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ORIGINAL REPORT

SUPPORT/SERVICES AND FAMILY CARERS OF PERSONS WITH STROKE IMPAIRMENT: PERCEIVED IMPORTANCE AND SERVICES RECEIVED

Barbro Krevers, PhD, ROT and Birgitta Öberg, PhD, RPT

From the Division of Physiotherapy, Department of Medical and Health Sciences, Linköping University, Linköping Sweden

***Objective:* To examine what family carers of persons with stroke impairment perceive as important support and service quality characteristics in relation to their experienced strain/burden, and to explore to what extent family carers receive support/services perceived as important.**

***Design:* Data from a cross-sectional study.**

***Subjects:* A sample of 183 family carers in Sweden, 64 experiencing lower and 119 experiencing higher strain/burden, a subsample of the EUROFAMCARE project.**

***Methods:* Carers were interviewed using a structured questionnaire.**

***Results:* There are few differences between carers experiencing high and low strain/burden in what they perceive and receive in terms of important support and service quality characteristics. Information, relief, and counselling support/services are highly valued. It is also important that services improve quality of life, and have good process qualities regarding interaction with staff and individualization. Most services regarded as important are received by less than 60% of carers.**

***Conclusion:* The variation is rather high on an individual level in terms of what carers regard as important, indicating that factors other than negative impact may influence their perceptions of support/service and service quality. Thus, it is important to know carers' perceptions in order to individualize support/service, and thus make it more available and efficient.**

Key words: family carers; stroke; support; service; burden; quality.

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Correspondence address: Barbro Krevers, Division of Physiotherapy, Department of Medical and Health Sciences, Linköping University, SE-581 83 Linköping, Sweden. E-mail: barbro.krevers@liu.se

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INTRODUCTION

Family carers of persons with stroke impairment (PS) often report low quality of life. Factors associated with carers' quality of life include the high burden due to caregiving, psychosocial factors, and the functioning of the PS (1–4). Over the past decade, it has been suggested that formal healthcare and social work providers should partner with family carers and the persons receiving care to improve the caring situation (5, 6). Arguably, it is essential to respect and treat family carers as persons with their own needs and not to view them just as caring resources for the disabled person and as alleviating the need for formal health and social work care (7). An essential question is how to support these family carers and improve their situations. Besides a lack of appropriate support/services, other barriers prevent family carers and the cared for from getting the support/services they need. Sometimes disabled persons or their family carers do not use a service even if it is available, possibly due to perceived low service quality, mistrust, and high cost (8). This emphasizes that support/services must also correspond to user views of support/service needs and service quality (9).

Information, practical problem-solving, healthcare, and emotional/social support are support/services often requested by family carers of PS (10–13). Since high burden is associated with carers' quality of life, it would be useful to examine whether family carers with different levels of strain/burden perceive different types of support/service and service quality characteristics as differing in importance. A question that also arises is whether there are differences in the extent to which carers who experience different levels of strain/burden consider that they receive the support/services and the service quality they value. Such knowledge would be useful for decisions concerning how to direct and provide support/services for family carers.

This study examines the situation of family carers of PS, and what these carers perceive as important support/services and service quality characteristics in relation to the experienced negative impact of caregiving. The objective is also to explore to what extent family carers receive the support/services and quality characteristics they perceive as important.

METHODS

The present data are based on a subsample from the Swedish part of the EUROFAMCARE-project, which also involved 5 other European countries: Germany, Greece, Italy, Poland, and the UK. EUROFAMCARE focused on the situation of family caregiving of older people and their service use and needs. The participating countries followed a common study protocol concerning criteria, sampling strategies, and a shared assessment tool (14). The recruitment strategy aimed to obtain representation of various care arrangements and geographical areas in each country. Approximately 1000 carers per country were interviewed using a structured questionnaire. The EUROFAMCARE project was approved by ethics committees in each of the 6 countries involved.

In this paper, "support" refers mostly to informal support, e.g. help from family and friends, while "service" is formally provided by an organization. Persons who have had a stroke are referred to as

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"persons with stroke impairment" (PS), and family carers are referred to simply as "carers".

