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Dyads' combined perception of rehabilitation needs one year after stroke: a mixed methods study

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Abstract

Objectives: The aim of the study was to explore the associations between the dyad's (person with stroke and informal caregiver) perception of the person with stroke's rehabilitation needs and stroke severity, personal factors (gender, age, sense of coherence), the use of rehabilitation services, amount of informal care and caregiver burden. Further, the aim was to explore the personal experience of everyday life changes amongst persons with stroke and their caregivers and their strategies for handling these one year after stroke.

Design: A mixed methods design was used combining quantitative and qualitative data and analyses.

Setting: Data were mainly collected in the participants' homes and from the computerised register at the Stockholm County Council.

Outcome measures: Data were collected through established instruments and open-ended interviews. Data on the use of rehabilitation services were obtained from the computerised register at the Stockholm County Council. The dyad's perceptions of the person with stroke's rehabilitation needs were assessed by the persons with stroke and their informal caregivers. The results were combined and classified into three groups: met, discordant (i.e. not in agreement) and unmet rehabilitation needs.

Participants: 86 persons with stroke (mean age 73 years, 38% women) and their caregivers (mean age 65 years, 40% women).

Results: Fifty-two percent of the dyads perceived that the person with stroke's need for rehabilitation was met 12 months after stroke. Met rehabilitation needs were associated with less severe stroke, more coping strategies for solving problems in everyday activities and less caregiver burden.

Conclusion: Rehabilitation interventions need to focus on both improving or sustaining the individuals' physical and cognitive functioning as well as supporting the dyads' process of psychological and social adaptation after stroke.

Strengths and limitations of this study

- A mixed method approach that uses both quantitative and qualitative analysis, as in this study, contributes to a more comprehensive picture of rehabilitation after stroke.
- A major strength of this study was the dyadic perspective which adds valuable knowledge regarding the use of a systemic approach in rehabilitation as well as the importance of the social environment.
- The data from the open-ended questions was not rich enough to make comparisons between the partners in the dyads. Instead the answers from the persons with stroke and the caregivers were analysed separately and compared between persons with stroke and caregivers on a group level.
- The use of set answers on a statement about rehabilitation needs only provides generalised information. Future studies would benefit from more in-depth knowledge on the characteristics of rehabilitation needs and the dyad's expectations for rehabilitation after stroke.

Introduction

It is recommended that rehabilitation after a stroke should be patient-centred i.e., based on the needs identified by the person with stroke.[1,2] Nevertheless, one year after stroke 33-49% perceive unmet rehabilitation needs.[3-5] These perceptions have been shown to be associated with several aspects such as a younger age [6] and greater disability.[5-6] The type [7] and amount of rehabilitation services received [8], as well as social support and internal resources of confidence, have been shown to be important factors in the perception of met rehabilitation needs. [9] Sense of coherence (SOC) refers to a global orientation that enables us to view the world and our individual environment as comprehensible, manageable and meaningful. [10] A person with a strong SOC is thought to have access to more personal resources that help them adjust successfully to traumatic events in life such as a stroke. However, the knowledge with regard to plausible associations of SOC and perceived needs for rehabilitation after stroke is limited and further studies are needed. [5]

With shorter hospital stays and more care and rehabilitation being delivered at home, the patient's families and friends are likely to be more involved and have increased responsibilities for informal care and rehabilitation after a stroke. Studies have shown that the people with whom someone shares their everyday life with have an important role in rehabilitation. [11-14] Moreover, informal caregivers identify more unmet rehabilitation needs than the people with stroke do themselves [15], and when a stroke influences the everyday lives that people share, informal caregivers should be more involved in the rehabilitation process. [11-14] However, informal caregivers themselves are often elderly and are in need of support to help cope with the burden of care in everyday life after stroke. [16-18] Thus, it is imperative that we consider how both the people with stroke and also their caregivers perceive rehabilitation needs, as well as plausible associations between such perceptions and caregiver burden.

Several qualitative studies have shed light on how the everyday life of dyads (i.e. two persons involved in an ongoing relationship or interaction) are intertwined and these studies highlight couples' interdependency after a partner's stroke. [11-14] These results emphasise the need for studies that focus not only on the person with stroke or the caregiver but instead adopt a broader perspective such as that of the dyad. No studies have been found that focus on the perceptions of rehabilitation needs after stroke from a dyadic perspective nor the plausible associations between such perceptions and caregiver burden.

Although many individuals still experience rehabilitation needs one year after stroke, [3-5] rehabilitation is often concluded within the first three months. An understanding of the rehabilitation process can be increased both by having a dyadic perspective of post-stroke rehabilitation needs as well as learning plausible associations with such aspects such as personal factors, stroke severity and caregiver burden. Such knowledge can presumably help through both identifying dyads that are still in need of support in everyday life after the first year and also guide rehabilitation professionals when developing interventions. Furthermore, the use of a mixed methods design which combines qualitative and quantitative data from a broader perspective may provide opportunities to shed new light on the complex processes involved in post-stroke rehabilitation. Therefore, the aim of the study was to explore the associations between the dyad's perception of rehabilitation needs and stroke severity, personal factors (gender, age, SOC), the use of rehabilitation services, amount of informal care and caregiver burden. Further, the aim was to explore the personal experience of everyday life changes amongst persons with stroke and their informal caregivers and their strategies for handling these one year after stroke.

Methods

This study used a mixed methods design combining quantitative and qualitative data and analyses. The data for this study was collected in the context of a prospective observational study of the rehabilitation process after stroke named ‘Life After Stroke phase 1’ (LAS-1). All the patients with stroke admitted to one of three stroke units at the Karolinska University Hospital between May 15, 2006 and May 14, 2007 were eligible for inclusion in LAS-1 and 349 were included. After informed consent, the baseline assessment within the first week after stroke and follow-ups at 3, 6 and 12 months after stroke onset were carried out, mainly during home visits, by a research assistant (i.e. a purposely trained occupational therapist or a physiotherapist). The persons with stroke were asked to identify an informal caregiver. The caregiver chosen by the person with stroke could be a partner, a son or daughter, or a friend. Data from the caregivers were collected during the home visits or if the caregiver was not present, via a questionnaire which was left for the caregiver and was to be returned by post in a stamped envelope.

The participants in the present study were participants in the LAS-1 (people with stroke and their informal caregivers) who had answered a question concerning the fulfilment of rehabilitation needs of the person with stroke at the 12-months follow-up. The study was approved by the Regional Ethical Review Board in Stockholm, Sweden.

Data collection

Persons with stroke

Data on sex, age and stroke severity at baseline were collected by means of interviews and from the medical records. Using the Barthel Index [19] stroke severity was categorised as mild (scores 50-100) or moderate/severe (scores 0-49). [20]

Through employing a questionnaire previously used in studies of people with stroke [5, 7, 21]data regarding the need for, and satisfaction with the health care services received was collected at 12 months after stroke. The questionnaire is based on a taxonomy developed by Ware [22] and covers different dimensions that are thought to influence patients' satisfaction with care. The persons with stroke rated levels of agreement in relation to 14 statements concerning the different dimensions on a five-graded Likert scale with 'agree' and 'do not agree at all' as the endpoints. One particular statement addresses the level of fulfilment regarding rehabilitation needs and was therefore chosen as the dependent variable for this study: 'I have received the rehabilitation that my condition has required'. The scores on the statement were dichotomized into 'agree' i.e. met needs for rehabilitation (1-2 on the Likert scale) or 'do not agree' i.e. unmet needs for rehabilitation (3-5 on the Likert scale).

To assess SOC at 12 months, the 13-item version of the SOC-scale was used. [10] The questionnaire consists of 13 items rated on a seven-graded Likert scale. The total score ranges from 13 (weak SOC) to 91 (strong SOC). Data on the use of inpatient (days) and outpatient (contacts) rehabilitation services were obtained from the computerised register at the Stockholm County Council.

Open-ended questions were used to collect data at 12 months after stroke regarding changes in managing daily activities after stroke and strategies for handling problems that arose. The questions were framed as such: '1a) how do you think your daily activities work for you today? 1b) is there anything that has changed (mention three examples of activities that have become harder to perform)? 2) Do you have any thoughts about how this (activities that have changed) might work better, such as how you could solve the problem?' The answers to the questions were either written down by the participant or answered orally by the participant and then written down by the research assistant.

Informal caregiver

Data on sex, age and the caregiver's relation to the person with stroke were collected at three months after stroke by means of interviews. A corresponding questionnaire was used to collect data on the caregiver's perception of need for, and satisfaction with the health care services received by the person with stroke at 12 months after stroke. Levels of agreement with 10 statements relating to the different dimensions thought to influence satisfaction with care were rated by caregivers on a five-graded Likert scale with ‘agree’ and ‘do not agree at all’ as the endpoints. The questionnaires used to collect data from caregivers and from the persons with stroke respectively contained four coinciding statements. The same statement, addressing fulfilment of rehabilitation needs, was chosen for both the persons with stroke and the caregivers: ‘My next-of-kin has received the rehabilitation that his/her condition has required’. The scores on the statement were dichotomized into ‘agree’ i.e. met needs for rehabilitation (1-2 on the Likert scale) or ‘do not agree’ i.e. unmet needs for rehabilitation (3-5 on the Likert scale).

Caregiver burden was assessed at 12 months using the Caregiver Burden Scale [23], and self-reported data on informal care (yes or no) from caregivers were collected in an interview. The caregivers were asked if there were any activities of daily living in which the participant had needed his/her assistance or supervision that, prior to stroke onset, had been performed independently by the participant.

An open-ended question on changes in daily life since the next-of-kin's stroke was used to collect data at 12 months after stroke. The question was framed as: 'Can you name the three greatest changes (in your everyday life after your next-of-kin's stroke) to you personally?' The answers to the questions were either written down by the caregiver or answered orally by the participant and then written down by the research assistant.

