

**Spouses' need for information and satisfaction with the patient's care and rehabilitation after stroke. Importance of depression and prescheduled follow-up**

Berg Anu, Tapiola Tero, Hujala Maija

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Spouses' need for information and satisfaction with the patient's care and rehabilitation after stroke.  
Importance of depression and prescheduled follow-up.

Anu Berg<sup>1</sup>, Tero Tapiola<sup>1</sup>, Maija Hujala<sup>2</sup>

<sup>1</sup>Neurological Unit, South Karelia Central Hospital, South Karelia Social and Health Care District,  
Lappeenranta, Finland

<sup>2</sup>School of Business and Management, Lappeenranta University of Technology, Lappeenranta,  
Finland

Corresponding author: Anu Berg, South Karelia Central Hospital, Valto Käkelän katu 1, 53130  
Lappeenranta, Finland. E-mail: [anu.berg@eksote.fi](mailto:anu.berg@eksote.fi)

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## Abstract

**Objectives:** We aimed to study the information needs of the spouses of stroke survivors, and whether the functional ability, depressive mood, or demographic factors of the survivors or spouses associate with the information needs or satisfaction with care. We also investigated whether prescheduled follow-up improves information provision.

**Methods:** Ninety-six spouses of consecutive stroke survivors completed a questionnaire on their information needs and satisfaction with care 21 months post-stroke. The results of samples before (n=59) and after (n=37) the implementation of the prescheduled follow-up were compared.

**Results:** Before the follow-up, 75% of the spouses had received information on stroke and the well-being of the survivor, with 31% having received information on the survivors' and 18% on the spouses' own mood. The information provision improved after the follow-up: 86%, 44%, and 50%, respectively. The need for more information and satisfaction with care were associated with the spouse's depression, but not with functional impairment.

**Conclusions:** Even if information on stroke is satisfactorily provided, the mood and well-being of spouses is often neglected. Information provision and support can be improved with systematic prescheduled follow-up.

**Practice implications:** Our results suggest the routine assessment of the depressive symptoms and needs of spouses of stroke survivors.

## Introduction

Stroke affects not only the stroke survivors but also the lives of their families. Spouses of stroke survivors are most often the ones who take on a new role as a caregiver. They have to learn new information and manage new tasks, all the while having to cope with their own emotions in a changed situation. Caregivers often experience an increased burden, depression, and a poorer quality of life (QOL) [1-4].

In recent years, there has been increasing interest in caregivers' needs. In their systematic reviews, Pindus et al. [5], Luker et al. [6], Zawawi et al. [7], and Denham et al. [8] highlighted inadequate information provision as one of the most often reported unmet needs. Caregivers want more information on, for instance, stroke, stroke symptoms, medications, expected recovery, rehabilitation, and various services [5,7,9,10]. The caregivers' need for information is recognized globally in different health care systems [11-12]. In addition to information needs, managing one's own emotional responses and caring for oneself are challenges often experienced by spouse caregivers [6-8]. A caregiver's need for emotional and psychological support is also one of the most often unmet needs expressed by health care professionals [11-14]. Studies on factors associating with the unmet needs of caregivers are scarce. The caregiver's needs are found to be more numerous, when the stroke survivor's level of dependence is high [15]. The reported results on the association between the age and unmet needs of spouses are inconsistent [12,15]. Furthermore, in a study by Xia et al. [11], spouses with a higher education and those living in urban areas were more likely to request for more information than those with a lower education and living in rural areas.

The continuity of care [5] and appropriately timed information [14] are important for caregivers.

Considering the need for emotional support, the sense of being cared for is important during all phases from the acute phase onwards [6,10]. The highest need for information and support has been found to occur when preparing for discharge from the hospital and during the first few months at home [10]. Caregivers are often dissatisfied with the lack of proactive follow-up during this transition [5]. However, the challenges faced by spouse caregivers may evolve over time, and their need for information may increase and diversify with time [10]. The need for peer support becomes of greater importance later during the community care phase, as caregivers want to share their concerns and learn practical tips [10].