Study subjects

For inclusion in the EUROFAMCARE study, subjects had to be 18 years of age or older and provide care for at least 4 h per week to someone aged 65 years or older. Persons who did not speak the national language were excluded. The Swedish subjects in the EUROFAMCARE study comprise 921 carers (15). The present study added further inclusion criteria: the cared-for person should have had a stroke and the carer should have completed the negative-impact scale of the Carers of Older People in Europe (COPE) index (16). This is because the study population was divided into 2 groups depending on the strain/burden arising from the caring situation, i.e. lower and higher negative-impact (NI) groups based on the COPE index NI scale (see the Statistics subsection, below). One exclusion criterion was used: those caring for PS living in sheltered housing or institutional care were excluded.

The present study sample includes 183 family carers of PS. The lower-NI group contains 64 carers with values of 7–11 on the NI scale of the COPE index. The higher-NI group contains 119 carers with values of 12–28 on the NI scale. The characteristics of carers and PS are presented in Table I. The carers were recruited mainly using the following methods: random sampling from the population list, then contacted by telephone or post (50%); snowball sampling (20%); contacts with healthcare or social work staff (16%); by advertisement (8%); and contacts with voluntary/religious organizations (4%).

Instruments

The EUROFAMCARE Group developed a common assessment tool, which is a structured questionnaire comprising standardized instruments as well as scales and items developed by the Group (17). Each country could add a few country-specific items: in Sweden a question was added concerning why the cared-for person needed support and care. The presented results are based on demographic data and the following instruments/questions (see Tables I–IV):

Family carer

General health. An overall question from Short Form-36 (SF-36) (18) and health-related quality of life: EQ-5D (19).

Caring situation. COPE index with a response ranging from 1 = never to 4 = always (20); based on 3 newly validated sub-scales (16):

- *Negative impact scale:* 7 questions on emotional wellbeing, physical health, overly-demanding caring, difficulties in relationships, feeling trapped, and financial difficulties.
- *Positive value scale:* 4 questions on coping with caring, finding caring worthwhile, relationship with the person cared-for, and appreciation for providing care.
- *Quality of support scale:* 4 questions on support received from friends or neighbours, family, health and social services, and overall support in the caring role.

The importance of 14 different types of support/service and 12 different service quality characteristics were rated "not, quite, and very important", and whether these were received were rated "mostly yes, mostly no" (17). The results concerning received support/services and quality characteristics are based solely on the proportions of carers who rated given support/services and accompanying quality characteristics as "very important" (see Tables III–IV). The support/services were categorized into 4 groups: information, relief, counselling, and financial support (see Table III). The service quality characteristics were categorized into 4 groups: structure, process – interaction, process – individualized, and results (see Table IV). The categorization was carried out by 2 researchers.

