

## SPECIAL REPORT

## CARE FOR CARERS OF STROKE PATIENTS: EVIDENCE-BASED CLINICAL PRACTICE GUIDELINES

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**Carers of stroke patients provide informal care ranging from physical help to psychosocial support. As a result, these carers may experience high levels of burden, associated with characteristics of the patients and of the carers themselves. This burden can result in a deterioration of the carers' health status, social life and well-being. The carers may thus be seen as colleagues of professional carers in sharing the care for the patient, but they should also be seen as "patients" having problems and special needs themselves. In this paper new Dutch clinical practice guidelines are presented. These guidelines are formulated in response to an expressed need to improve professional support for this group. We believe these guidelines are also relevant for other countries, since the evidence was gathered through systematic searches of international literature and none of the guidelines that we were able to find in other countries already included this evidence. New, or more detailed topics in the Dutch guidelines, in comparison with existing international guidelines, are added (e.g. young children). Three topics concerning carer burden are presented in more detail in this paper, which are based on systematic literature searches: partners at risk of burden, assessing burden in carers and interventions for carers.**

*Key words:* stroke, carers, clinical practice guidelines.

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### INTRODUCTION

Most survivors of stroke return home after discharge where care is provided largely by informal carers such as the spouse, close family members or neighbours. Informal care varies from physical help with activities of daily living to psychosocial support concerning coping with a sometimes dramatically changed daily life. As a result, carers of stroke patients may experience high levels of burden in terms of high feelings of responsibility, constant anxiety, decreased social activities and loneliness (1, 2). High levels of burden are associated with

characteristics of the patients (e.g. physical and cognitive impairments) and of the carers themselves (e.g. depressed mood) and are associated with deterioration of the carers' own health status, social life and well-being (3). Carer depression can, in turn, worsen the depression of a stroke survivor and predict poor response to rehabilitation (4, 5). Carers of stroke patients may thus be seen as colleagues of the professional carers in sharing the care for the patient, but carers should also be seen as "clients" having problems and special needs themselves. Interventions for carers of stroke patients should be aimed at preventing the decrease in their quality of life and well-being, but also at increasing their participation in society (e.g. work, social activities).

Unfortunately, despite the evidence of burden in carers, the attention and care given to carers of patients is not standard in most stroke services. The development and implementation of clinical practice guidelines is an effective way to transfer scientific knowledge about care for carers of stroke patients into evidence-based interventions. Clinical practice guidelines have been developed and implemented in several countries and their positive impact on processes, outcome and patient satisfaction have been shown. For instance, in the USA compliance with post-acute stroke guidelines was associated with greater patient satisfaction (6). In addition, these guidelines (the Agency for Healthcare Research and Quality's Post-Stroke Rehabilitation Guidelines) have an impact on knowledge and practice patterns of acute care health professionals (7). Finally, and probably most importantly, adherence to guidelines is associated with improved functional outcome (8).

Close examination of several national guidelines on stroke rehabilitation (i.e. UK, USA, Scotland, Canada; 9–12) showed that – despite the known high levels of burden among close family members – clinical guidelines are primarily focused on the patients. The main topics of these guidelines concern information provision, supporting the carer through education, family workers or counselling, active involvement of family members, and sexuality. These guidelines are, however, formulated rather vaguely and are not binding; they therefore appear less useful in daily clinical practice. In addition, available evidence from the literature has only to a limited degree been

processed in these guidelines. In our opinion, therefore, the need for new evidence-based clinical practice guidelines focusing on carers of stroke patients is high. We have recently developed such guidelines, which are integrated in the Dutch national guidelines on stroke rehabilitation (National Heart Foundation, 13). In this paper we present the development and the content of these Dutch clinical practice guidelines (14). Specific attention is additionally given to the literature and corresponding guidelines concerning predictors of burden (identification of carers at risk of high perceived burden at an early stage), assessment of burden, and potentially successful interventions to decrease burden. We believe these guidelines are also relevant for other countries as, since the evidence was gathered through systematic searches of the international literature and none of the guidelines that we were able to find already included this evidence.