Satisfaction with care and rehabilitation signals a higher quality of services. In two Cochrane reviews by Foster et al. [16] and Crocker et al. [17], active information provision was found to reduce caregivers' anxiety and depression slightly, but passive information provision did not have a significant effect on the caregivers' mood or satisfaction with the information about recovery or rehabilitation. In addition to information, the emotional and psychological needs of caregivers may be even more important. There are studies in which caregivers were offered planned follow-up during the transition from hospital to the home. The study by Kalra et al. [18], where the caregiver received three to five sessions tailored to the needs of the individual patient before discharge, as well as a follow-up session at home, showed a positive effect on caregiver mood and the burden experienced. Bakas et al. [19] found that an intervention with weekly calls for up to eight weeks post-discharge and a booster session one month later reduced depressive symptoms within a subgroup of depressed caregivers. However, not all follow-up schemes have significant effects on caregiver outcome [20]. The role of nursing in successful stroke care transitions is highlighted, and systematic assessments of caregiver preparedness and tailored caregiver care plans are suggested [21].

In order to be able to provide effective and targeted caregiver interventions with information and support, we need to be aware of the neglected areas of information and to identify caregivers with the highest need for support. More research is needed on specific information needs and associated factors. The caregiver's challenges evolve with time, but longer follow-up studies are scarce.

In the South Karelia Social and Health Care District, a follow-up system for all stroke patients was implemented in 2011 in order to develop secondary prevention. Two prescheduled appointments, the first at three and the second at six months, were assigned. If the patient so wished, the first appointment was at home; the second appointment was arranged at the local health care center. In addition to the stroke survivors, the caregivers were invited to join the patient at both appointments, and their mood was screened and they were given the possibility to discuss any questions they wished to bring up. The follow-up system is described in more detail in the study by Berg et al. [22]. In the current study, we aimed to investigate 1) the types of information that the caregivers of stroke survivors needed before and after the prescheduled follow-up; 2) whether the functional ability of the survivors, the depressive mood of the survivors or the caregivers, or any demographic factors were associated with the information needs or satisfaction with care and rehabilitation; and 3) whether the prescheduled follow-up helped in fulfilling the information needs of caregivers and increased their satisfaction with the care and rehabilitation during longer follow-up.

## Methods

Patient and spouse inclusion and the measures used are shown in Figure 1. The 2010 sample: All patients diagnosed with an acute stroke (ischemic infarction, intracerebral hemorrhage, and subarachnoid hemorrhage) at the Neurological Unit of South Karelia Central Hospital between 1 January and 30 June 2010 were screened retrospectively. The 2012 sample: After the

implementation of the systematic follow-up scheme in 2011, we prospectively enrolled all patients diagnosed with an acute stroke between 1 January and 30 June 2012 for the study. The 2010 sample was recruited at 21 ( $20.6 \pm 1.4$ ) months post-stroke and the 2012 sample at 4 ( $4.5 \pm 1.0$ ) months post-stroke. Patients who were too severely ill to be interviewed due to the stroke or other medical reasons (e.g., high-level residential care, moderate or severe dementia, severe aphasia, acute or terminal cancer, psychosis, myasthenia gravis, Parkinson's disease, severe alcoholic dependency) were excluded from the study. Only patients with spousal caregivers were included in this study.

The stroke survivors' functional ability was assessed with the Barthel Index (BI) [23] at the acute phase and 21 months post-stroke and their depressive symptoms with the Depression Scale DEPS [24] at 21 months. They were also asked if they were satisfied with their post-stroke care and rehabilitation. The spouses' needs for information and support were surveyed with a yes/no questionnaire containing 13 questions: They were asked whether they had (1) received information on stroke and its risks, (2) on the stroke survivor's health status and prognosis, (3) on how to help the survivor in transitions and other everyday functions, and (4) on social security and benefits. Furthermore, they were asked (5) whether the health care professionals had discussed the stroke survivor's mood and well-being with them, and (6) whether their own mood and well-being had been discussed. In addition, the caregivers were asked whether they would have needed more information on or assistance with the same six issues. They were also given the possibility to describe their information needs more specifically if they so wished. The spouses were also asked whether they were satisfied with the post-stroke care and rehabilitation that the survivor had received. Spouses' depression was assessed at 21 months with the DEPS. The Bakas Caregiver Outcomes Scale (BCOS) [25] was used to assess how the caregivers perceived their lives to have changed after stroke.

We calculated the percentages of the spouses' information needs. The 2010 sample was compared to the 2012 sample after the implementation of the follow-up system with Pearson's Chi-squared test and the t-test. The associations of information needs with the functional ability, depressive symptoms, and the age and gender of the stroke survivors, as well as the depressive symptoms and satisfaction of the spouses, were assessed with Pearson's Chi-squared tests and t-tests.