Data analysis

To determine the dyads' joint perception of rehabilitation needs, the dichotomized results of the statement concerning fulfilment of rehabilitation needs for both individuals in the dyad were combined and then classified into three groups: met, discordant (i.e. not in agreement) and unmet rehabilitation needs. The Kruskal-Wallis ANOVA was used first to determine if there was a difference between the three groups of combined perception of rehabilitation needs regarding age, SOC, use of inpatient (number of days) and outpatient (number of contacts) health care services and caregiver burden. The Mann Whitney U test was used for pairwise comparisons between the groups of combined perception of rehabilitation needs. The chi square test was used to analyse the differences between the groups of combined perception of rehabilitation needs with regard to sex, disease severity and informal care. Pairwise comparisons were adjusted for multiple comparisons using a p value of ≤ 0.01.

Data, in the form of answers to the standardised open-ended questions from the persons with stroke and their caregivers, were analysed through a content analysis. [24] The answers from the persons with stroke and caregivers were analysed separately and compared on a group level in each group (i.e. met, discordant and unmet needs of rehabilitation). In the first step of analysis all the data from the open-ended questions were read through thoroughly by the first, second and last author of this study. Each author coded the data individually and the codes were grouped into categories. In the following step, each of the three authors summarised the content of each of the six groups: met, unmet or discordant rehabilitation needs in the persons with stroke and caregivers respectively. The three authors discussed the categories and the summary descriptions until they reached consensus on a description of each group. Differences and similarities between the persons with stroke and the caregivers within the groups of met, discordant or unmet rehabilitation needs were also described. In a final step the quantitative and qualitative findings were compared according to mixed model analysis. [25] Three areas were identified into which the variation between all data from the different groups could be described. These areas constituted the themes/headings of the results.

Results

Of the 349 persons with stroke from the LAS-1, 55 were deceased one year post stroke, 76 declined or were lost to follow-up, 15 persons had not answered the statement 'I have received the rehabilitation that my condition has required' and 117 had no identified caregiver. This left 86 persons with stroke and their caregivers at the 12-month follow-up. The characteristics of the persons with stroke, the use of health care services, amount of informal care and the caregiver's burden are presented in table 1. In the sample, 58 (67%) had mild stroke and 28 (33%) had moderate/severe stroke. Among the 86 caregivers, 62 were partners, 6 were children of the person with stroke and 18 people did not state the relationship clearly. The mean age of the caregivers was 65 years, 39 were women and 17 were men (44 caregivers had missing data on age and 20 had missing data on gender). Of the 263 persons with stroke not included in the present study the number of women was 128 (49%); mean age was 72 years; and 148 (56%) had mild stroke.

Among the dyads, 45 (52%) perceived that the person with stroke's rehabilitation needs were met at 12 months, 11 (13%) perceived that the rehabilitation needs were unmet, and 30 (35%)

were not in agreement. Of the persons with stroke, 61 (71%) perceived that their needs for rehabilitation were met and 25 (29%) perceived unmet needs for rehabilitation. In the caregivers, 57 (66%) perceived met rehabilitation needs for the person with stroke and 29 (34%) unmet rehabilitation needs.

Stroke severity was associated with the dyads' rehabilitation needs

In table 2, results from the comparative analyses are presented. A larger proportion of people with mild stroke were in dyads that perceived met rehabilitation needs compared to dyads who did not (p=0.002). The same results were found in the standardised open-ended questions given by the persons with stroke and their caregivers. In the dyads where rehabilitation needs were met several persons with stroke reported that they lived their lives as they did before their stroke. The same did not apply to persons with stroke in the dyads where unmet or discordant needs were recorded. Instead, within these dyads several persons with stroke reported great difficulties in walking and their dependence on a wheelchair or a walker. This was described by one participant as: 'I find it harder to walk. I have walking difficulties and I have to use a walker. My balance has been very affected.' Dyads whose rehabilitation needs were met reported less severe walking difficulties for the persons with stroke e g., that they only had difficulties walking long distances and in walking without a stick. One example from a participant described the following change: 'I haven't fully recovered my ability to walk or my balance, but they are much better than nine months ago. I can go out into the garden independently even without a walking stick, though I usually have a stick.' Further, in dyads whose rehabilitation needs were met, the persons with stroke described more specific problems such as weakness in the arm and hand, reduced fine hand use and reduced sensitivity in the hand; these problems caused limitations in activities such as playing the piano, peeling potatoes and buttoning clothes. In contrast, in dyads which recorded unmet or

discordant rehabilitation needs, the persons with stroke often reported having to give up a task in advance and had limitations in more physically demanding activities such as going to buy groceries; going to the toilet and getting dressed; and gardening. Further, persons with stroke who described other major life events occurring after the stroke were all found to be among the dyads reporting unmet rehabilitation needs. Examples of major life events reported were a new stroke, pneumonia or multiple diagnoses, such as dementia or chronic obstructive pulmonary disease.

Dyads' rehabilitation needs related to the persons with stroke's use of strategies to overcome problems

The statistical analyses identified no differences in perception of rehabilitation needs with regard to sex, age or the use of rehabilitation services. Persons with stroke in dyads reporting met rehabilitation needs had a higher SOC than in discordant dyads (p=0.002) (see table 2). In the dyads that had met or discordant rehabilitation needs almost all persons with stroke, whose rehabilitation needs were perceived as met, described how they handled everyday problems. Strategies included engaging in physical exercise, such as going for walks. One specific strategy was to pause during the activity when things became 'too much'. Others mentioned using aids or a partner to compensate when problems emerged. Additional strategies were: to think ahead to avoid problems; to try to find a solution to the problem; to set goals; and to refuse to give up. One participant described how he found solutions to overcome problems. He expressed this as: 'I don't give up. I train at home through coming up with activities such as cutting logs and making a new saw horse. I am a retired technician and am used to finding solutions.' Furthermore, in the dyads where rehabilitation needs were met, most individuals with stroke had ideas about what needed to improve, such as being able to cycle or drive a car. They also knew how to improve, like integrating training into everyday life and to keep pushing themselves and practicing. Others described how they used strategies,

or aids, or reported that they had adapted to the situation by stopping doing things. This finding can be compared against those with unmet rehabilitation needs who did not have strategies to overcome the difficulties they experienced. One person claimed: 'I have no specific strategy to train my body and soul, I have lost the will or my spark.' People in this group expressed a feeling of dependence on others for their rehabilitation. Several persons with stroke described how they lacked willpower and found it difficult to take initiatives while others reported an inner drive to make things work, but did not have a strategy to achieve this. Furthermore, the persons with stroke in dyads with unmet rehabilitation needs often felt that rehabilitation had ended too early. Just as those in dyads with unmet needs, the individuals with stroke in discordant dyads wanted to receive more rehabilitation as a strategy or as a solution to their problems.

Caregivers perceived less caregiver burden in dyads where rehabilitation needs were met

Results from the statistical analyses showed that in dyads where rehabilitation needs were met the caregivers perceived a lower caregiver burden compared to dyads with unmet rehabilitation needs (p=0.03) and discordant dyads (p=<0.001) (see table 2). No difference was found among dyads in regard to the number of persons with stroke receiving informal care. We found that the next-of-kin in all groups reported taking greater responsibility for household chores such as cooking, washing and cleaning. They also reported needing to take more initiatives and responsibility for safety, planning and creating routines for everyday life. Furthermore, caregivers in all the dyads described their anxieties. For instance the person with stroke might have a new stroke or another medical problem. Caregivers in all the groups also reported feeling homebound. They felt unable to leave the person with stroke alone and, consequently, had less time to do things on their own. In addition to feeling greater responsibility, both caregivers with met and unmet rehabilitation needs in discordant dyads

described how they no longer kept their own interests and hobbies such as dancing and visiting their summer house.

Regardless of whether the persons with stroke perceived met or unmet rehabilitation needs, caregivers who perceived unmet rehabilitation needs for the person with stroke had less time for their social life: family and friends did not keep in touch and they had less time to spend with friends and/or other people. This quote by a caregiver mirrors this sentiment: 'The greatest change is not being able to socialise with a female friend, relax and spend time with my children and grandchildren.' In contrast, only a few of the caregivers where rehabilitation needs were met described less active social lives. Instead, these caregivers noted advantages that came from the stroke, such as spending more time with the family, having a more profound relationship and seeing each other more often. This advantage was expressed by a spouse saying: 'One great plus for our family is that my husband has got so much more time to spend with all of us (after his stroke).'

Discussion

About half of the dyads perceived that the person with stroke's rehabilitation needs were met one year after stroke. The results showed that the people whose rehabilitation needs were met had suffered a less severe stroke and stroke-related difficulties and had more strategies for solving everyday problems, while caregivers had a lower caregiver burden. Further, equal proportions of persons with stroke and caregivers perceived that there were unmet rehabilitation needs. These findings are different from earlier studies where the caregivers identified more unmet needs than those people with stroke. [15] Moreover, only 29% of the persons with stroke in the present study perceived an unmet need for rehabilitation which is markedly lower than the 43% reported in a previous national Swedish one-year follow-up

study. [3] It is possible that the small sample in the present study partly explains these disparate results. Another possible explanation is that the inclusion criteria in the present study involved participation by a caregiver who may have been engaged in the rehabilitation process, which might have influenced the perceived rehabilitation needs. A large proportion, 35%, of the dyads were not in agreement which implies that a dyadic approach needs to be considered when devising post-stroke rehabilitation.

The findings show that the perception of rehabilitation needs one year after stroke differs between dyads in relation to stroke severity and major life events. Stroke severity and perceived stroke-related difficulties were less severe in dyads which reported met rehabilitation needs as compared to dyads where the stroke was more severe and where discordant or unmet needs were reported. More major life events were reported in the qualitative data among the discordant dyads and the dyads with unmet needs. This result was not surprising and it is also in line with previous studies which have shown that persons with severe stroke perceive more unmet rehabilitation needs. [5-6] Persons with stroke in dyads where rehabilitation needs were met reported that they lived their lives as they did before the stroke. It may seem apparent that a more severe stroke means more unmet needs for rehabilitation. However, these results also point to a need for rehabilitation interventions that focus both on improving or sustaining physical and cognitive functioning as well as helping to adapt to life post stroke, including systematic support to the caregivers.

