Supportive care needs of caregivers of individuals following stroke: A synopsis of research

By Laura MacIsaac, Margaret B. Harrison and Christina Godfrey

Abstract
Approximately 75% of stroke survivors are discharged from hospital to the community with varying degrees of residual neurological deficits (Heart & Stroke Foundation of Ontario, 2003). As a part of a masters’ thesis, a systematic review was conducted to synthesize the research related to the identification of family needs during the acute phase of stroke in order to facilitate successful transition into the role of caregiver. Relevant articles were identified using: CINAHL, MEDLINE, All EBM Reviews, Psych Info, Embase, and AARP Ageline (1978 to December 2007). A Supportive Care Needs Framework (SCNF) (Fitch, 1994; 2008) was used to collect and analyze data. The utility of this framework was evaluated in capturing the spectrum of needs of the family caregivers of patients with stroke. Ten qualitative studies and seven quantitative studies were identified and analyzed by the author. The studies were equivocal in their reports of needs not being identified and addressed during hospitalization. The SCNF provided a comprehensive means of organizing the broad spectrum of needs of this population reported in the literature. No new domains were uncovered in the review.

A review of the supportive care needs of caregivers of individuals following stroke
Stroke is the third leading cause of death in Canada (Heart & Stroke Foundation of Ontario, 2003) and one of the leading causes of disability. The sudden presentation of stroke thrusts family members abruptly into the unexpected role of caregiver with limited time to prepare (Exall, 1999). Typically after hospitalization many individuals return to the community with spouses most frequently assuming the role of primary caregiver (Mackenzie, Perry, Lockhart, Cottee, Cloud, et al., 2007; Grant, Elliott, Weaver, Glandon, Raper, et al., 2006). Inadequate preparation of these caregivers places not only them at risk of physical and mental health issues, but, ultimately, the person with stroke (Ski & O’Connell, 2007; Grant, Bartolucci, Elliott, & Giger, 2000). In order to improve preparation for this caregiving role, health care providers will need to focus on the family needs beginning in the acute hospitalization period. In this way, plans for self-reported needs could be integrated into the plan of care and addressed before transition from acute care. There is evidence of dissatisfaction with information, support and preparation for the skills required to successfully transition into this new role amongst family members during this acute phase (Garrett & Cowdell, 2005; O’Connell, Baker, & Prosser, 2003). The literature suggests that the current standard of care in providing caregiver information prior to discharge does not address the wide spectrum of supportive care needs.

Assessment of the full constellation of supportive care needs is becoming a pressing and unmet aspect of current practice. The prevailing approach has been a didactic style of information provision to family and other lay care providers to assist in the transition to this role. In a recent systematic literature review (MacIsaac, Godfrey, & Harrison, 2006) guided by the Joanna Briggs methodology (Joanna Briggs Institute, 2008), we examined the results of studies evaluating the effectiveness of information and psychosocial support interventions for informal caregivers of stroke patients. Four random controlled trials (Kalra, Evans, & Perez, 2004; Smith, Forster, & Young, 2004; Mant, Carter, Wade, & Winner, 2000; Rodgers, Atkinson, & Bond, 1999) studied the effects of information not only on caregiver knowledge, but also on caregivers’ emotional health and quality of life. The findings were equivocal in terms of the effect of these interventions in all but the Kalra et al. trial (2004), with no clear indications for practice. In scrutinizing these studies it became evident that issues identified by caregivers with stroke typically involves a multitude of individual, as well as

Le besoin de soins de soutien des aidants d’individus qui ont eu un accident vasculaire cérébral: un sommaire de la recherche

Résumé
overlapping needs, e.g., securing transportation in order to attend informational sessions and having a friend or family member accompany for psychosocial support. It appears studies to date have largely focused on specific needs, e.g., information and emotional support, rather than the full spectrum and/or combination of needs. This lack of comprehensive assessment is compounded by the lack of a supportive care framework to guide practitioners in this complex dimension of stroke care.

