Published in final edited form as:

J Neurosci Nurs. 2008 February ; 40(1): 48–54.

Emotional Support, Physical Help, and Health of Caregivers of Stroke Survivors

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Abstract

Guided by Orem's self-care deficit nursing theory, the purpose of this descriptive comparative study was to examine the emotional support, physical help, and health of caregivers of stroke survivors. Seventy-three caregivers from the Midwest participated in a parent study that examined their experience of caring during the first 12 months after stroke. Caregivers were randomized to an online intervention of support and education ($n = 36$ Web users) or a control group ($n = 37$ non-Web users). A secondary analysis of data collected during telephone interviews at baseline, 3, 6, and 12 months after stroke was performed. No significant mean differences were found between Web and non-Web users in the above variables at these points in time. Consequently, the caregivers were merged into one group, and the relationships among the variables at the different points in time were analyzed. Significant, moderately positive relationships were found between emotional support and physical help at baseline, 3, and 12 months. There were also significant, moderately positive relationships between emotional support and caregiver health at 6 and 12 months. Results highlight the importance of caregivers (*dependent care agents* in Orem's terms) establishing an adequate self-care system that provides emotional support and physical help. Findings also denote the need for nurses (as caring agents) to assess caregiver health later in the caring process and be aware of its relationship to emotional support.

An estimated 750,000 Americans suffer a new or recurrent stroke each year. Currently, there are more than 5 million stroke survivors alive, with as many as 30% of them being permanently disabled as a result of the stroke. It was estimated that Americans would pay \$62.7 billion in 2007 for stroke-related medical costs and disability (American Heart Association, & American Stroke Association, 2007). Most of these stroke survivors are cared for in the home by family members (Dorsey & Vaca, 1998; Singh & Cameron, 2005; Ski & O'Connell, 2005).

Due to the acute nature of the disease, many caregivers of stroke survivors enter the caring role abruptly and have little time to adapt (Kerr & Smith, 2001; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005). Many caregivers feel inadequately prepared to face the emotional and physical challenges of caring for someone with a disability (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; Kerr & Smith), suggesting that the early weeks and months after discharge are an uncertain and vulnerable time for caregivers (Grant, Glandon, Elliot, Giger, & Weaver, 2004). Despite these findings, few studies have specifically addressed the needs and experiences of first-time caregivers of people with stroke during the initial phase of caring (Bakas et al.; Grant et al., 2004; Pierce et al., 2004) and how these needs and experiences change over time.

The purpose of this descriptive, comparative study was to examine the emotional support, physical help, and health of caregivers of stroke survivors during the first 12 months of caring and whether these variables were affected by an online intervention of support and education. The research question was:

- Is there a difference in emotional support, physical help, and health of caregivers of stroke survivors who receive an online intervention versus those who do not at four points in time over the course of 1 year?

This study was guided by Orem's (2001) self-care deficit nursing theory, which is based on the concept of *self-care*, where individuals perform specific learned activities to maintain health and well-being. A self-care deficit occurs if total self-care actions do not meet needs. Nurses have specialized abilities, known as *nursing agency*, to help people with self-care deficits. Orem's theory was chosen for this study because caregivers, as dependent care agents, have a dual role of caring for themselves (self-care agency) and for another person whose self-care demands cannot be independently met (dependent care agency).

Relevant Literature Review

Caregivers and Emotional Support

The need for emotional support is evidenced in the literature. Dorsey and Vaca (1998) stated, "Caregivers, no matter what personality, need support and respite from care to be successful in their efforts" (p. 64). Qualitative studies involving 22 caregivers of stroke survivors by Kerr and Smith (2001) and 14 caregivers by Bakas and colleagues (2002) identified emotional support as a significant caregiver need. Informally provided emotional support is critical because many caregivers of stroke survivors are apprehensive to use formal support because of concerns such as the finances needed, quality of care provided, or time spent away from the care recipient (Winslow, 2003).