The study was approved by the Ethics Committee of the South Karelia Social and Health Care District. The patients and their caregivers gave their written informed consent.

## Results

The inclusion of patients and their spouses is presented in Figure 1. Of the total of 398 consecutive patients screened, 207 stroke survivors were included, and 126 of them had a spouse. Of the spouses, 59 returned the questionnaires in the 2010 sample and 37 in the 2012 sample. The 2010 and 2012 samples did not differ from each other in terms of their Barthel Indices or the age and gender of the patients or spouses (Table 1).

Of all the spouses, the majority reported having received information on stroke and its causes and risks, as well as on the health status and prognosis of the survivor (79% and 67%, respectively). Almost half of the spouses reported having received information and guidance on how to help the survivor in daily life, as well as information on social security and financial support (46% and 45%, respectively). Only a minority of the spouses could recall being given information on the mood and well-being of the survivor or discussing their own well-being (36% and 29%, respectively). The percentages in the two samples separately are presented in Table 2.



Of all spouses, 41% reported a need for more information on the health and prognosis of the survivor (causes of stroke, examinations, medication, rehabilitation, epilepsy; prognosis, possibility of a relapse). Roughly a third of the spouses reported a need for more information on stroke (35%) as well as the mood and well-being of the survivor (changes in survivor's personality, depression, aggression; 35%), in addition to needing more discussions on their own well-being and mood (emotional support, somebody asking how they are, discussions without the survivor, peer support; 30%). A minority of the spouses reported the need for more information on social security, financial support, and benefits (sick leave and retirement, filling out applications; 29%) and on how to help the survivor in daily life ("how to help but not too much"; 22%). Some spouses reported a need for more rehabilitation for the stroke survivor and a day off for themselves and support in housekeeping duties. The percentages in the two samples separately are reported in Table 3.

Spouses who reported not having received information were caregivers of stroke survivors with a better functional ability (Table 4). The difference was most clearly seen in questions regarding social security and financial support, as well as regarding stroke information. Of these spouses, 71%–75% would have liked to receive more information on stroke, its causes and risks, and on the well-being and prognosis of the survivor, while 32%–43% would have liked to receive more information on the other areas. The information needs were not significantly associated with the survivor's functional ability at the acute phase or at 21 months, nor was there a significant association with the age or gender of the survivors or their spouses. The need for more information on the mood and well-being of the survivor and on the spouse's own well-being was associated with the spouse's depressive symptoms, as measured with the DEPS (8.2 vs 4.5,  $p < 0.05$  and 9.3 vs 3.9,  $p < 0.05$ , respectively).

The spouses of stroke survivors reported receiving information more often in 2012, when the prescheduled follow-up scheme had been implemented, than in 2010 before the follow-up scheme was adopted (Table 2). The greatest and statistically significant increase was seen in the discussion on the spouse's own well-being and mood and in information and guidance on how to help the survivor in daily life. However, the need for more information remained at the same levels in the 2010 and 2012 samples (Table 3). There was only a trend-like non-significant decrease from 2010 to 2012 in the need for information on the well-being and prognosis of the survivor (47% vs 31%,  $p = 0.18$ ). Caregiver DEPS scores also did not differ between the 2010 and 2012 samples (6.5 [SD 6.8] vs 6.0 [SD 5.6]).

Of all spouses, 79% were satisfied with the care and rehabilitation of their spouses; the rate was 80% among stroke survivors. There was no significant difference in the spouses' or stroke survivors' satisfaction with care and rehabilitation between the 2010 sample and the 2012 sample (77% vs 82% and 79% vs 86%). Spouses' satisfaction was slightly associated with the spouses' depressive symptoms: 85% of the caregivers with no significant depressive symptoms (DEPS score under 10) were satisfied with the care and rehabilitation, whereas 67% of those who had a DEPS score of 10 or more were satisfied (Pearson's Chi-square 3.77, df 1,  $p = 0.05$ ). The age, gender, or functional impairment of the patient did not associate with the spouse's satisfaction. The spouses' perceptions of the changes in their lives were more positive in 2012 after the implementation of the follow-up scheme than in 2010, when considering their relationship with the stroke survivor and their own physical functioning (0.5 vs 0.0,  $p < 0.05$  and 0.0 vs -0.5,  $p = 0.05$ , respectively). However, the total BCOS scores in 2010 and 2012 did not differ from each other significantly (56.2 [SD11.7] vs 59.1 [SD 12.1],  $p = 0.26$ ).