In looking to other complex populations for innovations with assessment for supportive care needs, a framework designed for the cancer population appears to have potential for those dealing with stroke. The Supportive Care Needs Framework (SCNF) (Fitch, 1994; 2008) has been widely used in oncology, spanning the continuum of care from screening and diagnosis through to palliation (see Figure 1). Locally, it was used in a study identifying the needs of the parent caregivers of children with cancer (Kerr, Harrison, Medves, & Tranmer, 2004). There are parallels between stroke and oncology groups as complex medical populations, such as the high need for family and other lay caregiver involvement in care, the complex trajectory from diagnosis and treatment to discharge or palliation, as well as wide-ranging combinations and types of need.

In the SCNF (Fitch, 1994; 2008), six domains of needs are seen to be influenced by factors such as age, gender, education, religion, place of residence, family, social support, and personality. The domains of needs include informational, emotional, psychosocial, physical, practical and spiritual needs that patients and their families experience, as they move through the cancer continuum. Another important aspect of the model is the recognition of transitions through phases of care from screening/diagnosis to palliation. Informal caregivers of patients with stroke experience changing needs, as the patient progresses across the continuum. Four spectrums (pre-diagnosis, diagnosis, referral, and treatment) occur during the acute phase of stroke. Rehabilitation and survivorship follow during the sub-acute period. The final three spectrums include recurrent disease, palliation and bereavement, which may also apply to the stroke population.

Our aim with this systematic review was to assess the evidence on the spectrum of supportive care needs of informal caregivers of patients following stroke in order to evaluate the SCNF for use with caregivers during the acute phase of stroke care. As a first step it is important in assessing the appropriateness and evaluating the “fit” of the SCNF with the stroke population, as a guiding framework for comprehensive assessment. To evaluate this empirically, a systematic review of stroke research studies where supportive care needs were reported was undertaken to address the following objectives:

1. Describe the SCNF categories of need that have been reported in the stroke research literature.
2. Determine the spectrum of needs during the acute phase from admission to hospital with the diagnosis of stroke until discharge to home, rehabilitation or long-term care.
3. Evaluate the SCNF as a means of describing and categorizing the specific needs in the six domains and if modifications are required for use with the stroke population, e.g., additional domains uncovered in the stroke literature.

Review methods to assess the evidence related to supportive care needs search retrieval and appraisal procedures

In consultation with a Queen’s University library scientist, research reports were located with a focus on the supportive care needs of informal caregivers of patients with acute stroke. A wide range of studies were sought including randomized controlled trials, non-random controlled, pre- and post-trials or qualitative studies. Using a multi-step approach, the search strategy and retrieval process was designed to locate the relevant papers in an iterative fashion. Initial search terms included: cerebrovascular accident, caregiver support, caregiver needs, information, depression, and psychosocial. A second search of the same databases was conducted adding the key terms: cerebrovascular accident, caregiver assessment and needs assessment. Three articles were retrieved and excluded after reading the abstract, as none were stroke-related. Finally, a manual search of the reference lists of relevant articles was conducted. No new studies were identified. The databases searched included: CINAHL (January 1996 to December 2007), MEDLINE (1996 to December Week 4, 2007), All EBM Reviews, Psych Info (1967 to December Week 4, 2007), Embase (1996 to 2007, Week 50), and AARP Ageline (1978 to December 2007).

Limitations were: restriction to articles in English, publications after 1996 when the philosophy of stroke management changed. By 1996, with the introduction of thrombolytics in treating ischemic stroke (Brown, 2001), a transformation from symptom management to active and emergent treatment occurred that would have influenced informational and supportive interventions offered to family caregivers.