Caregivers and Physical Help

Several studies highlight concerns that caregivers of stroke survivors have regarding the physical aspects of care, such as enhancing mobility, preventing falls, and assisting with bathing and toileting (Bakas et al., 2002; Kerr & Smith, 2001). Strain caused by the frequent bending, lifting, and moving required at high levels of care can be especially difficult for older caregivers (Fultner & Raudonis, 2000; McGarry & Arthur, 2001). The majority of emotional support and physical help is provided informally (Dorsey & Vaca, 1998; Singh & Cameron, 2005; Ski & O'Connell, 2005), and caregivers emphasize the importance of friends and family helping with physical aspects of care, such as activities of daily living (Moore, Maiocco, Schmidt, Guo, & Estes, 2002). Dewey and colleagues (2002) reported that 66% of primary caregivers of stroke survivors received some form of physical help from relatives and friends.

Caregivers and Health

Studies show the negative effects caring can have on caregiver health. White, Mayo, Hanley, and Wood-Dauphinee (2003) examined quality of life in 97 stroke caregivers, and Teel, Duncan, and Lai (2001) assessed the health of 83 stroke caregivers during the first 6 months of caring. Results revealed that caregivers reported very little change in their physical health. Despite this stability, they reported physical symptoms, including fatigue, headaches, joint pain, problems falling asleep, depressive symptomatology, recurrent sorrow, scheduling and finance problems, and difficulties with family support (Teel et al.; White et al.). Sit, Wong, Clinton, Li, and Fong (2004) conducted a cross-sectional descriptive study examining the physical health of 102 caregivers. Results showed 83% of participants reported fatigue and stress, with approximately 40% of these respondents reporting somatic symptoms that echoed the findings of White and colleagues. In general, despite increased chronic conditions associated with aging, the majority of elderly people, which includes many caregivers of stroke survivors, still rate their overall health as *good* or *very good* (Denning et al., 1998).

Relationships Among Emotional Support, Physical Help, and Caregiver Health

Although the positive effects of social support, which includes emotional support and physical help, on psychological well-being have been well documented in the literature (Sit et al., 2004; Van den Heuvel, Witte, Sanderman, & Mayboom-de Jong, 2001), the relationship between social support and physical health is not as clear. The assumption behind a possible relationship is based on the buffering effects of social support (Choi & Wodarski, 1996; Grant et al., 2006). Grant and colleagues (2006) found that high levels of social support were associated with higher levels of well-being and general health among 52 caregivers of stroke survivors. Sit and colleagues concluded that without assistance or support, caregivers of stroke survivors were likely to become the “second patient in the family” (p. 822). Other researchers have found that social support had no direct effect on the health of caregivers (Grant, Elliott, Giger, & Bartolucci, 2001; Gräsel, Biehler, Schmidt, & Schupp, 2005; Raina et al., 2004).

Caregivers and Online Support

With the advent of the Internet, healthcare information is available 24 hours a day. Based on a recent Harris Poll, the number of American adults who seek health information online is estimated to be 117 million and has increased from 66% of American adults in 2002 to 74% in 2005 (Harris Interactive, 2005). Millions of stroke survivors and their caregivers are included in this group of “Internet surfers” (Govoni, Pierce, & Steiner, 2003).

Online support groups managed by professionals are gaining credibility by being held to rigorous standards and by demonstrating increased positive outcomes (Larkin, 2000). Research conducted on the use of ComputerLink, a computer-based support system for caregivers of people with Alzheimer disease, has shown its effectiveness in reducing strain in some caregivers (Bass, McClendon, Brennan, & McCarthy, 1998). Relatively little research has been conducted on computer technology and its role in assisting stroke caregivers in the home. In 2002, Pierce, Steiner, and Govoni conducted a 3-month feasibility study with five urban caregivers using an online intervention for education and support. Caregivers reported they were satisfied, in general, with the intervention. They also rated their health as *average to good* and their satisfaction with caring as *moderate to extreme* (Pierce et al., 2002). Computer and online interventions such as this provide the opportunity to receive personalized information through discussion groups and opportunities to ask a nurse specialist specific questions (Steiner & Pierce, 2002).