## METHODS

Carer related topics were identified by interviewing Dutch researchers in the field of carers of stroke patients, and by a panel of experts. The members of the expert panel that was formed to formulate the guidelines were representatives of patient organizations and a multidisciplinary panel of clinical experts (general practitioner, nursing home physician, rehabilitation physician, social workers, nurses, etc.). The expert-clinicians were all representatives of national professional organizations. A literature search in Medline from 1966 to March 2003, PsychINFO (1984 – March 2003), AMED (1985 – March 2003) and CINAHL (1982 – March 2003) was carried out. For the search, the keywords “stroke AND caregiver(s)” and “stroke AND carer(s)” were used. Articles written in English were selected. Clinical practice guidelines were formulated on the basis of this systematic literature searches and expert opinion in case evidence was lacking. The research results were ordered according to the following levels of evidence. Level 1 (strong evidence) supported by at least 2 independent studies, such as meta-analyses or high-quality randomized controlled trials (RCTs). Level 2 (moderate evidence) supported by at least 2 independent studies, such as RCTs or other studies comparing groups of patients. Level 3 (limited evidence) supported by research other than level 1 or 2 (i.e. cohort studies, descriptive studies, control groups unknown, no blinded outcome assessment). And level 4 (consensus), supported by expert opinion.

A Delphi procedure was conducted consisting of 2 meetings and a final round by post. During the meetings, the evidence from the literature was presented and ordered into relevant topics. The experts decided upon the choices and descriptions of the topics, and added topics that were relevant even without or with only little supporting evidence (such as interventions for young children of stroke patients, and sexuality and intimacy). On the basis of the existing evidence, guidelines were formulated by the authors and approved by the majority of the experts (i.e. 75% of the participants agreed), while the guidelines on the basis of expert opinion were formulated during the expert

meetings. Again, acceptance of such a guideline was done via a process of approval by the majority of the group. The final version of the document was commented on by post, because it was expected that only textual changes would be necessary at that stage.

## RESULTS

### *Clinical practice guidelines*

The final version of the guidelines contains 13 topics, which are listed in Table I. In total 29 guidelines and recommendations were defined, of which 18 were evidence-based (level 1 through 3). In Appendix 1 all guidelines are presented. (Supporting evidence is available through the first author.)

In the present paper the guidelines on carer burden are illustrated shortly as an example of the underlying evidence from the literature and its translation into clinical practice guidelines. These topics are the identification of carers at risk of burden, the assessment of burden with standardized instruments, and interventions for carers aimed at reducing burden or improving quality of life of family members of stroke patients. In addition to the literature search on the keywords “stroke AND caregiver(s)” and “stroke AND carer(s)”, we searched for “burden assessment”, “intervention study” for carers of stroke patients, or for stroke patients and their carers, if the intervention for the carers was described and for “prediction”.

*1. Carers at risk.* Carers at risk for high burden in the long term can be identified in an early stage on the basis of characteristics of the carers and of the patients. Studies investigating factors predicting such a high burden are however scarce. In cross-sectional studies 5 categories of variables have been identified that influence carer functioning: stroke patient characteristics (such as physical and cognitive impairments, disability or behavioural problems) (15, 16), carers demographic characteristics (15, 16), psychological variables (such as coping style, sense of coherence) (17, 18), (dys)harmony in the family

Table I. Topics of the Dutch guidelines on carers of stroke patients and number of guidelines per level of evidence. (No values are given for level 1)

Topic	Level 2	Level 3	Level 4
Partners at risk of burden		1	
Assessing burden	1		1
Interventions	1		2
Information provision and education	1	2	1
Differences in complaints between patients and carers		1	
Depression		1	
Primary care		1	1
Rehabilitation services		3	1
Long-term consequences		1	
Fellow sufferers		2	1
Young children		2	1
Sexuality and intimacy		1	2
Societal involvement			1
Total	3	15	11

