroke 16 (52%).

The logistic regression analysis regarding socio-demographic factors and stroke severity showed that participants with mild stroke (odds ratio (OR) 0.23, confidence intervals (CI) 0.09–0.61, $P = 0.002$) as well as moderate/severe stroke (OR 0.10, CI 0.03–0.36, $P = <0.001$) were less likely to report met needs for rehabilitation compared to those with very mild stroke.

Use of rehabilitation services

All participants in the study received initial rehabilitation either at the acute stroke unit or, in a number cases ($n = 11$), at a comprehensive stroke unit (combined acute and rehabilitation). There were a considerable number of combinations of rehabilitation services provided during the first year after stroke, as displayed in Fig. 1. Among the participants with very mild stroke, all 10, who had been in

Table 2 Baseline characteristics, socio-demographic factors and met needs for rehabilitation and Barthel Index at 12 month for the total sample and for the three groups

	Total <i>n</i> = 173	Very mild <i>n</i> = 59	Mild <i>n</i> = 83	Moderate/ severe <i>n</i> = 31
Socio-demographic factors				
Sex men/women	100/73	39/20	44/39	17/14
Age, years (mean, SD)	68 (14)	63 (14)	70 (14)	71 (12)
Civil status (living with a partner/living alone)	107/64 ¹	39/20	44/37 ²	24/7
Education (>9 years/≤9 years)	95/73 ³	38/20 ⁴	41/39 ⁵	16/14 ⁶
Personal finances (satisfactory/not satisfactory)	88/64 ⁷	39/15 ⁸	39/35 ⁹	10/14 ¹⁰
At stroke onset				
Barthel Index (median, quartiles)	90 (60, 100)	100 (100, 100)	85 (65, 90)	25 (15, 40)
Previous stroke	47	16	25	6
Previous TIA	11	4	5	2
Hypertension	100	31	45	24
Diabetes mellitus	37	9	18	10
Ischemic/hemorrhagic stroke	146/27	53/6	70/13	23/8
Initial health-care use				
Stroke unit, acute				
Number of participants	162	59	73	30
Days: median/range ¹¹	7/1–26	6/1–19	7/2–23	7.5/2–26
Stroke unit, comprehensive ¹²				
Number of participants	11	0	10	1
Days: median/range ¹¹	16/6–31		15/6–23	31/31–31
Other specialized care in the acute phase				
Number of participants	24	6	15	3
Days: median/range ¹¹	3/1–36	3.5/1–6	3/1–5	3/2–36
12 months after stroke				
Barthel Index (median, quartiles)	100 (95, 100)	100 (100, 100)	100 (95, 100)	95 (75, 100)
Met rehabilitation needs <i>n</i> (%)	116 (67)	50 (85)	50 (60)	16 (52)

¹*n* = 171.²*n* = 81.³*n* = 168.⁴*n* = 58.⁵*n* = 80.⁶*n* = 30.⁷*n* = 152.⁸*n* = 54.⁹*n* = 74.¹⁰*n* = 24.¹¹Median/range for those who have received the service.¹²Combined acute and rehabilitation.

contact with day care rehabilitation, reported met needs for rehabilitation. Met needs for rehabilitation were furthermore reported by all the participants with very mild and mild stroke who had not received any rehabilitation beyond the stay at the stroke unit.

Amount of rehabilitation

The number of visits was not associated with met needs for rehabilitation in any of the groups of stroke severity.

Service level

The service level was not associated with met needs for rehabilitation in any of the groups of stroke severity.

Operator level

For participants with very mild and mild stroke, the operator level was not related to met needs for rehabilitation. Whereas for participants with moderate/severe stroke, logistic