Table I. *Characteristics of carers and of persons with stroke impairment*

	Lower NI-group $n = 64$	Higher NI-group $n = 119$	Total $n = 183$
Characteristics, carers			
Female sex, %	73.0	79.0	76.9
Spouse/partner; %	62.5	80.7*	74.3
Impossible or difficult to replace carer in case of illness, %	64.1	86.6*	78.7
Received support/service designed for carer during the last 6 months, %	12.5	24.4	20.2
Age, mean (SD)	67.0 (12.7)	69.6 (9.3)	68.7 (10.7)
Care duration (months of support for PS), mean (SD)	55.0 (45.3)	59.1 (50.9)	57.6 (48.9)
Time of provided support (h/week), mean (SD)	47.5 (54.5)	68.0 (56.5)*	60.9 (56.5)
Number of needs domains in which carer supports PS (1–8), mean (SD)	5.2 (1.5)	6.3 (1.3)*	6.3 (1.5)
Number of received support/service designed for carer during the last 6 months, mean (SD)	0.2 (0.5)	0.4 (0.9)*	0.4 (0.8)
General health (5–1 = excellent), median (quartiles)	3.0 (2.0;4.0)	3.0 (3.0;4.0)*	3.0 (3.0;4.0)
Health-related quality of life (–0.594–1 = full health), median (quartiles)	0.80 (0.73;1.00)	0.73 (0.73;0.85)*	0.80 (0.73;0.85)
Negative impact (4–28 = highest negative), median (quartiles)	9.5 (8.0;11.0)	14.0 (13.0;16.0)*	13.0 (11.0;15.0)
Positive value (4–16 = highest positive), median (quartiles)	15.0 (14.0;16.0)	14.0 (12.0;15.0)*	14.0 (12.0;16.0)
Quality of support (4–16 = highest quality of support), median (quartiles)	13.0 (10.0;16.0)	11.0 (9.0;14.0)*	12.0 (9.0;14.0)
Characteristics, persons with stroke impairment			
Female sex, %	45.3	31.9	36.6
Memory problems, %	37.5	60.5*	52.5
Behavioural problems, sometimes or most of the time, %			
Endangering behaviour or wandering	6.3	18.6*	14.3
Difficulties with conversation, lack of insight, or uncooperative	21.9	50.0*	40.1
Upsetting behaviour	12.5	28.2*	22.7
Age, mean (SD)	79.3 (6.4)	76.9 (7.5)*	77.7 (7.2)
Number of domains in which the PS need support (1–8), mean (SD)	5.7 (1.4)	6.6 (1.0)*	6.3 (1.3)
Number of domains in which the PS need more support (1–8), mean (SD)	0.4 (0.9)	1.2 (1.6)*	0.9 (1.5)
P-ADL (5–100 = independent), median (quartiles)	85.0 (60.0;90.0)	70.0 (45.0;85.0)*	75.0 (45.0;85.0)
I-ADL (0–12 = independent), median (quartiles)	5.0 (2.0;7.0)	2.0 (1.0;5.0)*	3.0 (1.0;6.0)

*Significant difference at the 0.05 level between the 2 groups.

PS: person with stroke impairment; SD: standard deviation.

Person with stroke impairment

Personal activities in daily life (P-ADL). Barthel index (21); Instrumental ADL (I-ADL): Modified Duke OARS assessment (17, 22).

Behaviour. Modified Behavioural and Instrumental Stressors in Dementia (BISID) (17, 23).

Procedure

Those subjects who met the inclusion criteria and agreed to participate (based on a study overview) were informed of the study in detail, told of the right to withdraw from it at any time, and assured that their data would remain confidential. Participating carers could choose between telephone and face-to-face interviews; most chose telephone interviews.

Statistics

The median value on the NI scale of the COPE index for the whole Swedish sample in the EUROFAMCARE study ($n=921$) was used as the cut-off point for grouping the present sample into lower (≤ 11) and higher (≥ 12) NI categories, as there is no "clinical" cut-off score on that scale.

χ^2 analysis was used for 2-sided comparisons of proportions of dichotomized variables. Fisher's exact test (2-sided) was used when an expected cell count was less than 5 in a cross-tabulation and thus inappropriate for χ^2 analysis. In order to examine the differences between the higher- and lower-NI groups, an independent sample t-test was used for interval scales and the Mann–Whitney U-test was used for ordinal scales. A p-value of 0.05 or less was considered significant. SPSS 17.0 was used for the analyses.

RESULTS

The results show that carers provide considerable support for the PS. The higher-NI group has a strained/burdened situation considering both "subjectively" as to their quality of life and "objectively", e.g. in terms of PS level of impairment. The NI-group found less positive values in their caring situations and experienced poorer-quality support as reported in the COPE index than did the lower-NI group. According to the carers, the PS in the higher-NI group needed more supplementary support than did PS cared for by the lower-NI group (Table I). Emotional/psychological/social support was the supplementary support most requested for the PS by carers in both groups. No differences were evident between the groups concerning how many services the PS received in each domain from service organizations (Table II).

Types of support/service

There are 2 differences between the 2 groups concerning what they perceive as important support. More carers in the lower-NI group considered opportunities for the PS to undertake enjoyable activities as a very important support/service, while more carers in the higher-NI group considered help planning future care as very important (Table III).

The results concerning how various types of support/service were received refer solely to the proportion of carers who rated a support/service as "very important". The results indicate 1 difference between the 2 groups: fewer carers in the higher-NI group considered they received information about the PS's disease (Table III).

Service quality characteristics

Generally, all the specified service quality characteristics were considered very important by most carers and the results show no significant differences between the 2 groups. Especially important were "process – interaction" quality characteristics, e.g. respectful treatment and being listened to, and "result" characteristics, such as improved quality of life for the carer and the PS (Table IV).