(18), and social support (15, 16). Prospective studies are needed to examine factors that might predict high carer burden at an early stage. Apart from our own, recently finished study (19), in which we identified passive coping style of the carer as the most important predictor of carer burden, we found only 3 studies investigating the prediction of burden (20–22). Blake et al. (20) predicted carer burden 6 months after stroke, based on measurements conducted 3 months after stroke. Mood, patient functional abilities and negative affectivity of the carer were predictors of carers' burden. Schulz et al. (21) predicted burden at 6 months by assessing determinants at the start of rehabilitation. Besides aspects related to the stroke (severity), carer depression was the most important predictor. Disharmony in the relation, age, income and health problems played only a minor role. The study of Thommessen et al. (22) investigated only patients' characteristics and carers' demographic variables as determinants. In this study impaired cognitive function was the only baseline patient characteristic that predicted a subsequent psychosocial burden on the carer. These few studies show that patients' disability and carers' psychological factors may be useful variables to predict carers' quality of life 1 year after stroke.

In conclusion, burden in carers of stroke patients can be predicted on the basis of characteristics of the patients, in particular the presence of cognitive impairments, but also on the basis of characteristics of the carers themselves, in particular psychological factors related to mood and depression.

2. *Assessment of carer burden.* There are several reasons why measuring carer strain or burden is important:

- to identify carers who perceive high levels of burden and who may be at risk for burn-out or physical problems;
- to evaluate (professional) support;
- to evaluate new rehabilitation interventions such as therapy at home and a shorter length of stay;
- to examine which aspects of caring lead to burden.

The concept of strain or burden of caring is broad and in the literature many instruments measuring the level of burden are found: our review revealed 16 different measures of carer burden which were used more than once in a stroke population (23). Nearly all instruments measure various dimensions of burden (competency, negative feelings, social relations, participation problems, physical and mental health and economic aspects). Most instruments were found to be reliable and valid, but lacked sufficient evidence for responsiveness. Comparison of instruments is done in only 3 studies (24–26). The Caregiver Strain Index (CSI) appears to be a useful and valid instrument, easy and quick to use and a cut-off point for experiencing high carer burden is available. In addition, the Caregiver Strain Index (CSI) is preferable in terms of feasibility and convergent validity (26).

3. *Interventions for carers.* A number of studies have been published recently in the stroke literature in which the effect of various interventions for carers or for patients and carers has

been evaluated. A total of 22 studies were discussed in our critical review (27). Most studies had an experimental design. The moment of inclusion into the study varied from immediately after the stroke to a few years later. Four types of interventions for carers of stroke patients were found to meet the inclusion criteria for intervention studies, differing in terms of focus, content and timing. Types of interventions were providing specialist services, (psycho)education, counselling and social support by peers.

Of these 22 studies, 10 reported positive results, such as reduction in burden and depression, improvement of knowledge, satisfaction with care, family functioning, quality of life, better problem solving skills, more social activities and social support. There was a correlation between type of intervention and level of success. Twelve studies investigated the provision of services aiming at facilitating and improving discharge; only 4 of these studies found significant improvements for the carer. A positive result was reported in 4 of the 6 studies on (psycho)education; however, in only 3 studies did the carer gain knowledge about stroke. In 3 of the 4 counselling studies a positive effect was shown. The only study on peer support found no significant difference in burden or emotional state in comparison with a control group. It was concluded that counselling gave the highest chance of positive results.

## DISCUSSION

In this paper evidence-based clinical practice guidelines for supporting carers of stroke patients are presented. These guidelines were formulated in response to an expressed need to improve professional support for carers of patients. As Langhorne et al. (28) stated in 2002 "stroke rehabilitation needs to establish and apply a solid evidence-base". In recent years the literature concerning carers of stroke patients has increased considerably, enabling us to formulate guidelines that are more specific and more evidence-based than existing guidelines from other countries that we were able to retrieve. New, or more detailed topics in the Dutch guidelines concern interventions for carers, differences between patients and carers in terms of complaints, primary care, long-term consequences, fellow sufferers, young children and societal involvement.