In dyads where rehabilitation needs were met, the persons with stroke had a higher SOC than those in dyads with discordant views. Although those with unmet rehabilitation needs reported few or no coping strategies for everyday problems, there was no difference with regard to SOC found between dyads with met and unmet rehabilitation needs. One explanation for these results might be that the group formed of dyads with unmet rehabilitation needs was small and may have lacked statistical power to detect differences. Further studies on the impact of SOC and the perception of rehabilitation needs are warranted and may guide the development of rehabilitation interventions that support people with stroke in their efforts to manage their life post stroke. SOC can be considered a disposition rather than a personal characteristic and thus, as some studies show, be modifiable through intervention. [26-27] Rehabilitation interventions that are informed by the components of the SOC construct, including comprehensibility, manageability and meaningfulness, could result in comprehensive and individualised approaches to rehabilitation after stroke. For example, people with moderate or severe stroke might need more guidance in finding their own coping strategies for how to handle everyday problems. A major limitation of this study is that the SOC-scale was not administered to the caregivers. This would have added valuable information to the interpretation of the results with regard to SOC.

The findings also showed that caregiver burden was rated lower in dyads with met rehabilitation needs and some caregivers also reported social advantages after the stroke. This is compared to caregivers in dyads with unmet and discordant needs who rated higher caregiver burden and less active social lives. Still, the number of persons with stroke receiving informal care did not differ between the groups. This suggests that the caregiver's sense of burden is related to a more severe stroke or feeling more responsible for planning and organising activities. A clinical consequence of these results could be to focus on reducing the caregiver burden by, for example, offering relief, especially to dyads with unmet and discordant rehabilitation needs, so that caregivers can maintain their social lives.

One of this study's limitations is that the question about perceived rehabilitation needs does not define what constitutes rehabilitation; instead each participant defined what rehabilitation meant to them. The use of a set answers on a statement about rehabilitation needs only provides generalised information. Future studies would benefit from more in-depth knowledge on the characteristics of rehabilitation needs and the dyad's expectations for post-stroke rehabilitation. Another limitation is that there was missing data regarding the caregivers due to incomplete questionnaires returned by post.

A mixed method approach that uses both quantitative and qualitative analysis, as in this study, contributes to a more comprehensive picture of post-stroke rehabilitation. The qualitative data adds information about the participants' perception whereas the quantitative data can more easily be compared with other studies and generalised to similar samples. However, the data from the open-ended questions was not rich enough to compare the partners in the dyads with one another. Instead the answers from the persons with stroke and from the caregivers were analysed separately and compared between persons with stroke and caregivers on a group level.

The findings in this study confirm those of previous studies that used the more traditional perspective of studying the person with stroke [4-9] or the caregiver [16-18] separately. This study's unique contribution was the dyadic perspective, which adds valuable knowledge regarding the use of a systemic approach in rehabilitation as well the importance of the social environment. [28] This stresses the integration of caregivers and other significant individuals in the rehabilitation system. [29] Through gaining a dyadic perspective on how rehabilitation needs are related to such aspects such as personal factors, stroke severity and caregiver burden, we can increase our understanding of this perspective and thus guide rehabilitation professionals when providing interventions. Future studies need to explore and evaluate the effects of using a dyadic perspective throughout rehabilitation.

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Author's contribution:

LE and CY drafted the study. LE, UJ and CY performed the data analyses. All authors made critical revisions and approved the final manuscript.

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Table 1. Characteristics of the persons with stroke, use of health care services, informal care and caregiver burden.

Variable	Total sample, n=86	Met needs, n=45	Discordant, n=30	Unmet needs, n=11
Age: years, median (IQR)	72.5 (63-79.8)	75 (64-78)	71 (62.2-82.5)	74 (68.5-80.5)
Gender: women, n	33	18	11	4
Stroke severity: mild / moderate-severe, n *(Barthel Index, range of scores 0-100)*	57 / 28*	34 / 10†	21 / 9	3 / 8
Sense of coherence: median (IQR) *(Sense of coherence scale, range of scores 13-91)*	79.5 (69-87.8)‡	83 (74-89)§	71 (65.8-81)ǁ	79 (65-90)¶
Inpatient care and rehabilitation: days, median (IQR)	14 (7-36)	14 (6-31)	11.5 (7-35)	24 (19-56)
Outpatient rehabilitation: contacts, median (IQR)	3 (1-23.2)	3 (1-20)	8 (1-28.5)	1 (0-23)
Caregiver burden: median (IQR) *(Caregiver burden scale, range of scores 22-88)*	38 (26-51)	28 (23-44)	46 (36.2-55)	56 (34-63.5)
Informal care: has received, n	42**	20††	17	5§§

*n=85, †n=44, ‡n=74, §n=39, ǁn=26, ¶n=9, **n=83, ††=43, §§=10

Table 2. Categorization of the independent variables, categorization of dyads' perception of rehabilitation needs, p values

Independent variable	Perception of rehabilitation needs	P value
Age, years	Met / Unmet / Discordant	0.60
Sex, male / female	Met / Unmet	0.82
	Met / Discordant	0.77
	Unmet / Discordant	0.98
Sense of coherence, scores	Met / Unmet	0.48
	Met / Discordant	**0.002**
	Unmet / Discordant	0.40
Stroke severity, mild / moderate-severe	Met / Unmet	**0.002**
	Met / Discordant	0.48
	Unmet / Discordant	0.03
Inpatient care and rehabilitation, days	Met / Unmet / Discordant	0.12
Outpatient rehabilitation, contacts	Met / Unmet / Discordant	0.38
Caregiver burden, scores	Met / Unmet	**0.003**
	Met / Discordant	**<0.001**
	Unmet / Discordant	0.47
Informal care, has received / has not received	Met / Unmet	1.00
	Met / Discordant	0.39
	Unmet / Discordant	0.73

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The combined perceptions of people with stroke and their carers regarding rehabilitation needs one year after stroke: a mixed methods study

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The combined perceptions of people with stroke and their carers regarding rehabilitation needs one year after stroke: a mixed methods study

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Abstract

Objectives: The aim of the study was to explore the associations between the dyad's (person with stroke and informal caregiver) perception of the person with stroke's rehabilitation needs and stroke severity, personal factors (gender, age, sense of coherence), the use of rehabilitation services, amount of informal care and caregiver burden. Further, the aim was to explore the personal experience of everyday life changes amongst persons with stroke and their caregivers and their strategies for handling these one year after stroke.

Design: A mixed methods design was used combining quantitative and qualitative data and analyses.

Setting: Data were mainly collected in the participants' homes.

Outcome measures: Data were collected through established instruments and open-ended interviews. The dyad's perceptions of the person with stroke's rehabilitation needs were assessed by the persons with stroke and their informal caregivers using a questionnaire based on Ware's taxonomy. The results were combined and classified into three groups: met, discordant (i.e. not in agreement) and unmet rehabilitation needs. To assess sense of coherence (SOC) in persons with stroke, the SOC-scale was used. Caregiver burden was assessed using the Caregiver Burden Scale. Data on the use of rehabilitation services were obtained from the computerised register at the Stockholm County Council.

Participants: 86 persons with stroke (mean age 73 years, 38% women) and their caregivers (mean age 65 years, 40% women).

Results: Fifty-two percent of the dyads perceived that the person with stroke's need for rehabilitation was met 12 months after stroke. Met rehabilitation needs were associated with less severe stroke, more coping strategies for solving problems in everyday activities and less caregiver burden.

Conclusion: Rehabilitation interventions need to focus on supporting the dyads' process of psychological and social adaptation after stroke. Future studies need to explore and evaluate the effects of using a dyadic perspective throughout rehabilitation.

Strengths and limitations of this study

- A mixed method approach that uses both quantitative and qualitative analysis, as in this study, contributes to a more comprehensive picture of rehabilitation after stroke.
- A major strength of this study was the dyadic perspective which adds valuable knowledge regarding the use of a systemic approach in rehabilitation as well as the importance of the social environment.
- The data from the open-ended questions was not rich enough to make comparisons between the partners in the dyads. Instead the answers from the persons with stroke and the caregivers were analysed separately and compared between persons with stroke and caregivers on a group level.
- The use of set answers on a statement about rehabilitation needs only provides generalised information. Future studies would benefit from more in-depth knowledge on the characteristics of rehabilitation needs and the dyad's expectations for rehabilitation after stroke.

Introduction

It is recommended that rehabilitation after a stroke should be patient-centred i.e., based on the needs identified by the person with stroke.[1,2] Nevertheless, one year after stroke 33-49% perceive unmet rehabilitation needs.[3-5] These perceptions have been shown to be associated with several aspects such as a younger age [6] and greater disability.[5-6] The type [7] and amount of rehabilitation services received [8], as well as social support and internal resources of confidence, have been shown to be important factors in the perception of met rehabilitation needs. [9] Sense of coherence (SOC) refers to a global orientation that enables us to view the world and our individual environment as comprehensible, manageable and meaningful. [10] A person with a strong SOC is thought to have access to more personal resources that help them adjust successfully to traumatic events in life such as a stroke. However, the knowledge with regard to plausible associations of SOC and perceived needs for rehabilitation after stroke is limited and further studies are needed. [5]

With shorter hospital stays and more care and rehabilitation being delivered at home, the patient's families and friends are likely to be more involved and have increased responsibilities for informal care and rehabilitation after a stroke. Studies have shown that the people with whom someone shares their everyday life with have an important role in rehabilitation. [11-14] Moreover, informal caregivers identify more unmet rehabilitation needs than the people with stroke do themselves [15], and when a stroke influences the everyday lives that people share, informal caregivers should be more involved in the rehabilitation process. [11-14] However, informal caregivers themselves are often elderly and are in need of support to help cope with the burden of care in everyday life after stroke. [16-18] Thus, it is imperative that we consider how both the people with stroke and also their caregivers perceive rehabilitation needs, as well as plausible associations between such perceptions and caregiver burden.