An initial on-line review of the articles, title and abstract if available, was conducted to assess eligibility based on two broad inclusion criteria: 1) focus on informal caregivers of patients with an acute stroke, who would be providing care upon the patients’ discharge from hospital, and 2) data available about the identified unmet supportive care needs of the caregivers early in the caregiving experience. Initially, studies involving only the acute hospitalization period were sought. However, few of the studies retrieved focused on this phase of the care trajectory, so studies conducted in the first two years post-stroke that reported caregiver needs...
experienced in the acute phase were included. These included studies conducted during the rehabilitation phase and after discharge home. We also examined studies reporting adverse caregiver outcomes resulting from specific unmet needs.

The quality of the studies was assessed using checklists for experimental and observational studies developed by the Joanna Briggs Institute (Appendix A). Studies not clearly articulating the timing of the data collection post-stroke and those with methodological problems including performance and attrition bias were eliminated. Data extraction from the articles meeting the inclusion criteria was completed using a standard structured abstract form (Harrison, 1998). The extraction tables provided information relating to the authors, journal, study characteristics (study design, setting, sample, study focus and measurements), findings, methodological considerations, and implications for the current review. Information from the data extraction tables was then used to develop a table for synthesis of data.

### General results

Twenty-one published papers reporting on 17 unique studies met the inclusion criteria and were included in the final set for the caregiver needs analyses (Appendix B). Main reasons for exclusion were: the papers were not primary studies; the study focused on the patient rather than the caregiver; did not address caregiver needs during the acute hospitalization period; or had methodological flaws.

The majority of studies included both qualitative studies \((n = 10)\), phenomenological, grounded theory and exploratory and quantitative \((n = 7)\) including descriptive or mixed methods designs. Within the 17 studies, sample sizes ranged between seven and 90 participants in the qualitative grouping, and 30 to 232 participants in the quantitative ones.

### Category of needs

All caregiver needs identified in the 17 studies were catalogued and then categorized according to the six general domains of the SCNF. There was evidence of a wide range of reported needs and

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<tr>
<th>Stroke Caregiver Research</th>
<th>Domains of Supportive Care Needs Framework</th>
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<tbody>
<tr>
<td></td>
<td>Informational</td>
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<tr>
<td>Bakas, Austin, Okonkwo, Lewis, &amp; Chadwick (2002)</td>
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<td>Brazil, Roberts, Jode, &amp; VanderBent (2000)</td>
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<td>Chow, Wong, &amp; Poon (2007)</td>
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<td>Coombs (2007)</td>
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<td>Garrett &amp; Cowdell (2005)</td>
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<td>Grant, Elliott, Weaver, Glandon, Raper et al. (2006); Grant, Weaver, Elliott, Bartolucci, &amp; Giger (2004); Grant, Bartolucci, Elliott, &amp; Giger (2000)</td>
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<td>Grant, Elliott, Giger, &amp; Bartolucci (2001)</td>
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<td>King &amp; Semik (2006)</td>
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<td>King, Carlson, Shade-Zeldow, Bares, Roth, et al. (2001)</td>
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<td>Mackenzie, Perry, Lockhart, Cottee, Cloud, &amp; Mann (2007)</td>
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<td>Mak, Mackenzie, &amp; Lui (2007)</td>
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<td>Ski &amp; O’Connell (2007)</td>
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<td>Smith, Lawrence, Kerr, Langborne, &amp; Lees (2004)</td>
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<td>Wiles, Pain, Buckland, &amp; McLellan (1998)</td>
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examples within each domain reported from research with the stroke populations (see Table 1). Informational and psychosocial needs were most frequently reported (n = 15 studies), with emotional needs the third most common (n = 12 studies). Physical, practical and spiritual domains were documented, but less frequently. Each domain was explored for the types of need identified. It should be noted that we report the frequency of needs based on the number of research studies where a particular need within a domain is found. This is not necessarily an indication of how important the need is to caregivers.