Evidence is available on many different topics concerning carers (Table I). This evidence is mostly provided by correlational and descriptive studies (level 3) and expert opinion (level 4). The shift from level 4 to level 3 evidence is a positive sign. RCTs are, however, not yet executed on a large scale and therefore level 1 and 2 evidence is mostly lacking. Good quality RCTs are needed further to improve the evidence regarding professional support of carers of stroke patients.

In the Netherlands these new guidelines were adopted by the National Heart Foundation and have been integrated into the already existing national guidelines on rehabilitation after stroke. After publication, the guidelines were offered to many relevant healthcare organizations and were made available freely on the Internet ([www.hartstichting.nl](http://www.hartstichting.nl)). In addition, national

journals for healthcare professionals announced the edition (i.e. general practitioners, nursing home physicians, rehabilitation physicians, social workers and nurses). And finally, national workshops were organized to facilitate implementation into daily clinical practice.

Some limitations of our work should be noted. First, we selected only articles written in English; we acknowledge the fact that there might be relevant studies published in other languages. Secondly, the compilation of topics and decisions about statements were partly the result of a group process, most probably incorporating the preferences of the experts involved. However, we believe a more systematic or transparent process (i.e. using standardized forms for decision-making) was not appropriate at this stage, given the variability of the evidence collected. Much of the valuable information would then have been ignored.

In conclusion, high levels of burden are experienced among carers of stroke patients. The problems and needs of the informal carers should be recognized by healthcare professionals and attention should be given by them accordingly. There is evidence about successful interventions for carers of stroke patients suggesting that counselling seems to be the most effective in improving well-being of carers. Carers at risk of burden can be identified early in the process of rehabilitation on the basis of patient and carers' factors. The level of burden perceived by the carer can be assessed in a reliable and valid manner, for example using the Caregiver Strain Index, which is recommended for use in clinical practice.

We propose an integration of the guidelines presented in this paper into already existing guidelines on stroke management and rehabilitation. As healthcare professionals we surely need healthy carers to share the care of the patients with us.

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## APPENDIX 1: CLINICAL PRACTICE GUIDELINES

### 1.1. Partners at risk

Psychosocial burden in the long term can be predicted early in the rehabilitation process. Carers at risk of burden in the long term should be detected as early as possible and supported accordingly. At the start of the rehabilitation, carers at risk of high perceived burden are those with a depressed mood, a

passive coping style and living with a stroke patient with severe physical and/or cognitive impairments (level 3).

### 1.2. Assessment of carer burden

1. A consultation should always be offered to patient and carer after discharge home. During this contact, carer strain should be measured with a standardized instrument. The instrument can be sent to the carer beforehand (level 4).
2. Carer strain can be measured adequately with a burden scale. The Caregiver Strain Index (CSI) is most often used and preferable in terms of time and effort. In addition, the CSI has a cut-off point (level 2).

### 1.3. Interventions for carers

1. Counselling, aimed at active problem-solving behaviour and support seeking behaviour of the carer, has a positive effect on the mood and emotional well-being of the carer and on his or her capacity to maintain social support (level 2). This effect can be found in all phases after stroke.
2. Carers with high levels of burden (on the basis of a standardized measure) or with a higher risk of developing burden (on the basis of predictors) should receive adequate professional care, such as counselling, or partner support groups (level 4).
3. After discharge there should be contact with the carer at predetermined moments, such as 1, 4, 6 and 12 months post-discharge. During these contacts the problems and needs of the carer should be discussed. Professionals should define who will initiate this contact (level 4).

### 1.4. Information provision and education

1. Carers of stroke patients should be given information about the stroke in combination with individual education. In this way carers gain more knowledge about the nature of the disease and the related problems (level 2).
2. Several years after the stroke carers may still have questions, which can change during the process from information on the stroke itself to information on cognitive and behavioural consequences. Information should be unequivocal, should be repeated more than once, and should be tuned to the demands of the individual carers (level 3).
3. Current written information materials on stroke and its consequences are being read and rated positively by the carers. These materials should therefore be distributed or recommended in all phases after the stroke; websites can also be recommended as sources of information (level 3).
4. During the rehabilitation and chronic phase, information should be given about expected changes, such as financial changes and changes in family roles (level 4).