## Discussion and Conclusion

## Discussion

At 21 months post-stroke, most spouses of stroke survivors reported having received information on stroke, its causes, and risks, as well as on the well-being and prognosis of the survivor during the care and rehabilitation. **Information provision seems to be at a satisfactory level as regards facts about stroke: 79% of all spouses reported having received information on stroke-related topics.** In contrast, the well-being and mood of the caregivers are often neglected: only 29% of all spouses reported having had a discussion on their own well-being. The most often reported need for more information (41%) concerned the well-being and prognosis of the survivor, followed by information on stroke and the spouse's own well-being. Based on previous literature, we know these areas of information to be among the most often reported needs [6,7,12]. In the current study, we surveyed the subjective reports of spouse caregivers, and we do not know the extent to which the spouses recalled the information they had received [26].

**The pre-scheduled follow-up scheme significantly increased the amount of discussion on the spouses' own well-being and mood (from 18% to 50%) and the provision of information on how to help the survivor in daily life (from 37% to 66%). The increase did not reach statistical significance in other areas of information, although there was a trend-like overall increase from 2010 to 2012.** Follow-up appointments where the spouse caregivers were invited to join in gave them the opportunity to discuss challenges not yet present at the hospital or the rehabilitation unit and provided a possibility to reinforce the education of the spouses during discharge, an aspect found important also in the study by Heiberger et al. [26]. **Increasing the discussion on the spouses' own well-being can be a means to meet their desire to be heard and informed, which were the two key aspects identified in the review by Luker et al. [6]. The**

**stroke nurses and physical therapist who worked with the patients and their spouses took a training course on follow-up systems, including the topics of screening depressive symptoms and interviewing the stroke survivors and their spouses.** In our earlier study [22], after the implementation of the prescheduled follow-up, we found a significant increase in stroke survivors' mood screening, especially during the outpatient phase in later follow-up. For stroke survivors and their spouses, prescheduled follow-up aids in allowing them to experience a continuity of care [5,21,29].

**Although there was an increase in information provision and discussion on the spouses' own well-being, we found only minor statistical support for an impact on the overall well-being of the spouses.** In the BCOS, the spouses viewed the changes in their relationship with the stroke survivor and in their own physical functioning measured with the BCOS more positively in 2012 than in 2010. **The changes in the total BCOS score, DEPS score, and satisfaction with care and rehabilitation, however, did not reach significance.** Because of the small sample sizes, subtle differences may not have reached significance. **In particular, the high percentage of spouses who were already satisfied with care and rehabilitation in 2010 highlights this statistical problem.** The percentages in the current study (77% in 2010 and 82% in 2012) are higher than in local health care in Finland [27] and fairly similar to those found in a Swedish study on stroke rehabilitation [28]. **Satisfaction with care and rehabilitation could be expected to increase to some extent because of the follow-up. On the other hand, we did not have a specific depression intervention, and no major changes in depressive symptoms were therefore expected due to follow-up alone.**

**Providing more information does not necessarily decrease the subjective need for even more information. Roughly a third of the spouses wished to have received more information on**

**different topics, irrespective of the amount of information they had already received.**

**Furthermore,** even if the follow-up scheme increased the information delivery, it did not significantly decrease the desire for more information. Similarly, in a study by Xia et al. [11], spouses with a higher education requested more information. **A subjective need for information cannot be met solely by information provision. The need to be heard and supported also has to be taken in account.**

A clinically important and new finding was the association between the spouses' depressive symptoms and a need for more information on the mood and well-being of the survivor and on the spouses' own well-being. Our findings indicate the importance of routine screening of caregivers' depression in order to identify the spouses who are in need of more emotional support. A spouse's depressive symptoms were associated with poorer satisfaction, which was also found in a study by Lautamatti et al. [27]. The need for more information was not associated with the age or gender of the stroke survivors or their caregivers, nor with the functional ability of the stroke survivors, even if the spouses of stroke survivors with a good functional ability reported more often not having received information on various topic than did spouses of survivors with a poor functional ability. Inconsistent results from earlier studies in different cultural settings [11,15] may reflect differences in family responsibilities and societal support, etc. In addition, heterogeneous caregiver samples that include spouses, children, and other relatives cannot be compared with our results.