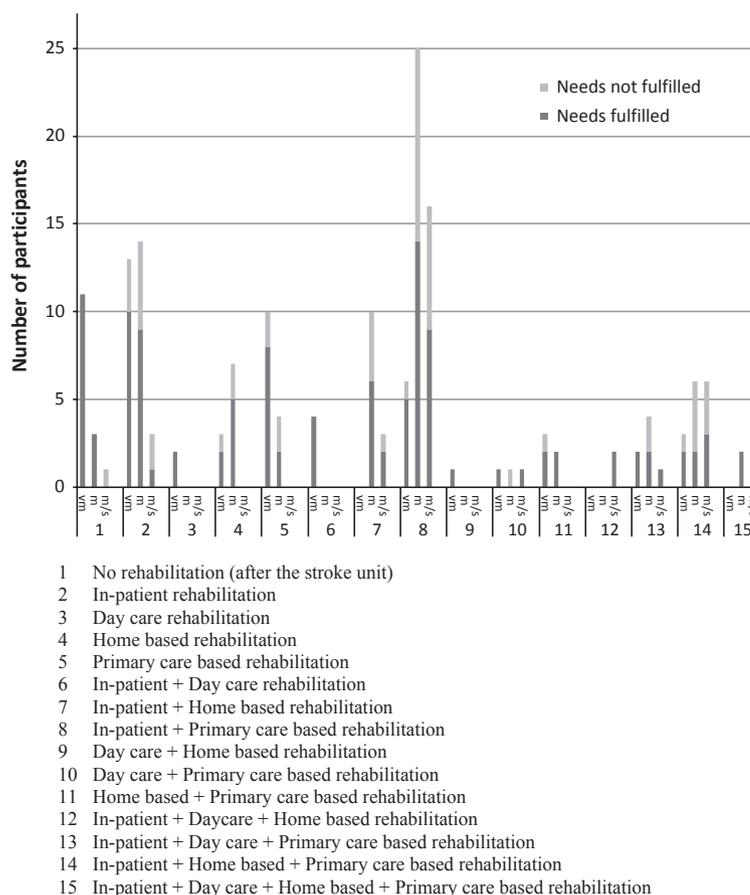


Figure 1 Number of participants with very mild stroke (vm), mild stroke (m) and moderate/severe stroke (m/s) who have used different rehabilitation services described at a service level the first year after stroke.

regression analysis showed that having been in contact with a physiotherapist at least once within each time period, during the *1st, 2nd and 3rd–4th quarters*, was associated with met needs for rehabilitation (OR 8.36, CI 1.40–49.88 $P = 0.020$).

Time

The importance of contact with a physiotherapist during different time periods in the course of the first year after stroke was further explored. The model’s result indicated a trend towards statistical significance for the interaction between the time variables *1st and 2nd quarters* and *3rd–4th quarters* ($P = 0.101$). Further investigation of the time variables in the model showed that the importance of the variable *1st, 2nd and 3rd–4th quarter* could not be

neglected. The final model showed that the interaction variable *1st, 2nd and 3rd–4th quarters* (i.e. at least one contact during each of the time periods) was associated with self-reported met needs for rehabilitation in participants with moderate/severe stroke (OR 8.36, CI 1.40–49.88 $P = 0.020$).

Discussion

This study is unique in the sense that several aspects of the provision of rehabilitation were explored in relation to meeting the participants’ self-reported rehabilitation needs. It is also unique due to its focus on the positive aspects of needs, that is, needs met. The results showed that contact with a physiotherapist during the *1st, 2nd and 3rd–4th quarters* in the course of the first year after stroke was associated with

meet needs for rehabilitation among people with moderate/severe stroke, whereas the service level and the amount of rehabilitation received were not associated with the needs for rehabilitation met.

Among people with very mild stroke, the results showed a high proportion of people whose need for rehabilitation had been met, whereas the proportion of needs met was lower in the other groups. This is congruent with findings in other studies where more severe disability has been associated with more unmet needs.^{7,10} The finding that participants with very mild and mild stroke, who did not receive any rehabilitation after the stay at the stroke unit, all reported met needs for rehabilitation might indicate that the stroke units involved have managed to identify those not in need of further rehabilitation.

Contact with a physiotherapist at least once during each of the time periods: 1st, 2nd and 3rd–4th quarters of the first year turned out to be of importance for rehabilitation needs met at 1 year after stroke among participants with moderate/severe stroke. There is strong evidence for the benefits, after stroke, of complex interventions by a multidisciplinary rehabilitation team, for example, care rehabilitation at a stroke unit or ESD service.^{36–38} But there is also evidence for the benefits of complex interventions by different professionals who work in rehabilitation.³⁹ The different professions involved in stroke rehabilitation have been reported as having common principles, for example task-oriented training,³⁹ but they may represent different values for the patients. In qualitative studies, people with stroke have described physiotherapy as the path to recovery.^{40–43} Furthermore, physiotherapy represents faith and hope;⁴⁴ it seems to have symbolic value as hope, but at the same time, it is criticized for not giving the support necessary to enable patients to go back to activities that are important to them.^{45,46} The result of the study suggests an association between having had contact with a physiotherapist and self-reported met needs for rehabilitation. A plausible interpretation of this result might be that

physiotherapy may provide a measure for further recovery^{40–43} but also contribute to maintenance of hope for further recovery.⁴⁴ However, the way this interacts with adaptation to the new situation after stroke needs further exploration.