**Information**

Need for information is frequently reported by new caregivers of patients afflicted with a stroke (n = 15 studies). Caregivers report dissatisfaction with the amount, quality and delivery of information (Mackenzie et al., 2007; Garrett & Cowdell, 2005; Smith, Lawrence, Kerr, Langhorne, & Lees, 2004; O’Connell, Baker et al., 2003). Written materials, when provided, were comprehensive (Mackenzie et al., 2007), but did not provide caregivers’ information specific to their family member (Mak, Mackenzie, & Lui, 2007; King & Semik, 2006; Smith, Lawrence, Kerr, Langhorne, & Lees, 2004; O’Connell et al., 2003; Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; Brazil, Roberts, Jode, & Vanderbent, 2000; Wiles, 1998).

Unfamiliar with stroke and the resulting deficits, caregivers reported not knowing what information was required to assist in providing care, resulting in an inability or reluctance to ask questions (O’Connell et al., 2003). Frustration was reported with the lack of availability of professional staff to provide information that was required to care for the person with stroke (Mackenzie et al., 2007; Smith et al., 2004). This led caregivers to seek other sources including books, but these sources did not address all their needs (O’Connell et al., 2003; Brereton et al., 2000). It is well documented that new caregivers seek and require written and verbal information from hospital staff in order to transition into the caregiving role (Mackenzie et al., 2007; Grant, Elliott, Weaver, Glandon, Raper, et al., 2006; Garrett & Cowdell, 2005; Grant, Weaver, Elliott, Bartolucci, & Giger, 2004; O’Connell et al., 2003; Grant, Bartolucci, Elliott, & Giger, 2000; Wiles, Pain, Buckland, & McLeLellan, 1998). These authors found that caregivers were unable to retain all verbal information when provided, and written resources provided them with the opportunity to revisit the information at a later time.

Important aspects of what information caregivers were seeking and trying to use was revealed in numerous studies. In an attempt to understand what was occurring, family members sought clinical information regarding etiology, diagnosis and prognosis in the immediate post-stroke period (O’Connell et al., 2003; Bakas et al., 2002; Brereton & Nolan, 2002). However, information alone was reported as inadequate, particularly when there was a skill component attached to it, e.g. safely transferring a stroke survivor with a paretic limb. Caregivers identified the need to *apply* information they received. Participation in basic care of the patient during hospitalization was cited as vital in developing and solidifying new information and skills (Ski & O’Connell, 2007; Kerr & Smith, 2001; Brereton et al., 2000). Later in the hospitalization period caregivers sought practical information, e.g. accessing equipment and the availability of community resources (Mackenzie et al., 2007; Ski & O’Connell, 2007; King & Semik, 2006; Kerr & Smith, 2001; O’Connell et al., 2003; Brazil et al., 2000; Wiles et al., 1998). This area was reported to be poorly addressed.

**Psychosocial needs**

Fifteen studies reported on the psychosocial needs of the caregivers of individuals experiencing stroke. The abrupt presentation and devastating physical, cognitive and emotional effects of stroke often result in caregiver fear and anxiety (Coombs, 2007; Brereton & Nolan, 2002). Caregivers describe the challenges of coping with an uncertain future (Grant, Elliot, Giger & Bartolucci, 2001) including the post-discharge care needs of the patient (Ski & O’Connell, 2007). This sense of uncertainty was prolonged when information was not provided (O’Connell et al., 2003). With uncertainty and lack of information, it is not surprising that caregivers report low levels of confidence in their new role and ability to provide care (King & Semik, 2006). Constructive feedback from health care professionals was reported as a means of acknowledging caregivers and increasing their sense of competence (Brereton & Nolan, 2002). These caregivers also reported that their knowledge of the patients’ pre-morbid functional status, preferences and personality traits was dismissed or just not used in planning care. Failure to include family in planning care also extended to the discharge process where family members report not being included in discharge planning meetings and team discussions (Brereton et al., 2002; Brazil, 2000).