Several qualitative studies have shed light on how the everyday life of dyads (i.e. two persons involved in an ongoing relationship or interaction) are intertwined and these studies highlight couples' interdependency after a partner's stroke. [11-14] These results emphasise the need for studies that focus not only on the person with stroke or the caregiver but instead adopt a broader perspective such as that of the dyad. No studies have been found that focus on the perceptions of rehabilitation needs after stroke from a dyadic perspective nor the plausible associations between such perceptions and caregiver burden.

Although many individuals still experience rehabilitation needs one year after stroke, [3-5] rehabilitation is often concluded within the first three months. An understanding of the rehabilitation process can be increased both by having a dyadic perspective of post-stroke rehabilitation needs as well as learning plausible associations with such aspects such as personal factors, stroke severity and caregiver burden. Such knowledge can presumably help through both identifying dyads that are still in need of support in everyday life after the first year and also guide rehabilitation professionals when developing interventions. Furthermore, the use of a mixed methods design which combines qualitative and quantitative data from a broader perspective may provide opportunities to shed new light on the complex processes involved in post-stroke rehabilitation. Therefore, the aim of the study was to explore the associations between the dyad's perception of rehabilitation needs and stroke severity, personal factors (gender, age, SOC), the use of rehabilitation services, amount of informal care and caregiver burden. Further, the aim was to explore the personal experience of everyday life changes amongst persons with stroke and their informal caregivers and their strategies for handling these one year after stroke.

Methods

This study used a mixed methods design combining quantitative and qualitative data and analyses. The data for this study was collected in the context of a prospective observational study of the rehabilitation process after stroke named ‘Life After Stroke phase 1’ (LAS-1). All the patients with stroke admitted to one of three stroke units at the Karolinska University Hospital between May 15, 2006 and May 14, 2007 were eligible for inclusion in LAS-1 and 349 were included. After informed consent, the baseline assessment within the first week after stroke and follow-ups at 3, 6 and 12 months after stroke onset were carried out, mainly during home visits through structured (questionnaires) and semi-structured (open-ended questions) interviews, by a research assistant (i.e. a purposely trained occupational therapist or a physiotherapist). The persons with stroke were asked to identify an informal caregiver. The caregiver chosen by the person with stroke could be a partner, a son or daughter, or a friend. Data from the caregivers were collected during the home visits through structured (questionnaires) and semi-structured (open-ended questions) interviews, or if the caregiver was not present, via a questionnaire which was left for the caregiver and was to be returned by post in a stamped envelope.

The participants in the present study were participants in the LAS-1 (people with stroke and their informal caregivers) who had answered a question concerning the fulfilment of rehabilitation needs of the person with stroke at the 12-months follow-up. The study was approved by the Regional Ethical Review Board in Stockholm, Sweden.

Data collection

Persons with stroke

Data on sex, age and stroke severity at baseline were collected by means of interviews and from the medical records. Using the Barthel Index [19] stroke severity was categorised as mild (scores 50-100) or moderate/severe (scores 0-49). [20]

Through employing a questionnaire previously used in studies of people with stroke [5, 7, 21] data regarding the need for, and satisfaction with the health care services received was collected at 12 months after stroke. The questionnaire is based on a taxonomy developed by Ware [22] and covers different dimensions that are thought to influence patients' satisfaction with care. The persons with stroke rated levels of agreement in relation to 14 statements concerning the different dimensions on a five-graded Likert scale with 'agree' and 'do not agree at all' as the endpoints. One particular statement addresses the level of fulfilment regarding rehabilitation needs and was therefore chosen as the dependent variable for this study: 'I have received the rehabilitation that my condition has required'. The scores on the statement were dichotomized into 'agree' i.e. met needs for rehabilitation (1-2 on the Likert scale) or 'do not agree' i.e. unmet needs for rehabilitation (3-5 on the Likert scale).

To assess SOC at 12 months, the 13-item version of the SOC-scale was used. [10] The questionnaire consists of 13 items rated on a seven-graded Likert scale. The total score ranges from 13 (weak SOC) to 91 (strong SOC). Data on the use of inpatient (days) and outpatient (contacts) rehabilitation services were obtained from the computerised register at the Stockholm County Council.

Open-ended questions were used to collect data at 12 months after stroke regarding changes in managing daily activities after stroke and strategies for handling problems that arose. The questions were framed as such: '1a) how do you think your daily activities work for you today? 1b) is there anything that has changed (mention three examples of activities that have become harder to perform)? 2) Do you have any thoughts about how this (activities that have changed) might work better, such as how you could solve the problem?' The answers to the questions were answered orally by the participant and then written down by the research assistant.

Informal caregiver

Data on sex, age and the caregiver's relation to the person with stroke were collected at three months after stroke by means of interviews. A corresponding questionnaire was used to collect data on the caregiver's perception of need for, and satisfaction with the health care services received by the person with stroke at 12 months after stroke. Levels of agreement with 10 statements relating to the different dimensions thought to influence satisfaction with care were rated by caregivers on a five-graded Likert scale with 'agree' and 'do not agree at all' as the endpoints. The questionnaires used to collect data from caregivers and from the persons with stroke respectively contained four coinciding statements. The same statement, addressing fulfilment of rehabilitation needs, was chosen for both the persons with stroke and the caregivers: 'My next-of-kin has received the rehabilitation that his/her condition has required'. The scores on the statement were dichotomized into 'agree' i.e. met needs for rehabilitation (1-2 on the Likert scale) or 'do not agree' i.e. unmet needs for rehabilitation (3-5 on the Likert scale).

Caregiver burden was assessed at 12 months using the Caregiver Burden Scale [23], and self-reported data on informal care (yes or no) from caregivers were collected in an interview. The caregivers were asked if there were any activities of daily living in which the participant had needed his/her assistance or supervision that, prior to stroke onset, had been performed independently by the participant.

An open-ended question on changes in daily life since the next-of-kin's stroke was used to collect data at 12 months after stroke. The question was framed as: 'Can you name the three greatest changes (in your everyday life after your next-of-kin's stroke) to you personally?' The answers to the questions were mainly answered orally by the participant and then written down by the research assistant or in some cases written down by the caregiver.

Data analysis

To determine the dyads' joint perception of rehabilitation needs, the dichotomized results of the statement concerning fulfilment of rehabilitation needs for both individuals in the dyad were combined and then classified into three groups: met, discordant (i.e. not in agreement) and unmet rehabilitation needs. The Kruskal-Wallis ANOVA was used first to determine if there was a difference between the three groups of combined perception of rehabilitation needs regarding age, SOC, use of inpatient (number of days) and outpatient (number of contacts) health care services and caregiver burden. The Mann Whitney U test was used for pairwise comparisons between the groups of combined perception of rehabilitation needs. The chi square test was used to analyse the differences between the groups of combined perception of rehabilitation needs with regard to sex, stroke severity and informal care. Pairwise comparisons were adjusted for multiple comparisons using a p value of ≤ 0.01.

Data, in the form of answers to the standardised open-ended questions were analysed through a content analysis. [24] The answers from the persons with stroke and caregivers were analysed separately and compared on a group level in each group (i.e. met, discordant and unmet needs of rehabilitation). In the first step of analysis all the data were read through thoroughly by the first, second and last author of this study. The data was coded individually by the three authors who then discussed the codes together and grouped them into categories inductively (see table 1). The authors summarised the content based on the categories in each of the groups: met, unmet or discordant rehabilitation needs in the persons with stroke and caregivers respectively. The summaries were discussed among the authors and a final description of each group was made. In a final step the quantitative and qualitative findings were compared according to mixed model analysis [25] and aggregated into three areas constituting the headings of the results. The qualitative findings were used to better describe and understand the quantitative results.

Results

Of the 349 persons with stroke from the LAS-1, 55 were deceased one year post stroke, 76 declined or were lost to follow-up, 15 persons had not answered the statement ‘I have received the rehabilitation that my condition has required’ and 117 had no identified caregiver. This left 86 persons with stroke and their caregivers at the 12-month follow-up. In the sample, 22 (26%) had experienced a previous stroke. The characteristics of the persons with stroke, the use of health care services, amount of informal care and the caregiver’s burden are presented in table 2. In the sample, 58 (67%) had mild stroke and 28 (33%) had moderate/severe stroke. Among the 86 caregivers, 62 were partners, 6 were children of the person with stroke and 18 people did not state the relationship clearly. The mean age of the caregivers was 65 years, 39 were women and 17 were men (44 caregivers had missing data on age and 20 had missing data on gender). Of the 263 persons with stroke not included in the present study the number of women was 128 (49%); mean age was 72 years; and 148 (56%) had mild stroke.

Among the dyads, 45 (52%) perceived that the person with stroke's rehabilitation needs were met at 12 months, 11 (13%) perceived that the rehabilitation needs were unmet, and 30 (35%)

were not in agreement. Of the persons with stroke, 61 (71%) perceived that their needs for rehabilitation were met and 25 (29%) perceived unmet needs for rehabilitation. In the caregivers, 57 (66%) perceived met rehabilitation needs for the person with stroke and 29 (34%) unmet rehabilitation needs.

Stroke severity was associated with the dyads' rehabilitation needs

In table 3, results from the comparative analyses are presented. A larger proportion of people with mild stroke were in dyads that perceived met rehabilitation needs compared to dyads who did not (p=0.002). The same results were found in the standardised open-ended questions given by the persons with stroke and their caregivers. In the dyads where rehabilitation needs were met most persons with stroke reported that they lived their lives as they did before their stroke. The same did not apply to persons with stroke in the dyads where unmet or discordant needs were recorded. Instead, within these dyads most persons with stroke reported great difficulties in walking and their dependence on a wheelchair or a walker. This was described by one participant as: 'I find it harder to walk. I have walking difficulties and I have to use a walker. My balance has been very affected.' Dyads whose rehabilitation needs were met reported less severe walking difficulties for the persons with stroke e g., that they only had difficulties walking long distances and in walking without a stick. One example from a participant described the following change: 'I haven't fully recovered my ability to walk or my balance, but they are much better than nine months ago. I can go out into the garden independently even without a walking stick, though I usually have a stick.' Further, in dyads whose rehabilitation needs were met, the persons with stroke described more specific problems such as weakness in the arm and hand, reduced fine hand use and reduced sensitivity in the hand; these problems caused limitations in activities such as playing the piano, peeling potatoes and buttoning clothes. In contrast, in dyads which recorded unmet or

discordant rehabilitation needs, the persons with stroke often reported having to give up a task in advance and had limitations in more physically demanding activities such as going to buy groceries; going to the toilet and getting dressed; and gardening. Further, persons with stroke who described other major life events occurring after the stroke were all found to be among the dyads reporting unmet rehabilitation needs. Examples of major life events reported were a new stroke, pneumonia or multiple diagnoses, such as dementia or chronic obstructive pulmonary disease.