Among the carers who rated a quality characteristic "very important", significantly fewer carers in the higher-NI group considered the received service improved the carers' quality of life and that care workers had the required skills and training. These 2 characteristics concern "result" and "structural" quality (Table IV).

Table II. *Support provided by the carer to the person with stroke impairment (PS), services received by the PS provided by a service organization, and PS needs for more support/service*

Domain	Lower NI-group $n=64$ %	Higher NI-group $n=119$ %	Total $n=183$ %
Domestic care			
Support provided by carer	89.1	96.6[F]	94.0
Receive service from organization	15.6	13.6	14.3
Need for more service for PS	6.3	24.8*	18.2
Organizing and managing care, support, and service			
Support provided by carer	84.4	91.5	89.0
Receive service from organization	3.1	5.1[F]	4.4
Need for more service for PS	3.1	11.1	8.3
Financial management			
Support provided by carer	76.6	90.5*	85.6
Receive service from organization	3.1	3.4[F]	3.3
Need for more service for PS	3.2	1.7[F]	2.2
Emotional/ psychological/ social support			
Support provided by carer	79.7	83.9	82.4
Receive service from organization	14.1	22.0	19.2
Need for more service for PS	15.9	35.7*	28.7
Mobility and transport			
Support provided by carer	70.3	84.0*	79.2
Receive service from organization	14.1	16.0	15.3
Need for more service for PS	6.3	15.4	12.2
Healthcare			
Support provided by carer	60.9	87.4*	78.1
Receive service from organization	20.3	15.1	16.9
Need for more service for PS	4.8	16.1	12.2
Physical/personal care			
Support provided by carer	54.7	75.6*	68.3
Receive service from organization	23.4	26.9	25.7
Need for more service for PS	7.8	14.5	12.2
Financial support			
Support provided by carer	3.2	18.1*	12.8
Receive service from organization	0.0	0.9[NA]	0.6
Need for more service for PS	0.0	0.9[NA]	0.6

*Significant difference at the 0.05 level between the 2 groups.

[F] Fisher's exact test.

[NA] Not applicable as expected cell count is zero or less than 1.

Table III. *Proportions of carers who consider different types of support/service as very important and the proportions receiving them*

Type of support/service	Perceived as very important, %			Received by those who rated the support/service as very important, %		
	Lower NI-group *n* = 64	Higher NI-group *n* = 119	Total *n* = 183	Lower NI-group	Higher NI-group	Total
Information						
Information about disease of the PS	85.9	81.5	83.1	83.3	66.3*	72.5
Information and advice about the type of help and support available and how to access it	70.3	75.6	73.8	60.0	51.7	54.5
Relief						
Opportunities for the PS to undertake activities he/she enjoys	70.3	53.8*	59.6	50.0	51.6	50.9
Opportunities for the carer to enjoy activities outside of caring	58.1	57.6	57.8	61.1	50.0	53.9
Opportunities to have a holiday or take a break from caring	58.7	55.1	56.4	47.2	46.0	46.5
Help to make the environment of the PS more suitable for caring	47.6	53.1	51.1	75.0	73.7	74.1
Opportunities to spend more time with the family	30.2	27.4	28.3	63.2	43.8	51.0
Possibility to combine caregiving with paid employment	17.2	9.4	12.2	90.0	63.6[F]	76.2
Counselling						
Opportunities to talk over problems as a carer	62.5	69.5	67.0	81.6	67.1	71.7
Opportunities to attend a carer support group	31.3	42.4	38.5	55.0	31.3	38.2
Help with planning for future care	21.9	37.3*	31.9	14.3	27.3[F]	24.1
Training to help develop the skills needed for caring	35.9	23.7	28.0	30.4	17.9	23.5
Help dealing with family disagreements	4.7	8.5[F]	7.1	33.3	44.4[F]	41.7
Financial support						
More money to help provide things needed to give good care	20.3	20.4	20.3	18.2	27.3[F]	24.2

*Significant difference at the 0.05 level between the 2 groups.

[F] Fisher's exact test.

PS: person with stroke impairment.