Methods

This study was a secondary analysis of data from a parent study that examined the experience of caring and the effects of Caring~Web©, an online intervention of education and support for stroke caregivers. The intervention's components include: (1) Ask the Nurse, an e-mail service where caregivers can ask confidential questions and receive answers from a nurse specialist; (2) Caretalk, a support group via e-mail where caregivers can discuss areas of interest with and receive help from other caregivers and the nurse; (3) Tip of the Month, customized information about stroke and caring that caregivers can easily access; and (4) Educational Links, educational information on a variety of topics from reliable, linked Web sites to meet caregivers' needs (Steiner & Pierce, 2002).

Participants

With Institutional Review Board approval, caregivers were recruited for the parent study from rehabilitation centers in northern Ohio and southern Michigan from May 2002 through December 2004. Inclusion criteria were based on the following characteristics:

- first-time stroke for the stroke survivor
- survivor discharged home with a caregiver after initial stroke treatment, although the caregiver did not necessarily have to be present in the home
- caregiver had to be able to read, write, and understand English.

Caregivers who met these criteria and consented to be in the study were randomized to the intervention (Web users) or control (non-Web users) group and were monitored for 1 year.

Measures

Three variables were used in this study: emotional support from family and friends, physical help from family and friends, and caregiver health. The data were collected at baseline, 3, 6, and 12 months during telephone interviews conducted by the same trained research assistant. Answers to questions were entered directly into an online database.

Two interview questions addressed the informal support caregivers received and responses were measured on a 3-point Likert scale: *not at all* (1), *somewhat* (2), or *a lot* (3). The questions were:

- Are you receiving emotional support from family members or friends in caring for your relative?
- Are you receiving physical help from family members or friends in caring for your relative?

These questions have been used in previous pilot work by the first two investigators.

Caregivers were also asked to rate their health on a 5-point Likert scale: *poor* (1), *fair* (2), *good* (3), *very good* (4), or *excellent* (5). This item was obtained from the *Multidimensional Functional Assessment of Older Adults* (Fillenbaum, 1988). Self-ratings of health have been recognized as simple, yet comprehensive measures of global health (Deeg & Kriegsman, 2003). Previous research has documented that self-rated health can serve as a predictor of future health outcomes (Benyamini, Idler, Leventhal, & Leventhal, 2000; Benyamini, Leventhal, & Leventhal, 2003; Deeg & Kriegsman).

Results

Sample

Seventy-three caregivers comprised the sample ($n = 36$ Web users and $n = 37$ non-Web users), which was predominately white (85%); female (75%); and divided among spouses (69%), adult children (19%), and friends (12%). Most caregivers were employed (53%), had completed 13 years of education (range = 7–23 years), and had an average age of 55 years (range = 23–79 years). Complete demographic characteristics are presented in Table 1.

Descriptive Statistics

In the Web user group, missing data for three caregivers of stroke survivors were handled by carrying the last entered value forward. Both the non-Web and Web users rated their emotional support as *somewhat* or *a lot* over the 12-month period (Table 2). The non-Web users' ratings of physical help decreased over time, while the Web users' ratings of physical help remained stable, with the most frequently reported response being *somewhat* (Table 3). Health ratings for both groups were stable throughout all time periods with *good* being the most frequently chosen health rating (Table 4).

Mann-Whitney U Test

A Mann-Whitney U test was conducted to analyze mean differences between the groups. There were no significant differences in emotional support, physical help, or caregiver health at baseline and 12 months, and consequently, other time periods were not analyzed. Due to the nonsignificant results of the Mann-Whitney U test, the groups were combined and relationships among the variables were explored.

Spearman Rho Correlations

When analyzing the sample as one group, Spearman Rho correlations revealed no significant relationships between physical help and caregiver health at any time period. There were, however, significant, moderately positive relationships between emotional support and physical help at baseline, 3, and 12 months ($p < .05$). There were also significant, moderately positive relationships between emotional support and caregiver health at 6 and 12 months ($p < .05$; Table 5).

Discussion

Social support, which includes both emotional support and physical help, often erodes over time for many caregivers of people with chronic conditions (Quittner, Glueckauf, & Jackson, 1990). Conversely, the majority of caregivers in this study reported receiving emotional support at least *somewhat* during the 1-year study. The group participating in the online intervention of education and support did not report higher ratings of emotional support. Contrary to the present study, Dorsey and Vaca (1998) noted that as time passes, social activities and contacts begin to diminish for caregivers of stroke survivors.