Dyads' rehabilitation needs related to the persons with stroke's use of strategies to overcome problems

The statistical analyses identified no differences in perception of rehabilitation needs with regard to sex, age or the use of rehabilitation services. Persons with stroke in dyads reporting met rehabilitation needs had a higher SOC than in discordant dyads (p=0.002) (see table 3). In the dyads that had met or discordant rehabilitation needs almost all persons with stroke, whose rehabilitation needs were perceived as met, described how they handled everyday problems. Strategies included engaging in physical exercise, such as going for walks. One specific strategy was to pause during the activity when things became 'too much'. Others mentioned using aids or a partner to compensate when problems emerged. Additional strategies were: to think ahead to avoid problems; to try to find a solution to the problem; to set goals; and to refuse to give up. One participant described how he found solutions to overcome problems. He expressed this as: 'I don't give up. I train at home through coming up with activities such as cutting logs and making a new saw horse. I am a retired technician and am used to finding solutions.' Furthermore, in the dyads where rehabilitation needs were met, most individuals with stroke had ideas about what needed to improve, such as being able to cycle or drive a car. They also knew how to improve, like integrating training into everyday life and to keep pushing themselves and practicing. Others described how they used strategies,

or aids, or reported that they had adapted to the situation by stopping doing things. This finding can be compared against those with unmet rehabilitation needs who did not have strategies to overcome the difficulties they experienced. One person claimed: 'I have no specific strategy to train my body and soul, I have lost the will or my spark.' People in this group expressed a feeling of dependence on others for their rehabilitation. Several persons with stroke described how they lacked willpower and found it difficult to take initiatives while others reported an inner drive to make things work, but did not have a strategy to achieve this. Furthermore, the persons with stroke in dyads with unmet rehabilitation needs often felt that rehabilitation had ended too early. Just as those in dyads with unmet needs, the individuals with stroke in discordant dyads wanted to receive more rehabilitation as a strategy or as a solution to their problems.

Caregivers perceived less caregiver burden in dyads where rehabilitation needs were met

Results from the statistical analyses showed that in dyads where rehabilitation needs were met the caregivers perceived a lower caregiver burden compared to dyads with unmet rehabilitation needs ($p=0.003$) and discordant dyads ($p=<0.001$) (see table 3). No difference was found among dyads in regard to the number of persons with stroke receiving informal care. We found that the next-of-kin in all groups reported taking greater responsibility for household chores such as cooking, washing and cleaning. They also reported needing to take more initiatives and responsibility for safety, planning and creating routines for everyday life. Furthermore, caregivers in all the dyads described their anxieties. For instance the person with stroke might have a new stroke or another medical problem. Caregivers in all the groups also reported feeling homebound. They felt unable to leave the person with stroke alone and, consequently, had less time to do things on their own. In addition to feeling greater responsibility, both caregivers with met and unmet rehabilitation needs in discordant dyads

described how they no longer kept their own interests and hobbies such as dancing and visiting their summer house.

Regardless of whether the persons with stroke perceived met or unmet rehabilitation needs, caregivers who perceived unmet rehabilitation needs for the person with stroke had less time for their social life: family and friends did not keep in touch and they had less time to spend with friends and/or other people. This quote by a caregiver mirrors this sentiment: 'The greatest change is not being able to socialise with a female friend, relax and spend time with my children and grandchildren.' In contrast, only a few of the caregivers where rehabilitation needs were met described less active social lives. Instead, these caregivers noted advantages that came from the stroke, such as spending more time with the family, having a more profound relationship and seeing each other more often. This advantage was expressed by a spouse saying: 'One great plus for our family is that my husband has got so much more time to spend with all of us (after his stroke).'

Discussion

About half of the dyads perceived that the person with stroke's rehabilitation needs were met one year after stroke. The results showed that the people whose rehabilitation needs were met had suffered a less severe stroke and stroke-related difficulties and had more strategies for solving everyday problems, while caregivers had a lower caregiver burden. Further, equal proportions of persons with stroke and caregivers perceived that there were unmet rehabilitation needs. These findings are different from earlier studies where the caregivers identified more unmet needs than those people with stroke. [15] Moreover, only 29% of the persons with stroke in the present study perceived an unmet need for rehabilitation which is markedly lower than the 43% reported in a previous national Swedish one-year follow-up

study. [3] It is possible that the small sample in the present study partly explains these disparate results. Another possible explanation is that the inclusion criteria in the present study involved participation by a caregiver who may have been engaged in the rehabilitation process, which might have influenced the perceived rehabilitation needs. A large proportion, 35%, of the dyads were not in agreement which implies that a dyadic approach needs to be considered when devising post-stroke rehabilitation. The discrepancy in perception between persons with stroke and caregivers in the discordant group may reflect that the individuals in the dyad are at different stages in their reorientation process or that there are problems related to awareness.

The findings show that the perception of rehabilitation needs one year after stroke differs between dyads in relation to stroke severity and major life events. Stroke severity and perceived stroke-related difficulties were less severe in dyads which reported met rehabilitation needs as compared to dyads where the stroke was more severe and where discordant or unmet needs were reported. More major life events were reported in the qualitative data among the discordant dyads and the dyads with unmet needs. This result was not surprising and it is also in line with previous studies which have shown that persons with severe stroke perceive more unmet rehabilitation needs. [5-6] Most persons with stroke in dyads where rehabilitation needs were met reported that they lived their lives as they did before the stroke. It may seem apparent that a more severe stroke means more unmet needs for rehabilitation. However, these results also point to a need for rehabilitation interventions that focus both on improving or sustaining physical and cognitive functioning as well as helping to adapt to life post stroke, including systematic support to the caregivers.

In dyads where rehabilitation needs were met, the persons with stroke had a higher SOC than those in dyads with discordant views. Although those with unmet rehabilitation needs reported few or no coping strategies for everyday problems, there was no difference with regard to SOC found between dyads with met and unmet rehabilitation needs. One explanation for these results might be that the group formed of dyads with unmet rehabilitation needs was small and may have lacked statistical power to detect differences. Further studies on the impact of SOC and the perception of rehabilitation needs are warranted and may guide the development of rehabilitation interventions that support people with stroke in their efforts to manage their life post stroke. SOC can be considered a disposition rather than a personal characteristic and thus, as some studies show, be modifiable through intervention. [26-27] Rehabilitation interventions that are informed by the components of the SOC construct, including comprehensibility, manageability and meaningfulness, could result in comprehensive and individualised approaches to rehabilitation after stroke. For example, people with moderate or severe stroke might need more guidance in finding their own coping strategies for how to handle everyday problems. A major limitation of this study is that the SOC-scale was not administered to the caregivers. This would have added valuable information to the interpretation of the results with regard to SOC.

The findings also showed that caregiver burden was rated lower in dyads with met rehabilitation needs and some caregivers also reported social advantages after the stroke. This is compared to caregivers in dyads with unmet and discordant needs who rated higher caregiver burden and less active social lives. Still, the number of persons with stroke receiving informal care did not differ between the groups. This suggests that the caregiver's sense of burden is related to a more severe stroke or feeling more responsible for planning and organising activities. A clinical consequence of these results could be to focus on reducing the caregiver burden by, for example, offering relief, especially to dyads with unmet and discordant rehabilitation needs, so that caregivers can maintain their social lives.

One of this study's limitations is that the question about perceived rehabilitation needs does not define what constitutes rehabilitation; instead each participant defined what rehabilitation meant to them. The use of a set answers on a statement about rehabilitation needs only provides generalised information. Future studies would benefit from more in-depth knowledge on the characteristics of rehabilitation needs and qualitative studies on the dyad's expectations for post-stroke rehabilitation. Another limitation is the small sample size which did not allow for analyses of plausible interactions between the different variables and that there was missing data regarding the caregivers due to incomplete questionnaires returned by post. However, the study was based on a cohort representing a population of all persons admitted to the stroke units during one year and the proportions of stroke severity are similar to a previous national Swedish one-year follow-up study. [3]

A mixed method approach that uses both quantitative and qualitative analysis, as in this study, contributes to a more comprehensive picture of post-stroke rehabilitation. The qualitative data adds information about the participants' perception whereas the quantitative data can more easily be compared with other studies and generalised to similar samples. However, the data from the open-ended questions was not rich enough to compare the partners in the dyads with one another. Instead the answers from the persons with stroke and from the caregivers were analysed separately and compared between persons with stroke and caregivers on a group level.

The findings in this study confirm those of previous studies that used the more traditional perspective of studying the person with stroke [4-9] or the caregiver [16-18] separately. This study's unique contribution was the dyadic perspective, which adds valuable knowledge regarding the use of a systemic approach in rehabilitation as well the importance of the social environment. [28] This stresses the integration of caregivers and other significant individuals in the rehabilitation system. [29] Through gaining a dyadic perspective on how rehabilitation needs are related to such aspects such as personal factors, stroke severity and caregiver burden, we can increase our understanding of this perspective and thus guide rehabilitation professionals when providing interventions. Future studies need to explore and evaluate the effects of using a dyadic perspective throughout rehabilitation.

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Author's contribution:

LE and CY drafted the study. LE, UJ and CY performed the data analyses. All authors made critical revisions and approved the final manuscript.