DISCUSSION

This paper is based on interviews with 183 family carers of PS. The results contribute new knowledge of how PS carers perceive and receive important types of service/support and their particular service quality characteristics. This is examined in relation to carers' level of strain/burden by comparing 2 groups: carers experiencing lower and higher negative impact due to caring. Despite several differences between the 2 groups' caring situations, there are few differences between them in what they perceive and receive in terms of *very important support/*

Table IV. *Proportions of carers who consider different service quality characteristics as very important and the proportions receiving them*

Service quality characteristics	Perceived as very important, %			Received by those who rated the characteristic as very important, %		
	Lower NI-group *n* = 64	Higher NI-group *n* = 119	Total *n* = 183	Lower NI-group	Higher NI-group	Total
Process – Interaction						
Care workers treat the PS with dignity and respect	98.4	99.1[F]	98.9	93.9	89.8[F]	91.2
Carer's views and opinions are listened to	93.8	92.2[F]	92.7	89.8	86.3	87.6
Care workers treat carers with dignity and respect	83.9	88.0	86.6	97.5	89.9[F]	92.4
Result						
The help provided improves the quality of life of the PS	93.7	92.2[F]	92.7	90.5	76.6	81.5
The help provided improves the carers' quality of life	76.2	79.3	78.2	90.9	73.0*	79.2
Process – Individualized						
Help is available when most needed	89.1	93.2	91.7	82.9	70.7	74.8
Help arrives at the time it is promised	84.1	85.1	84.7	88.2	88.6[F]	88.5
Help focuses on the carer's needs as well as those of the PS	62.5	69.0	66.7	86.2	70.0	75.3
The help provided fits in with carer's routines	41.0	52.6	48.6	94.1	71.4[F]	78.0
Structure						
Care workers have the skills and training they require	82.8	82.1	82.3	92.3	75.0*	80.9
Help is provided by the same care worker each time	76.6	72.6	74.0	68.6	63.5	65.3
The help provided is not too expensive	68.3	60.2	63.1	60.0	52.0	55.0

*Significant difference at the 0.05 level between the 2 groups.

[F] Fisher's exact test.

PS: person with stroke impairment.

service and *service quality characteristics* (in the following text, "very important" is usually shortened to "important"). The carers' values seem to correspond closely between the 2 groups. However, some types of support/service are important to many carers, while others are important to just a few. This indicates a rather high degree of individual-level variation in what carers regard as important. A study of carers of persons with dementia showed comparable results regarding the individual variation (24).

Many of the carers provided considerable support to the PS, but received limited *service designed for carers*. Therefore, much of the carers' assessment of received services and quality characteristics probably refers to services *directed to the PS*. Of the 14 different types of support and services, 10 were received by less than 60% of the sampled carers. Consequently several carers perceive they do not receive the support/services they consider important. Taking into consideration the reported demanding caring situation in the higher-NI group and their lower health and quality of life, these carers are not optimally supported. This might indicate that carers' strain/burden had no major influence on service organization decisions about service provision. Carers' perceptions regarding support/service are probably influenced by many aspects, such as previous experiences, expectations and personal situation, i.e. similar to the patients' evaluation process regarding care and rehabilitation (25). The carers' report might differ from the service providers' view on what they have provided; thus it is important also to ask about the carers' experiences. In Sweden, most services for older people and carers are public and are largely determined by healthcare/social work staff within frames supplied by higher authorities and legislation. However, research shows that family carers are seldom invited when social workers discuss support/service needs with the disabled person (26, 27). In other countries it has also been demonstrated that carer distress does not influence formal support provision (28). Though carer's mental health can affect the disabled person (29); supporting carers' wellbeing can thus also support the PS.