The small sample sizes are the major limitations of our study: subtle changes could not be confirmed statistically. Furthermore, the longer delay from recruitment to the study in the prospective 2012 sample than in the 2010 sample may have decreased the commitment to the follow-up and caused more late drop-outs. However, both the stroke-related and demographic variables are very similar in both groups. On the other hand, because all stroke patients in the health

care district are treated within the public health care system, and all acute strokes are referred to the neurological unit in the central hospital, the samples represent the stroke population very well. The enrolment of consecutive stroke survivors and the homogenous group of only spousal caregivers are among the strengths of this study.

## Conclusions

**Information on stroke is satisfactorily provided for the spouses of stroke patients, but their own mood and well-being are often neglected. Pre-scheduled follow-ups with depression screening significantly increased the discussions on the spouses' own well-being and mood but did not decrease the subjective needs for more information. The need to be heard and supported also has to be taken in account. The spouses' depressive symptoms were associated with their subjective need for information and support, and with their satisfaction with care and rehabilitation. It is important to identify spouses with depressive symptoms in order to be able to provide support and interventions.**

## Practice implications

Our results suggest the implementation of a routine assessment of the depressive symptoms and needs of the spouses of stroke survivors and highlight the importance of systematic pre-scheduled follow-up during the first year after stroke. However, more research is needed on efficient interventions regarding the well-being of spouses of stroke survivors.

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Table 1. Descriptive characteristics of the patient and spouse samples.

	Sample 2010 n = 59	Sample 2012 n = 37
Patient BI at acute phase $\pm$ SD	79.2 $\pm$ 6.8	77.3 $\pm$ 31.4
Patient BI at 21 mo $\pm$ SD	91.3 $\pm$ 17.7	92.9 $\pm$ 14.6
Patient mean age $\pm$ SD(y)	66.5 $\pm$ 11.4	67.9 $\pm$ 10.7
Spouse mean age $\pm$ SD (y)	64.2 $\pm$ 12.7	66.9 $\pm$ 9.5
Spouse gender, female n (%)	38 (64)	20 (54)

Table 2. Percentages of spouses who had received information on various topics before and after the implementation of pre-scheduled follow-up.

	Sample 2010 n (%)	Sample 2012 n (%)	Pearson Chi-square significance
Have you received information on...			
stroke, its causes, and risks	44/59 (75)	30/35 (86)	0.20 ns
the health status and prognosis of the survivor	37/58 (64)	23/31 (74)	0.32 ns
how to help the survivor in daily life	21/57 (37)	21/34 (66)	0.02 *
social security, financial support, and benefits	22/58 (38)	20/35 (57)	0.07 ns
Have you been discussed with on...			
the mood and well-being of the survivor	18/58 (31)	16/36 (44)	0.19 ns
on your own well-being and mood	10/58 (18)	17/36 (50)	0.002 **

Table 3. Percentages of spouses who would have needed more information before and after the implementation of pre-scheduled follow-up.

	Sample 2010 n (%)	Sample 2012 n (%)	Pearson's Chi- squared significance
Would you have needed more information on...			
stroke, its causes, and risks	17/49 (35)	9/26 (35)	0.99 ns
the health status and prognosis of the survivor	23/49 (47)	8/26 (31)	0.18 ns
how to help the survivor in daily life	10/47 (21)	6/27 (22)	0.92 ns
social security and financial support	16/49 (33)	6/27 (22)	0.34 ns
Would you have needed more discussion on...			
the mood and well-being of the survivor	17/51 (33)	10/27 (37)	0.74 ns
your own well-being and mood	16/48 (33)	7/28 (25)	0.45 ns

Table 4. The Barthel Indices (BI) in the acute phase after stroke among those spouses who reported having and received information and those who reported having not received information.

	Yes BI mean (SD)	No BI mean (SD)	T-test two-sided p
Have you received information on...			
stroke, its causes, and risks	75.2 (30.7)	90.5 (12.0)	< 0.001
the health status and prognosis of the survivor	75.8 (31.9)	84.1 (21.6)	ns
how to help the survivor in daily life	73.7 (35.1)	84.0 (19.7)	ns
social security and financial support	65.6 (34.9)	89.3 (15.9)	< 0.001
Have you been discussed with on...			
the mood and well-being of the survivor	68.4 (36.3)	84.6 (21.2)	< 0.05
your own well-being and mood	65.6 (40.4)	83.8 (19.9)	< 0.05