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Table 1. Examples of meaning units, codes and categories.

Meaning unit	Code	Category
I have difficulties to tie my shoes so I use shoes without laces.	Adapt his clothing	Strategies to overcome problems
I'm more homebound now. He does not want me going out for very long.	Homebound	Caregiver burden

Table 2. Characteristics of the persons with stroke, use of health care services, informal care and caregiver burden.

Variable	Total sample, n=86	Met needs, n=45	Discordant, n=30	Unmet needs, n=11
Age: years, median (IQR)	72.5 (63-79.8)	75 (64-78)	71 (62.2-82.5)	74 (68.5-80.5)
Gender: women, n	33	18	11	4
Stroke severity: mild / moderate-severe, n *(Barthel Index, range of scores 0-100)*	57 / 28*	34 / 10†	21 / 9	3 / 8
Sense of coherence: median (IQR) *(Sense of coherence scale, range of scores 13-91)*	79.5 (69-87.8)‡	83 (74-89)§	71 (65.8-81)‖	79 (65-90)¶
Inpatient care and rehabilitation: days, median (IQR)	14 (7-36)	14 (6-31)	11.5 (7-35)	24 (19-56)
Outpatient rehabilitation: contacts, median (IQR)	3 (1-23.2)	3 (1-20)	8 (1-28.5)	1 (0-23)
Caregiver burden: median (IQR) *(Caregiver burden scale, range of scores 22-88)*	38 (26-51)	28 (23-44)	46 (36.2-55)	56 (34-63.5)
Informal care: has received, n	42**	20††	17	5§§

*n=85, †n=44, ‡n=74, §n=39, ‖n=26, ¶n=9, **n=83, ††=43, §§=1

Table 3. Categorization of the independent variables, categorization of dyads' perception of rehabilitation needs, p values

Independent variable	Perception of rehabilitation needs	P value
Age, years	Met / Unmet / Discordant	0.60
Sex, male / female	Met / Unmet	0.82
	Met / Discordant	0.77
	Unmet / Discordant	0.98
Sense of coherence, scores	Met / Unmet	0.48
	Met / Discordant	**0.002**
	Unmet / Discordant	0.40
Stroke severity,	Met / Unmet	**0.002**
mild / moderate-severe	Met / Discordant	0.48
	Unmet / Discordant	0.03
Inpatient care and rehabilitation, days	Met / Unmet / Discordant	0.12
Outpatient rehabilitation, contacts	Met / Unmet / Discordant	0.38
Caregiver burden, scores	Met / Unmet	**0.003**
	Met / Discordant	**<0.001**
	Unmet / Discordant	0.47
Informal care,	Met / Unmet	1.00
has received / has not received	Met / Discordant	0.39
	Unmet / Discordant	0.73

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The combined perceptions of people with stroke and their carers regarding rehabilitation needs one year after stroke: a mixed methods study

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Abstract

Objectives: The aim of the study was to explore the associations between the dyad's (person with stroke and informal caregiver) perception of the person with stroke's rehabilitation needs and stroke severity, personal factors (gender, age, sense of coherence), the use of rehabilitation services, amount of informal care and caregiver burden. Further, the aim was to explore the personal experience of everyday life changes amongst persons with stroke and their caregivers and their strategies for handling these one year after stroke.

Design: A mixed methods design was used combining quantitative and qualitative data and analyses.

Setting: Data were mainly collected in the participants' homes.

Outcome measures: Data were collected through established instruments and open-ended interviews. The dyad's perceptions of the person with stroke's rehabilitation needs were assessed by the persons with stroke and their informal caregivers using a questionnaire based on Ware's taxonomy. The results were combined and classified into three groups: met, discordant (i.e. not in agreement) and unmet rehabilitation needs. To assess sense of coherence (SOC) in persons with stroke, the SOC-scale was used. Caregiver burden was assessed using the Caregiver Burden Scale. Data on the use of rehabilitation services were obtained from the computerised register at the Stockholm County Council.

Participants: 86 persons with stroke (mean age 73 years, 38% women) and their caregivers (mean age 65 years, 40% women).

Results: Fifty-two percent of the dyads perceived that the person with stroke's need for rehabilitation was met 12 months after stroke. Met rehabilitation needs were associated with less severe stroke, more coping strategies for solving problems in everyday activities and less caregiver burden.

Conclusion: Rehabilitation interventions need to focus on supporting the dyads' process of psychological and social adaptation after stroke. Future studies need to explore and evaluate the effects of using a dyadic perspective throughout rehabilitation.

Strengths and limitations of this study

- A mixed method approach that uses both quantitative and qualitative analysis, as in this study, contributes to a more comprehensive picture of rehabilitation after stroke.
- A major strength of this study was the dyadic perspective which adds valuable knowledge regarding the use of a systemic approach in rehabilitation as well as the importance of the social environment.
- The data from the open-ended questions was not rich enough to make comparisons between the partners in the dyads. Instead the answers from the persons with stroke and the caregivers were analysed separately and compared between persons with stroke and caregivers on a group level.
- The use of set answers on a statement about rehabilitation needs only provides generalised information. Future studies would benefit from more in-depth knowledge on the characteristics of rehabilitation needs and the dyad's expectations for rehabilitation after stroke.

Introduction

It is recommended that rehabilitation after a stroke should be patient-centred i.e., based on the needs identified by the person with stroke.[1,2] Nevertheless, one year after stroke 33-49% perceive unmet rehabilitation needs.[3-5] These perceptions have been shown to be associated with several aspects such as a younger age [6] and greater disability.[5-6] The type [7] and amount of rehabilitation services received [8], as well as social support and internal resources of confidence, have been shown to be important factors in the perception of met rehabilitation needs. [9] Sense of coherence (SOC) refers to a global orientation that enables us to view the world and our individual environment as comprehensible, manageable and meaningful. [10] A person with a strong SOC is thought to have access to more personal resources that help them adjust successfully to traumatic events in life such as a stroke. However, the knowledge with regard to plausible associations of SOC and perceived needs for rehabilitation after stroke is limited and further studies are needed. [5]

With shorter hospital stays and more care and rehabilitation being delivered at home, the patient's families and friends are likely to be more involved and have increased responsibilities for informal care and rehabilitation after a stroke. Studies have shown that the people with whom someone shares their everyday life with have an important role in rehabilitation. [11-14] Moreover, informal caregivers identify more unmet rehabilitation needs than the people with stroke do themselves [15], and when a stroke influences the everyday lives that people share, informal caregivers should be more involved in the rehabilitation process. [11-14] However, informal caregivers themselves are often elderly and are in need of support to help cope with the burden of care in everyday life after stroke. [16-18] Thus, it is imperative that we consider how both the people with stroke and also their caregivers perceive rehabilitation needs, as well as plausible associations between such perceptions and caregiver burden.

Several qualitative studies have shed light on how the everyday life of dyads (i.e. two persons involved in an ongoing relationship or interaction) are intertwined and these studies highlight couples' interdependency after a partner's stroke. [11-14] These results emphasise the need for studies that focus not only on the person with stroke or the caregiver but instead adopt a broader perspective such as that of the dyad. No studies have been found that focus on the perceptions of rehabilitation needs after stroke from a dyadic perspective nor the plausible associations between such perceptions and caregiver burden.

Although many individuals still experience rehabilitation needs one year after stroke, [3-5] rehabilitation is often concluded within the first three months. An understanding of the rehabilitation process can be increased both by having a dyadic perspective of post-stroke rehabilitation needs as well as learning plausible associations with such aspects such as personal factors, stroke severity and caregiver burden. Such knowledge can presumably help through both identifying dyads that are still in need of support in everyday life after the first year and also guide rehabilitation professionals when developing interventions. Furthermore, the use of a mixed methods design which combines qualitative and quantitative data from a broader perspective may provide opportunities to shed new light on the complex processes involved in post-stroke rehabilitation. Therefore, the aim of the study was to explore the associations between the dyad's perception of rehabilitation needs and stroke severity, personal factors (gender, age, SOC), the use of rehabilitation services, amount of informal care and caregiver burden. Further, the aim was to explore the personal experience of everyday life changes amongst persons with stroke and their informal caregivers and their strategies for handling these one year after stroke.

Methods

This study used a mixed methods design combining quantitative and qualitative data and analyses. This study was based on secondary analysis of data from a prospective observational study of the rehabilitation process after stroke named 'Life After Stroke phase 1' (LAS-1). All the patients with stroke admitted to one of three stroke units at the Karolinska University Hospital between May 15, 2006 and May 14, 2007 were eligible for inclusion in LAS-1 and 349 were included. After informed consent, the baseline assessment within the first week after stroke and follow-ups at 3, 6 and 12 months after stroke onset were carried out, mainly during home visits through structured (questionnaires) and semi-structured (open-ended questions) interviews, by a research assistant (i.e. a purposely trained occupational therapist or a physiotherapist). The persons with stroke were asked to identify an informal caregiver. The caregiver chosen by the person with stroke could be a partner, a son or daughter, or a friend. Data from the caregivers were collected during the home visits through structured (questionnaires) and semi-structured (open-ended questions) interviews, or if the caregiver was not present, via a questionnaire which was left for the caregiver and was to be returned by post in a stamped envelope.

The participants in the present study were participants in the LAS-1 (people with stroke and their informal caregivers) who had answered a question concerning the fulfilment of rehabilitation needs of the person with stroke at the 12-months follow-up. The study was approved by the Regional Ethical Review Board in Stockholm, Sweden.