Regarding the time factor, contact with a physiotherapist at least once during each of the time periods, during the 1st, 2nd and 3rd–4th quarters of the first year after stroke, was associated with met needs for rehabilitation. The first year after stroke has been described as four different phases.³⁵ The first two phases cover the onset and initial rehabilitation and are characterized by hard physical training and by beginning to make sense of the stroke. The third phase from 8 weeks until approximately 6 months after stroke consists of psychosocial and practical adjustment, and of testing out the body's capacity in a new environment, while the fourth phase beyond 6 months post-stroke is about getting on with life and resuming previously valued activities. A more active everyday life during the third and fourth phase may result in new rehabilitation needs and contact with rehabilitation professionals can possibly give support and comfort in new situations and thereby meet the new needs that arise. Qualitative studies have reported about needs for access to information, feedback and guidance at a later stage of recovery when the patients are ready for it and when services may be more relevant.^{40,44} Patients also record feelings of being abandoned following discharge.^{47,48} Another conclusion that can be drawn from the findings in this study is that contact with rehabilitation professionals during the third or fourth quarters might have met and prevented, or reduced, such needs and feelings.

This study is a first attempt to explore how different aspects of the provision of rehabilitation after stroke contribute to meeting needs for rehabilitation 1 year after stroke. It raises several methodological considerations. The strengths of the study are the use of register-based data regarding the use of rehabilitation and also the exclusion of proxy answers.

Bearing in mind that the provision of rehabilitation services is complex, the results should be interpreted with caution. The structure of factors influencing met needs applied here is necessarily a simplification, and possible interactions between the independent variables have not been thoroughly explored. With regard to the dependent variable, one should notice that the statement is negatively phrased (concerns unmet needs), whereas the analyses consider the positive aspect, that is, met needs. However, this was supported by results from cognitive interviews that has been performed regarding the statement:³² people who did not agree that they had unmet needs (here considered as having met needs) reported satisfaction with what they had received, for example home visits by a physiotherapist, speech and language therapy and did not express that they lacked anything. Moreover, with regard to the dichotomization of the dependent variable, a person who scored '3' (i.e. in the middle of the Likert-type response scale) was considered to have unmet needs for rehabilitation. This was based on the assumption that a score of '3' indicates that the person has not had his or her needs for rehabilitation completely met and consequently has partly unmet needs. We decided to consider a stay at the acute stroke unit that exceeded the median of the group (7 days) as in-patient rehabilitation. The rehabilitation offered there might not correspond to the rehabilitation offered at a dedicated rehabilitation unit, but the presence of a multidisciplinary team, which is one of the core components of a stroke unit, was considered as an assurance that rehabilitation was provided. In addition to considering rehabilitation services at service level and operator level, the services can also be considered at a *treatment level* that represents specific individual interventions. In this study, however, the treatment level was not taken into consideration. As we did not consider the treatment level, we chose the cut-off for what we considered a contact (≥ 1 visit). Even though one visit might not be considered as a treatment/intervention, this choice was based on the assumption that one

visit can bring the professionals' attention to rehabilitation needs. Moreover, we did not know whether the disability underlying the contacts with rehabilitation professionals was stroke-related or related to other health conditions. The participants in this study were a subset of the participants included in the LAS 1. According to statistics from the National Patient Register (NPR), 1231 patients received care for stroke at Karolinska University hospital during the inclusion period of LAS 1. However, stroke is considered to be somewhat over diagnosed in the NPR.⁴⁹ In the sample included in this study, it is reasonable to believe that people with very mild stroke are under-represented due to shortness of stay. An under-representation of people with very mild stroke may have increased the proportion of people with unmet needs for rehabilitation. Also people with very severe stroke can be under-represented due to unconsciousness and ethical considerations. However, as only people discharged home were included in this study, people with the most severe stroke may not have fulfilled that criteria, and this consequently may not have notably affected the results.

The sample is small, and consequently, there may be associations of clinical importance that have not been detected. Further studies would benefit from larger samples that, taking into consideration the diversity of disabilities experienced after stroke, could provide an opportunity to identify patterns of rehabilitation use that contribute to satisfying rehabilitation needs.

In conclusion, for people with moderate/severe stroke, contact with a physiotherapist at least once during each of the three periods, corresponding to the first, second and third/fourth quarters after stroke seems to be of importance for self-reported met rehabilitation needs. Consequently, continuity in rehabilitation during the first year and/or a re-assessment by a multidisciplinary team during the 3rd or 4th quarter after stroke would be beneficial. Such a re-assessment could attend to needs that have arisen during attempts to

resume previously valued activities and in the course of adaptation to a new life situation and would thereby contribute to meeting rehabilitation needs 1 year after stroke.

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Conflict of interest

The authors declare that they have no conflicts of interest.

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