Caregivers report a feeling of loss after a family member suffers a stroke (Coombs, 2007; Mackenzie et al., 2007; Bakas et al., 2002). A cumulative effect of perceived losses including the loss of a marital partner and changes in the relationship resulted in an overwhelming profound sense of loss by caregivers (Coombs, 2007). Often, the spouse with stroke was no longer able to provide emotional and physical support for the caregiver. Some caregivers reported feeling alone and challenged in making decisions by themselves (King et al., 2001). There was an expressed need to share their experiences with others (Mak et al., 2007). The availability of social support was related to greater life satisfaction (Grant et al., 2001). The lack of quality social support was reported as having a significant correlation in caregiver depression (Grant et al., 2006; Grant et al., 2004; King et al., 2001, Grant et al., 2000).

**Emotional needs**

Emotional needs were the second most frequently reported domain of need (n = 12). The stroke recovery period is often lengthy and the full degree of recovery may be unknown for quite some time. Caregivers reported that these “unknowns” caused high levels of stress and anxiety (Chow, Wong, & Poon, 2007; Smith et al., 2004; O’Connell et al., 2003; Kerr & Smith, 2001; Brereton et al., 2000). In one study, health care professionals who had a family member suffer a stroke reported their knowledge and experience in the field did not aid in coping with the anxiety caused by uncertainty (Brereton et al., 2000). It has been identified that caregivers need help to deal with the emotions brought on by the experience of the stroke (Chow et al., 2007) and in managing stress (King & Semik, 2006). A prolonged increase in stress can lead to depression (Grant et al., 2004).
Depression is a frequently reported outcome amongst the informal caregivers with rates cited between 20% and 40% (Ski & O’Connell, 2007; Grant, Weaver, Elliott, Bartolucci, & Giger, 2004; Grant, Bartolucci, Elliott, & Giger, 2000). There is emerging evidence detailing the supportive care needs of caregivers of patients with stroke. During the acute hospitalization period, an emerging issue is the vital importance of early identification and intervention of needs. Becoming a caregiver for an individual with stroke is a complex process (Brereton et al., 2000) with an array of multifaceted needs (Coombs, 2007; McCullagh et al., 2005; O’Connell et al., 2003; Brazil et al., 2000). Needs change as the patient transitions across the continuum of care (King & Semik, 2006; Garrett & Cowdell, 2005). The domains of needs are interconnected, affecting and being affected by each other with unmet needs in one domain having a ripple effect on the others. For example, caregivers report the constant worry and anxiety with lack of information and receiving progress reports from health care members (Mackenzie, 2007). This worry and anxiety, in turn, affects the caregivers’ physical and emotional health.
Numerous studies highlight the wide array of needs of these caregivers, yet there is little research addressing the spectrum of needs. A pressing practical issue is development of a reliable, valid and standardized means of identifying the spectrum of needs during the diagnosis through treatment phase of stroke care. Mackenzie et al. (2007) postulate that a structured assessment of caregivers’ needs is required to prioritize care and include caregivers in the decision-making process. Coombs (2007) also acknowledges the importance of assessment and proposes the development of a multidimensional assessment to ensure caregiver inclusion in the plan of care. The SCNF may provide guidance in future development of an assessment tool. Given the evidence about needs and the wide range of needs in each domain, it is vital for those of us working in stroke care to identify and address multiple needs. Only in this way will we be able to institute and tailor supportive interventions.

**Limitations**

This systematic literature review was conducted as a requirement of a master’s thesis. Studies were reviewed by only one reviewer. The review formed the groundwork and focus for the study. Ethics approval was not sought for the systematic review, but was a requirement of the study that followed. No funding was received for this review.

**Significance to nursing**

During transition from diagnosis to treatment with stroke, and from critical to unit-based acute care, nurses are an essential link. As the population ages, the number and age of stroke caregivers is expected to rise exponentially. Spouses, also aging with personal co-morbidities, most frequently assume the role of primary caregiver (Grant, Elliott, Weaver, Glandon, Raper, et al., 2006). In the fast-paced environment of acute care, the needs of family caregivers are often overlooked. Family caregivers play an integral role on the health care team, particularly in discharge planning. Successful transition of the patient and the family back to the community requires early identification of the wide spectrum of caregiver needs. The SCNF provides an overall guiding framework to organizing assessment data of caregiver needs.