Data collection

Persons with stroke

Data on sex, age and stroke severity at baseline were collected by means of interviews and from the medical records. Using the Barthel Index [19] stroke severity was categorised as mild (scores 50-100) or moderate/severe (scores 0-49). [20]

Through employing a questionnaire previously used in studies of people with stroke [5, 7, 21]data regarding the need for, and satisfaction with the health care services received was collected at 12 months after stroke. The questionnaire is based on a taxonomy developed by Ware [22] and covers different dimensions that are thought to influence patients' satisfaction with care. The persons with stroke rated levels of agreement in relation to 14 statements concerning the different dimensions on a five-graded Likert scale with 'agree' and 'do not agree at all' as the endpoints. One particular statement addresses the level of fulfilment regarding rehabilitation needs and was therefore chosen as the dependent variable for this study: 'I have received the rehabilitation that my condition has required'. The scores on the statement were dichotomized into 'agree' i.e. met needs for rehabilitation (1-2 on the Likert scale) or 'do not agree' i.e. unmet needs for rehabilitation (3-5 on the Likert scale).

To assess SOC at 12 months, the 13-item version of the SOC-scale was used. [10] The questionnaire consists of 13 items rated on a seven-graded Likert scale. The total score ranges from 13 (weak SOC) to 91 (strong SOC). Data on the use of inpatient (days) and outpatient (contacts) rehabilitation services were obtained from the computerised register at the Stockholm County Council.

Open-ended questions were used to collect data at 12 months after stroke regarding changes in managing daily activities after stroke and strategies for handling problems that arose. The questions were framed as such: '1a) how do you think your daily activities work for you today? 1b) is there anything that has changed (mention three examples of activities that have become harder to perform)? 2) Do you have any thoughts about how this (activities that have changed) might work better, such as how you could solve the problem?' The answers to the questions were answered orally by the participant and then written down by the research assistant.

Informal caregiver

Data on sex, age and the caregiver's relation to the person with stroke were collected at three months after stroke by means of interviews. A corresponding questionnaire was used to collect data on the caregiver's perception of need for, and satisfaction with the health care services received by the person with stroke at 12 months after stroke. Levels of agreement with 10 statements relating to the different dimensions thought to influence satisfaction with care were rated by caregivers on a five-graded Likert scale with 'agree' and 'do not agree at all' as the endpoints. The questionnaires used to collect data from caregivers and from the persons with stroke respectively contained four coinciding statements. The same statement, addressing fulfilment of rehabilitation needs, was chosen for both the persons with stroke and the caregivers: 'My next-of-kin has received the rehabilitation that his/her condition has required'. The scores on the statement were dichotomized into 'agree' i.e. met needs for rehabilitation (1-2 on the Likert scale) or 'do not agree' i.e. unmet needs for rehabilitation (3-5 on the Likert scale).

Caregiver burden was assessed at 12 months using the Caregiver Burden Scale [23], and self-reported data on informal care (yes or no) from caregivers were collected in an interview. The caregivers were asked if there were any activities of daily living in which the participant had needed his/her assistance or supervision that, prior to stroke onset, had been performed independently by the participant.

An open-ended question on changes in daily life since the next-of-kin's stroke was used to collect data at 12 months after stroke. The question was framed as: 'Can you name the three greatest changes (in your everyday life after your next-of-kin's stroke) to you personally?' The answers to the questions were mainly answered orally by the participant and then written down by the research assistant or in some cases written down by the caregiver.

Data analysis

To determine the dyads' joint perception of rehabilitation needs, the dichotomized results of the statement concerning fulfilment of rehabilitation needs for both individuals in the dyad were combined and then classified into three groups: met, discordant (i.e. not in agreement) and unmet rehabilitation needs. The Kruskal-Wallis ANOVA was used first to determine if there was a difference between the three groups of combined perception of rehabilitation needs regarding age, SOC, use of inpatient (number of days) and outpatient (number of contacts) health care services and caregiver burden. The Mann Whitney U test was used for pairwise comparisons between the groups of combined perception of rehabilitation needs. The chi square test was used to analyse the differences between the groups of combined perception of rehabilitation needs with regard to sex, stroke severity and informal care. Pairwise comparisons were adjusted for multiple comparisons using a p value of ≤ 0.01. [24]

Data, in the form of answers to the standardised open-ended questions were analysed through a content analysis. [25] The answers from the persons with stroke and caregivers were analysed separately and compared on a group level in each group (i.e. met, discordant and unmet needs of rehabilitation). In the first step of analysis all the data were read through thoroughly by the first, second and last author of this study. The data was coded individually by the three authors who then discussed the codes together and grouped them into categories inductively (see table 1). The authors summarised the content based on the categories in each of the groups: met, unmet or discordant rehabilitation needs in the persons with stroke and caregivers respectively. The summaries were discussed among the authors and a final description of each group was made. In a final step the quantitative and qualitative findings were compared according to mixed model analysis [26] and aggregated into three areas constituting the headings of the results. The qualitative findings were used to better describe and understand the quantitative results.

Results

Of the 349 persons with stroke from the LAS-1, 55 were deceased one year post stroke, 76 declined or were lost to follow-up, 15 persons had not answered the statement ‘I have received the rehabilitation that my condition has required’ and 117 had no identified caregiver. This left 86 persons with stroke and their caregivers at the 12-month follow-up. In the sample, 22 (26%) had experienced a previous stroke. The characteristics of the persons with stroke, the use of health care services, amount of informal care and the caregiver’s burden are presented in table 2. SOC data was only available for 74 of the 86 participants (see table 2). In the sample, 58 (67%) had mild stroke and 28 (33%) had moderate/severe stroke. Among the 86 caregivers, 62 were partners, 6 were children of the person with stroke and 18 people did not state the relationship clearly. The mean age of the caregivers was 65 years, 39 were women and 17 were men (44 caregivers had missing data on age and 20 had missing data on gender). Of the 263 persons with stroke not included in the present study the number of women was 128 (49%); mean age was 72 years; and 148 (56%) had mild stroke.

Among the dyads, 45 (52%) perceived that the person with stroke's rehabilitation needs were met at 12 months, 11 (13%) perceived that the rehabilitation needs were unmet, and 30 (35%)

were not in agreement. Of the persons with stroke, 61 (71%) perceived that their needs for rehabilitation were met and 25 (29%) perceived unmet needs for rehabilitation. In the caregivers, 57 (66%) perceived met rehabilitation needs for the person with stroke and 29 (34%) unmet rehabilitation needs.

Stroke severity was associated with the dyads' rehabilitation needs

In table 3, results from the comparative analyses are presented. A larger proportion of people with mild stroke were in dyads that perceived met rehabilitation needs compared to dyads who did not (p=0.002). The same results were found in the standardised open-ended questions given by the persons with stroke and their caregivers. In the dyads where rehabilitation needs were met most persons with stroke reported that they lived their lives as they did before their stroke. The same did not apply to persons with stroke in the dyads where unmet or discordant needs were recorded. Instead, within these dyads most persons with stroke reported great difficulties in walking and their dependence on a wheelchair or a walker. This was described by one participant as: 'I find it harder to walk. I have walking difficulties and I have to use a walker. My balance has been very affected.' Dyads whose rehabilitation needs were met reported less severe walking difficulties for the persons with stroke e g., that they only had difficulties walking long distances and in walking without a stick. One example from a participant described the following change: 'I haven't fully recovered my ability to walk or my balance, but they are much better than nine months ago. I can go out into the garden independently even without a walking stick, though I usually have a stick.' Further, in dyads whose rehabilitation needs were met, the persons with stroke described more specific problems such as weakness in the arm and hand, reduced fine hand use and reduced sensitivity in the hand; these problems caused limitations in activities such as playing the piano, peeling potatoes and buttoning clothes. In contrast, in dyads which recorded unmet or

discordant rehabilitation needs, the persons with stroke often reported having to give up a task in advance and had limitations in more physically demanding activities such as going to buy groceries; going to the toilet and getting dressed; and gardening. Further, persons with stroke who described other major life events occurring after the stroke were all found to be among the dyads reporting unmet rehabilitation needs. Examples of major life events reported were a new stroke, pneumonia or multiple diagnoses, such as dementia or chronic obstructive pulmonary disease.

Dyads' rehabilitation needs related to the persons with stroke's use of strategies to overcome problems

The statistical analyses identified no differences in perception of rehabilitation needs with regard to sex, age or the use of rehabilitation services. Persons with stroke in dyads reporting met rehabilitation needs had a higher SOC than in discordant dyads (p=0.002) (see table 3). In the dyads that had met or discordant rehabilitation needs almost all persons with stroke, whose rehabilitation needs were perceived as met, described how they handled everyday problems. Strategies included engaging in physical exercise, such as going for walks. One specific strategy was to pause during the activity when things became 'too much'. Others mentioned using aids or a partner to compensate when problems emerged. Additional strategies were: to think ahead to avoid problems; to try to find a solution to the problem; to set goals; and to refuse to give up. One participant described how he found solutions to overcome problems. He expressed this as: 'I don't give up. I train at home through coming up with activities such as cutting logs and making a new saw horse. I am a retired technician and am used to finding solutions.' Furthermore, in the dyads where rehabilitation needs were met, most individuals with stroke had ideas about what needed to improve, such as being able to cycle or drive a car. They also knew how to improve, like integrating training into everyday life and to keep pushing themselves and practicing. Others described how they used strategies,

or aids, or reported that they had adapted to the situation by stopping doing things. This finding can be compared against those with unmet rehabilitation needs where persons with stroke in dyads with unmet needs did not report strategies to overcome the difficulties they experienced and only some persons with stroke with unmet needs in the discordant dyads reported strategies. One person claimed: ‘I have no specific strategy to train my body and soul, I have lost the will or my spark.’ People in this group expressed a feeling of dependence on others for their rehabilitation. Several persons with stroke described how they lacked willpower and found it difficult to take initiatives while others reported an inner drive to make things work, but did not have a strategy to achieve this. Furthermore, the persons with stroke in dyads with unmet rehabilitation needs often felt that rehabilitation had ended too early. Just as those in dyads with unmet needs, the individuals with stroke in discordant dyads wanted to receive more rehabilitation as a strategy or as a solution to their problems.