Information about available services and the PS's disease are the most requested types of support/service, despite many carers having long experience as carers. Whether the carers actually do not receive information or whether they do not recall receiving it, several carers do not have the information they want. A review confirms that providing information is a complex and difficult task, there is unfortunately no clear evidence for what is the best way to provide information that can affect carer mood (30). Moreover, it is important for most carers that the PS has a satisfying life, i.e. service should improve PS quality of life and enable the PS to participate in enjoyable activities. Such support may *relieve* the carers, as they put considerable effort into emotionally supporting the PS. It has been indicated that healthier older people more actively pursue various interests (31). Obviously, enjoyable activities may encourage the PS to remain active and sustain their health. Respite services are important to several carers and can bring opportunities for carers to carry out activities outside caring. Thus respite services, as well as how to provide information to carers, are important fields to investigate and develop further. *Counselling support* is also requested by many carers. It has been found that counselling programmes seem most likely to have a positive outcome when comparing different types of interventions for carers (32). According to the present study *financial support* is not a big issue for most carers in Sweden, unlike in many other countries (8). This is probably connected to the Swedish welfare system, which grants all citizens a state pension at age 65 years. Most healthcare and social services are subsidized and have maximum cumulative fees. However, of those carers in the study who do consider financial support very important, few received it.

Considerations

The Swedish sample in the EUROFAMCARE project is reasonably comparable to samples used in other Swedish population-based studies of carers of older people and can therefore be considered representative (15). Most PS carers ended up in the higher-NI group (see Statistics subsection, above). This emphasizes that carers of PS often experience high levels of strain/burden. In addition, other factors known to increase caregiver burden differed between the groups (1, 4). Hence, the 2 groups represent carers perceiving lower and higher levels of strain/burden, as there was also a significant difference in the NI scale between the 2 groups.

Although the overall sample is large relative to those used in most studies of carers´ perception of support and service, the statistical power is occasionally weak because few relevant cases are compared in some specific analyses. Though proper methods have been used, the results should be interpreted cautiously in these cases.

In conclusion, factors other than negative impact seem to influence carers' perceptions of support/services and service quality, as the variation is rather high on an individual level in terms of what carers regard as important. The results emphasize that it is important to understand carers' perceptions in order to individualize support/services and thus make them more available and efficient. This requires a variety of support/services offering information, relief and counselling. Furthermore, the support/services ought to possess certain quality characteristics regarding process, structure and attained results that are important to carers. Most carers consider it important that support/services improve both their and the PS's quality of life. In order to develop services, these and other important needs from the carers' perspective, ought to be evaluated regularly, with the aim of reducing carers' level of strain/burden.