Ratings of physical help decreased steadily at each time period from *a lot* to *not at all* for the non-Web users, but remained stable for the Web users; Web users always rated their receipt of physical help as *somewhat*. Similar to the trend in this study, Sit and colleagues (2004) found that caregivers' needs for physical help were not being adequately identified or addressed as early as 12 weeks after discharge. However, Mann-Whitney U tests revealed that there were no significant differences in the amount of emotional support or physical help received by the non-Web and Web users.

The most frequent health rating for both groups of caregivers at all four time periods was *good*. This rating is not an indication of poor or excellent health. The health status of the caregivers prior to entering the study was not examined. It is possible that preexisting illnesses or conditions may have influenced the caregivers' baseline perceptions of their health (Schulz & Beach, 1999). This finding confirms previous research conducted by Pierce and colleagues (2002) on caregivers of stroke survivors; Dening and colleagues (1998) on an elderly cohort; and Beach, Schulz, Yee, and Jackson (2000) on caregivers over a 1-year period, all using the same rating scale as this study. Findings also revealed that caregivers' perceived health remained stable over time, which is supported by White and associates (2003) and Teel and colleagues (2001).

To reiterate, however, Mann-Whitney U results showed no significant differences between caregivers in the non-Web and Web-user groups, and consequently, the two groups were merged into one to conduct correlation analyses. Although caregivers of stroke survivors have concerns regarding the physical aspects of the caregiving experience (Bakas et al., 2002; Kerr & Smith, 2001) and emphasize the importance of receiving physical help from family and friends (Dewey et al., 2002; Moore et al., 2002), correlation analyses did not find a significant relationship between physical help and caregiver health during this 1-year study.

Significant, moderately positive relationships between emotional support and physical help at baseline, 3, and 12 months ($p < .05$) were revealed. Therefore, an assumption can be made that when family and friends provide physical help, they are also providing emotional support to caregivers. Emotional support and physical help may not be completely separate phenomena. Caregivers view physical help and emotional support from family and friends as essential to coping with the challenges of caring for a person with stroke (O'Connell & Baker, 2004). Family and friends have an emotional connection to caregivers and stroke survivors. Family, friends, and caregivers who provide informal support, and especially caregivers, feel a sense of responsibility to care for stroke survivors (Winslow, 2003). When caregivers of stroke survivors receive emotional support from family and friends, it may influence their perception of physical help, forming a connection between the two factors. A similar concept involving perceptions was described by Sit and colleagues (2004) in their examination of the social network size of caregivers.

Significant, moderately positive relationships between emotional support and caregiver health at 6 and 12 months ($p < .05$) were also found. The need for emotional support to cope with the challenges of caring has been well-documented in the literature (Bakas et al., 2002; Dorsey & Vaca, 1998; Kerr & Smith, 2001). These findings agree with those of Grant and colleagues (2006) and Sit and associates (2004), showing a positive association between emotional support and caregiver health. Van den Heuvel and colleagues (2001) reported that caregivers who were satisfied with emotional support among other characteristics experienced less strain, greater mental well-being, and more vitality. The present study validates the assumption that support from an informal network may act as a buffer and protect against poor health outcomes in caregivers (Choi & Wodarski, 1996; Grant et al., 2006). However, testing of this assumption has yet to yield conclusive results (Grant et al., 2001; Gräsel et al., 2005; Raina et al., 2004). The results of this study illuminate the importance of informal social networks to provide emotional support for caregivers of stroke survivors. Finally, the positive relationship between emotional support and caregiver health occurring at later months shows that the caregiving experience is a long-term process, and continuous support is needed throughout this challenging time.

Limitations

All participants were recruited from urban rehabilitation centers in Ohio and Michigan and were mainly Caucasian. This limits the generalizability of the study's findings to those

caregivers whose relatives with stroke have access to this type of facility and live in this locale. The ordinal level of measurement of the data for this study limited statistical analyses that could be performed to non-parametric statistics.