Caregivers perceived less caregiver burden in dyads where rehabilitation needs were met

Results from the statistical analyses showed that in dyads where rehabilitation needs were met the caregivers perceived a lower caregiver burden compared to dyads with unmet rehabilitation needs (p=0.003) and discordant dyads (p=<0.001) (see table 3). No difference was found among dyads in regard to the number of persons with stroke receiving informal care. We found that the next-of-kin in all groups reported taking greater responsibility for household chores such as cooking, washing and cleaning. They also reported needing to take more initiatives and responsibility for safety, planning and creating routines for everyday life. Furthermore, caregivers in all the dyads described their anxieties. For instance the person with stroke might have a new stroke or another medical problem. Caregivers in all the groups also reported feeling homebound. They felt unable to leave the person with stroke alone and, consequently, had less time to do things on their own. In addition to feeling greater responsibility, both caregivers with met and unmet rehabilitation needs in discordant dyads

described how they no longer kept their own interests and hobbies such as dancing and visiting their summer house.

Regardless of whether the persons with stroke perceived met or unmet rehabilitation needs, caregivers who perceived unmet rehabilitation needs for the person with stroke had less time for their social life: family and friends did not keep in touch and they had less time to spend with friends and/or other people. This quote by a caregiver mirrors this sentiment: 'The greatest change is not being able to socialise with a female friend, relax and spend time with my children and grandchildren.' In contrast, only a few of the caregivers where rehabilitation needs were met described less active social lives. Instead, these caregivers noted advantages that came from the stroke, such as spending more time with the family, having a more profound relationship and seeing each other more often. This advantage was expressed by a spouse saying: 'One great plus for our family is that my husband has got so much more time to spend with all of us (after his stroke).'

Discussion

About half of the dyads perceived that the person with stroke's rehabilitation needs were met one year after stroke. The results showed that the people whose rehabilitation needs were met had suffered a less severe stroke and stroke-related difficulties and had more strategies for solving everyday problems, while caregivers had a lower caregiver burden. Further, equal proportions of persons with stroke and caregivers perceived that there were unmet rehabilitation needs. These findings are different from earlier studies where the caregivers identified more unmet needs than those people with stroke. [15] Moreover, only 29% of the persons with stroke in the present study perceived an unmet need for rehabilitation which is markedly lower than the 43% reported in a previous national Swedish one-year follow-up

study. [3] It is possible that the small sample in the present study partly explains these disparate results. Another possible explanation is that the inclusion criteria in the present study involved participation by a caregiver who may have been engaged in the rehabilitation process, which might have influenced the perceived rehabilitation needs. A large proportion, 35%, of the dyads were not in agreement which implies that a dyadic approach needs to be considered when devising post-stroke rehabilitation. The discrepancy in perception between persons with stroke and caregivers in the discordant group may reflect that the individuals in the dyad are at different stages in their reorientation process or that there are problems related to awareness.

The findings show that the perception of rehabilitation needs one year after stroke differs between dyads in relation to stroke severity and major life events. Stroke severity and perceived stroke-related difficulties were less severe in dyads which reported met rehabilitation needs as compared to dyads where the stroke was more severe and where discordant or unmet needs were reported. More major life events were reported in the qualitative data among the discordant dyads and the dyads with unmet needs. This result was not surprising and it is also in line with previous studies which have shown that persons with severe stroke perceive more unmet rehabilitation needs. [5-6] Most persons with stroke in dyads where rehabilitation needs were met reported that they lived their lives as they did before the stroke. It may seem apparent that a more severe stroke means more unmet needs for rehabilitation. However, these results also point to a need for rehabilitation interventions that focus both on improving or sustaining physical and cognitive functioning as well as helping to adapt to life post stroke, including systematic support to the caregivers.

In dyads where rehabilitation needs were met, the persons with stroke had a higher SOC than those in dyads with discordant views. Although those with unmet rehabilitation needs reported few or no coping strategies for everyday problems, there was no difference with regard to SOC found between dyads with met and unmet rehabilitation needs. One explanation for these results might be that the group formed of dyads with unmet rehabilitation needs was small and may have lacked statistical power to detect differences. Further studies on the impact of SOC and the perception of rehabilitation needs are warranted and may guide the development of rehabilitation interventions that support people with stroke in their efforts to manage their life post stroke. SOC can be considered a disposition rather than a personal characteristic and thus, as some studies show, be modifiable through intervention. [27-28] Rehabilitation interventions that are informed by the components of the SOC construct, including comprehensibility, manageability and meaningfulness, could result in comprehensive and individualised approaches to rehabilitation after stroke. For example, people with moderate or severe stroke might need more guidance in finding their own coping strategies for how to handle everyday problems. Since stroke severity was less severe in dyads which reported met rehabilitation needs it is likely to be a confounding variable as mild stroke may result in minor problems to overcome, whereas severe stroke may lead to major problems to overcome requiring more complex or intensive strategies. Furthermore, the findings are based on self-report and since the participants were not specifically asked to comment on strategies it is possible that they had some strategies in place that they did not mention in the interviews. A major limitation of this study is that the SOC-scale was not administered to the caregivers. This would have added valuable information to the interpretation of the results with regard to SOC.

The findings also showed that caregiver burden was rated lower in dyads with met rehabilitation needs and some caregivers also reported social advantages after the stroke. This is compared to caregivers in dyads with unmet and discordant needs who rated higher caregiver burden and less active social lives. Still, the number of persons with stroke receiving informal care did not differ between the groups. This suggests that the caregiver's sense of burden is related to a more severe stroke or feeling more responsible for planning and organising activities. A clinical consequence of these results could be to focus on reducing the caregiver burden by, for example, offering relief, especially to dyads with unmet and discordant rehabilitation needs, so that caregivers can maintain their social lives.

One of this study's limitations is that the question about perceived rehabilitation needs does not define what constitutes rehabilitation; instead each participant defined what rehabilitation meant to them. The use of a set answers on a statement about rehabilitation needs only provides generalised information. Future studies would benefit from more in-depth knowledge on the characteristics of rehabilitation needs and qualitative studies on the dyad's expectations for post-stroke rehabilitation. Another limitation is the small sample size which did not allow for analyses of plausible interactions between the different variables and that there was missing data regarding the caregivers due to incomplete questionnaires returned by post. However, the study was based on a cohort representing a population of all persons admitted to the stroke units during one year and the proportions of stroke severity are similar to a previous national Swedish one-year follow-up study. [3]

A mixed method approach that uses both quantitative and qualitative analysis, as in this study, contributes to a more comprehensive picture of post-stroke rehabilitation. The qualitative data adds information about the participants' perception whereas the quantitative data can more easily be compared with other studies and generalised to similar samples. However, the data from the open-ended questions was not rich enough to compare the partners in the dyads with one another. Instead the answers from the persons with stroke and from the caregivers were analysed separately and compared between persons with stroke and caregivers on a group level.

The findings in this study confirm those of previous studies that used the more traditional perspective of studying the person with stroke [4-9] or the caregiver [16-18] separately. This study's unique contribution was the dyadic perspective, which adds valuable knowledge regarding the use of a systemic approach in rehabilitation as well the importance of the social environment. [29] This stresses the integration of caregivers and other significant individuals in the rehabilitation system. [30] Through gaining a dyadic perspective on how rehabilitation needs are related to such aspects such as personal factors, stroke severity and caregiver burden, we can increase our understanding of this perspective and thus guide rehabilitation professionals when providing interventions. Future studies need to explore and evaluate the effects of using a dyadic perspective throughout rehabilitation.

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Author's contribution:

LE and CY drafted the study. LE, UJ and CY performed the data analyses. All authors made critical revisions and approved the final manuscript.

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Table 1. Examples of meaning units, codes and categories.

Meaning unit	Code	Category
I have difficulties to tie my shoes so I use shoes without laces.	Adapt his clothing	Strategies to overcome problems
I'm more homebound now. He does not want me going out for very long.	Homebound	Caregiver burden

Table 2. Characteristics of the persons with stroke, use of health care services, informal care and caregiver burden.

Variable	Total sample, n=86	Met needs, n=45	Discordant, n=30	Unmet needs, n=11
Age: years, median (IQR)	72.5 (63-79.8)	75 (64-78)	71 (62.2-82.5)	74 (68.5-80.5)
Gender: women, n	33	18	11	4
Stroke severity: mild / moderate-severe, n *(Barthel Index, range of scores 0-100)*	57 / 28*	34 / 10†	21 / 9	3 / 8
Sense of coherence: median (IQR) *(Sense of coherence scale, range of scores 13-91)*	79.5 (69-87.8)‡	83 (74-89)§	71 (65.8-81)‖	79 (65-90)¶
Inpatient care and rehabilitation: days, median (IQR)	14 (7-36)	14 (6-31)	11.5 (7-35)	24 (19-56)
Outpatient rehabilitation: contacts, median (IQR)	3 (1-23.2)	3 (1-20)	8 (1-28.5)	1 (0-23)
Caregiver burden: median (IQR) *(Caregiver burden scale, range of scores 22-88)*	38 (26-51)	28 (23-44)	46 (36.2-55)	56 (34-63.5)
Informal care: has received, n	42**	20††	17	5§§

*n=85, †n=44, ‡n=74, §n=39, ‖n=26, ¶n=9, **n=83, ††=43, §§=1

Table 3. Categorization of the independent variables, categorization of dyads' perception of rehabilitation needs, p values

Independent variable	Perception of rehabilitation needs	P value
Age, years	Met / Unmet / Discordant	0.60
Sex, male / female	Met / Unmet	0.82
	Met / Discordant	0.77
	Unmet / Discordant	0.98
Sense of coherence, scores	Met / Unmet	0.48
	Met / Discordant	**0.002**
	Unmet / Discordant	0.40
Stroke severity,	Met / Unmet	**0.002**
mild / moderate-severe	Met / Discordant	0.48
	Unmet / Discordant	0.03
Inpatient care and rehabilitation, days	Met / Unmet / Discordant	0.12
Outpatient rehabilitation, contacts	Met / Unmet / Discordant	0.38
Caregiver burden, scores	Met / Unmet	**0.003**
	Met / Discordant	**<0.001**
	Unmet / Discordant	0.47
Informal care,	Met / Unmet	1.00
has received / has not received	Met / Discordant	0.39
	Unmet / Discordant	0.73