The Ontario Local Health Integration Networks (LHINS) are committed to keeping individuals in their homes as long as possible. This is evident by the number of Aging at Home Projects funded by these networks. The evidence is clear that unprepared caregivers risk adverse physical and mental health problems when the patient returns to the home (Ski & O’Connell, 2007; Berg, Psych, Palomaki, Lonqvist, Lehtihalmes, et al., 2005; Choi-Kwon, Kim, Kwon & Kim, 2005; Grant, Bartolucci, Elliott & Giger, 2000) increasing the potential of the stroke survivor requiring institutional care. An understanding of the full spectrum of needs would aid in the development of a business case for increased funding.

The needs identified in this review reinforce the critical role of inter-professional collaboration in the care of the patient with stroke and the family caregiver. The preponderance of time spent by the nurse at the bedside places him or her in the unique position of identifying needs earlier than other team members. Meeting these needs, however, entails a team approach. The most frequently identified needs in the literature were those involving information, psychosocial support and emotional support. Consulting with social workers, therapists and physicians in developing a plan of care is essential in ensuring these needs are met.

As patients transition from diagnosis in the emergency department to treatment and discharge to rehabilitation or the community, the needs of the family members change. Bedside nurses with a holistic approach to assessment and care can consult with and refer family caregivers to team members with expertise in the caregivers’ changing needs. As coordinators of care, nurses identify the needs, mobilize the team and evaluate outcomes of interventions across the continuum. The six broad domains of the SCNF provide guidance in the continuing assessment and evaluation of interventions in meeting specific caregiver needs across the trajectory.

**Implications for future research**

It is recommended that a needs assessment survey be developed using a framework such as the SCNF (Fitch, 1994; 2008) to capture the needs of this population of caregivers. This survey would assist nurses to assess and identify the caregiver’s full spectrum of needs and aid in the development of a plan of care to address these. It would also inform health service decision-makers in planning programs to meet the identified supportive care needs of this group.

**Conclusion**

This review provides a synopsis of the broad spectrum of supportive care needs of the informal caregivers during the acute phase of stroke. Using the SCNF, all the needs reported in the literature were captured with no new domains uncovered. The utility of this framework in early identification of supportive care needs of this population will be evaluated in the phase two of this study.

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References


Appendix A. Critical Appraisals

Critical Appraisal for Experimental Studies

Reviewer _____________________________________________________ Date ____________________
Author _______________________________________________________ Year _____________________

Overall appraisal: Include _______ Exclude ______ Seek further info _______

Comments (including reasons for exclusion): ________________________________________________________________________________

Critical Appraisal for Observational Studies

Reviewer _____________________________________________________ Date ____________________
Author _______________________________________________________ Year _____________________

Overall appraisal: Include ______ Exclude ______ Seek further info ______

Comments (including reasons for exclusion): _______________________________________

1 Joanne Briggs Institute, Reviewers' Manual 2008 edition


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<tr>
<th>Cinahl (107)</th>
<th>Medline (98)</th>
<th>Psychinfo (31)</th>
<th>AARP (44)</th>
<th>EBM Reviews (6)</th>
<th>Embase (10)</th>
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Potential articles identified and screened for retrieval (n = 296)

Studies retrieved for more detailed evaluation (n = 86)

Full article retrieved and read to confirm match with inclusion criteria (n = 31)

Final set of studies for analysis (n = 17)

Studies excluded (n = 210)
- Duplicates (n = 135)
- Reviews (n = 15)
- Community or rehab based (n = 56)
- Research ongoing (n = 4)

Studies excluded (n = 55)
- Methodological criteria (n = 5)
- Timing of data collection unclear (n = 6)
- Minimal information on acute phase (n = 37)
- Other (n = 7)

Studies excluded (n = 14)
- Patient focused (n = 6)
- Minimal data on the needs in the acute stroke period (n = 8)