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REFERENCES

1. McCullagh E, Brigstocke G, Donaldson N, Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. Stroke 2005; 36: 2181–2186.
2. Jönsson AC, Lindgren I, Hallstrom B, Norrving B, Lindgren A. Determinants of quality of life in stroke survivors and their informal caregivers. Stroke 2005; 36: 803–808.
3. Larson J, Franzen-Dahlin A, Billing E, von Arbin M, Murray V, Wredling R. Predictors of quality of life among spouses of stroke patients during the first year after the stroke event. Scand J Caring Sci 2005; 19: 439–445.
4. Morimoto T, Schreiner AS, Asano H. Caregiver burden and health-related quality of life among Japanese stroke caregivers. Age Ageing 2003; 32: 218–223.
5. van Heugten C, Visser-Meily A, Post M, Lindeman E. Care for carers of stroke patients: evidence-based clinical practice guidelines. J Rehabil Med 2006; 38: 153–158.
6. Brereton L, Nolan M. 'Seeking': a key activity for new family carers of stroke survivors. J Clin Nurs 2002; 11: 22–31.
7. Scottish Executive. The future of unpaid care in Scotland. Headline report and recommendations. London: OPM, Scottish Executive; 2005.
8. Lamura G, Mnich E, Nolan M, Wojszel B, Krevers B, Mestheneos L, et al. Family carers' experiences using support services in Europe: empirical evidence from the EUROFAMCARE study. Gerontologist 2008; 48: 752–771.
9. Thompson AG, Sunol, R. Expectations as determinants of patient satisfaction: concepts, theory and evidence. Int J Qual Health Care 1995; 7: 127–141.
10. Jones SP, Auton MF, Burton CR, Watkins CL. Engaging service users in the development of stroke services: an action research study. J Clin Nurs 2008; 17: 1270–1279.
11. Mackenzie A, Perry L, Lockhart E, Cottee M, Cloud G, Mann H. Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring. Disabil Rehabil 2007; 29: 111–121.
12. Robinson L, Francis J, James P, Tindle N, Greenwell K, Rodgers H. Caring for carers of people with stroke: developing a complex intervention following the Medical Research Council framework. Clin Rehabil 2005; 19: 560–571.
13. Smith LN, Lawrence M, Kerr SM, Langhorne P, Lees KR. Informal carers' experience of caring for stroke survivors. J Adv Nurs 2004; 46: 235–244.
14. EUROFAMCARE consortium, editor. Services for supporting family carers of elderly people in Europe: Trans-European survey report. Hamburg, Germany: Medical University of Hamburg – Eppendorf; 2006. Available from: http://www.uke.de/extern/eurofamcare/publikationen.php?abs=8.
15. Krevers B, Magnusson H, Johansson L, Öberg B. Services for supporting family carers of elderly people in Europe: the national survey report for Sweden. University of Hamburg Medical Centre of Hamburg-Eppendorf; 2006. Available from: http://www.uke.de/extern/eurofamcare/publikationen.php?abs=9.
16. Balducci C, Mnich E, McKee KJ, Lamura G, Beckmann A, Krevers B, et al. Negative impact and positive value in caregiving: validation of the COPE Index in a six-country sample of carers. Gerontologist 2008; 48: 276–286.
17. McKee K, Balducci C, Krevers B, Mnich E, Prouskas C, Wojszel B. The EUROFAMCARE Common Assessment Tool (CAT): item and scale development and description. In: EUROFAMCARE Consortium, editor. Services for supporting family carers of elderly people in Europe: Trans-European survey report. Hamburg University Medical Centre of Hamburg-Eppendorf. Available from: http://www.uke.de/extern/eurofamcare/publikationen.php?abs = 3; 2006.
18. Brazier JE, Harper R, Jones NM, O'Cathain A, Thomas KJ, Usherwood T, et al. Validating the SF-36 health survey questionnaire: new outcome measure for primary care. BMJ 1992; 305: 160–164.
19. Brooks R. EuroQol: the current state of play. Health Policy 1996; 37: 53–72.
20. McKee KJ, Philp I, Lamura G, Prouskas C, Oberg B, Krevers B, et al. The COPE index – a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. Aging Ment Health 2003; 7: 39–52.
21. Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. Md State Med J 1965; 14: 61–65.
22. Fillenbaum GG, Smyer MA. The development, validity, and reliability of the OARS multidimensional functional assessment questionnaire. J Gerontol 1981; 36: 428–434.
23. Keady J, Nolan M. Behavioural and Instrumental Stressors in Dementia (BISID): refocussing the assessment of caregiver need in dementia. J Psychiatr Ment Health Nurs 1996; 3: 163–172.
24. Alwin J, Oberg B, Krevers B. Support/services among family caregivers of persons with dementia-perceived importance and services received. Int J Geriatr Psychiatry 2010; 25: 240–248.
25. Krevers B, Närvänen A-L, Öberg B. Patient evaluation of the care and rehabilitation process – within geriatric hospital care. Disabil Rehabil 2002; 24: 482–491.
26. Olaison A, Cedersund E. Home care as a family matter? Discursive positioning, storylines and decision-making in assessment talk. Commun Med 2008; 5: 145–158.
27. Janlov AC, Hallberg IR, Petersson K. Family members' experience of participation in the needs of assessment when their older next of kin becomes in need of public home help: a qualitative interview study. Int J Nurs Stud 2006; 43: 1033–1046.
28. Simon C, Kumar S, Kendrick T. Formal support of stroke survivors and their informal carers in the community: a cohort study. Health Soc Care Community 2008; 16: 582–592.
29. Wilz G, Barskova T. Evaluation of a cognitive behavioral group intervention program for spouses of stroke patients. Behav Res Ther 2007; 45: 2508–2517.
30. Smith J, Forster A, House A, Knapp P, Wright J, Young J. Information provision for stroke patients and their caregivers. Cochrane Database Syst Rev 2008; (2): CD001919.
31. Häggblom-Kronlöf G, Sonn U. Interests that occupy 86-year-old persons living at home: Associations with functional ability, self-rated health and sociodemographic charateristics. Aust Occup Ther J 2005; 53: 196–204.
32. Visser-Meily A, van Heugten C, Post M, Schepers V, Lindeman E. Intervention studies for caregivers of stroke survivors: a critical review. Patient Educ Couns 2005; 56: 257–267.