### 1.5. Differences in complaints between patients and carers

Patients and carers often do not agree about the consequences of the stroke when asked separately. This concerns mainly the less visible consequences, such as cognitive or emotional and behavioural problems. Healthcare professionals should be alert

to these differences, especially during the chronic phase after stroke, because these differences can lead to family problems. When professionals are asked to intervene, it is important to assess the complaints of the patients and their carers separately (level 3).

### 1.6. Depression

Carers of stroke patients can become depressed and healthcare professionals should be alert to these problems during rehabilitation but also in the long term. Depression of carers is related to the degree of disabilities of the patient and the burden of the carer. Severe depression should be treated with education or information provision about the symptoms, time course and self management techniques, medication and support by the general practitioner (level 3).

### 1.7. Primary care

1. Professionals in primary care should keep in contact with the carers in all phases after stroke, because there is evidence that carers have specific needs (level 3).
2. Professionals should be alert to increase in burden in the chronic phase after stroke because the support from the environment can decrease and the health status of both patient and carer can decrease as well (level 4).

### 1.8. Involvement of carers in the rehabilitation process

1. Carers should be involved actively in the rehabilitation process because there is evidence that through active involvement satisfaction with care will increase. Active involvement can be realized by carers attending therapy sessions or organizing carer support groups (level 3).
2. When stroke patients visit their own home at the weekends, these visits should be evaluated with both the patient and the carer; the carer may have questions or problems of his or her own (level 4).
3. During inpatient rehabilitation, a carer support group should be organized (level 3).
4. During inpatient rehabilitation, the multidisciplinary team should discuss which team members will support the family of the patient with stroke (level 3).

### 1.9. Long-term consequences

Even after 1 year post-stroke, carer strain should be reassessed regularly, because the strength and the supporting power of the carer can diminish, despite a stable status of the patient. Cognitive consequences can become more pronounced in daily life in the long term, which increases burden. In addition, disappointment about lack of recovery and lasting disabilities can influence the level of burden (level 3).

### 1.10. Fellow sufferers

1. Carers in need of extra support should be recommended to join carer support groups of fellow sufferers because there is

evidence that these carers are more satisfied and experience higher feelings of support (level 3).

2. Professionals of the multidisciplinary team should actively invite carers to join carer support groups, because carers then appear to be motivated more strongly to join (level 3).
3. Patients and their families should be informed about the existence and activities of patient organizations (level 4).

#### *1.11. Young children of stroke patients*

1. The development of young children can be influenced negatively by the possible changes in the family situation after stroke. Children should therefore be supported actively in order to live with the lasting consequences of the stroke of the parent (level 3).
2. Supporting children of stroke patients should be elaborated in a protocol and should be offered with the consent of the parents. In the protocol should be written who, when and how support to the children will be offered (level 4).
3. Both the patient and the healthy parent should be supported in the changes within the family and the role as parent. This should be a regular theme in the support of the

individual carer and can be a topic of the carer support group (level 3).

#### *1.12. Sexuality and intimacy*

1. Patients and spouses are often not satisfied with their sexual functioning after stroke; sexuality and intimacy should therefore be discussed with (married) couples (level 3).
2. Changes in sexual functioning should be discussed with patients and spouses at different moments during the rehabilitation process, such as at discharge and at follow up. Professional support should be offered when necessary. The multidisciplinary team should discuss explicitly which members of the team will support the (married) couple (level 4).
3. Sexuality and intimacy should be discussed during carer support groups. Information should be given about the nature and causes of these changes (level 4).

#### *1.13. Societal involvement*

Respite care should be offered to relieve the carer and to create opportunities for societal involvement of the carer (level 4).