Implications

Nurses, which Orem (2001) refers to as *nurse agents*, can be invaluable sources of support and providers of education for new caregivers of stroke survivors; they are often in an ideal position to address the needs and concerns of caregivers due to their close contact with patients and their families. Many times, nurses are the first healthcare professionals to initiate discussion of outcomes and rehabilitation, and they continue to follow caregivers and stroke survivors after discharge (Bakas et al., 2002; Dorsey & Vaca, 1998).

Caregivers of stroke survivors have a dual role of caring for themselves and for another person whose self-care demands cannot be independently met. This dual role, conceptualized by Orem (2001) as *self-care agency* and *dependent care agency*, puts great difficulty and burden on these caregivers (Sit et al., 2004; Tooth et al., 2005). It is important for nurses to assess the health condition of caregivers prior to discharge, and in community settings whenever possible, to ensure that the challenges of caring will not cause them to become the second patient instead of the caregiver (Sit et al.). Each caregiver's situation is unique (Smith, Lawrence, Kerr, Langhorne, & Lees, 2004), so it is important for nurses to plan caring strategies for the needs of caregivers, make caregivers consciously aware of these strategies, and implement and evaluate the plan to meet those needs. For example, caregivers should be encouraged to seek out and accept support from family members and friends. The caregivers' informal network should be assessed by nurses prior to discharge and throughout the caregiving process. If informal support is lacking, nurses can direct caregivers to the appropriate stroke-related services, such as online information, support groups, or in-home respite.

Recommendations for Future Study

Recommendations for future study include examining a more ethnically and geographically diverse group of caregivers to increase the generalizability of the findings. In addition, a comparison with other types of caregivers (e.g., caregivers of patients with dementia) would provide information on whether these findings are unique to caregivers of stroke survivors.

Summary

The results of this study highlight the importance of caregivers, as dependent care agents, establishing an adequate self-care system that provides emotional support and physical help. Findings also denote the need for nurses, as caring agents, to assess caregiver health later in the caring process and be aware of its relationship to emotional support. Also, nurses should be aware that the level of emotional support a caregiver receives will affect their health. However, the level of physical help in this study was not related to caregivers' health during the first year of caring. The interplay among these variables is complicated during the first year of caring and may affect the caregivers' ability to provide optimal care.

Acknowledgements

We would like to thank all caregivers for their participation in this study. The members of the research team for the parent study are recognized for their work. A National Institute of Nursing Research, National Institutes of Health Grant (RO1 NR007650) supported the parent study.

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Table 1
Demographic Profile of Caregivers of Stroke Survivors (N = 73)

Characteristic	Study Totals		Non-Web User Group (n = 37)		Web User Group (n = 36)	
	Frequency	%	Frequency	%	Frequency	%
Gender						
Male	18	24.7	7	18.9	11	30.6
Female	55	75.3	30	81.1	25	69.4
Age (years)						
20–30	2	2.7	2	5.4	0	0
31–40	9	12.3	3	8.1	6	16.7
41–50	14	19.2	8	21.6	6	16.7
51–60	23	31.5	12	32.4	11	30.5
61–70	15	20.6	7	18.9	8	22.2
71–80	10	13.7	5	13.5	5	13.9
Relationship						
Wife	34	46.6	19	51.4	15	41.7
Husband	16	21.9	7	18.9	9	25.0
Daughter	13	17.8	7	18.9	6	16.7
Son	1	1.4	0	0	1	2.8
Friend	9	12.3	4	8.1	5	11.1
Race/Ethnicity						
American Indian or Alaskan Native	1	1.4	1	2.7	0	0
Asian/Pacific Islander	0	0	0	0	0	0
Black, not of Hispanic origin	9	12.3	5	13.5	4	11.1
Hispanic	1	1.4	0	0	1	2.8
White, not of Hispanic origin	62	84.9	31	83.8	31	86.1
Education						
None	1	1.4	0	0	1	2.8
Grade school (1–8 years)	5	6.8	1	2.7	4	11.1
High school (9–12 years)	29	39.7	19	51.4	10	27.8
College (13–16 years)	30	41.1	15	40.5	15	41.6
Graduate school (>16 years)	8	11.0	2	5.4	6	16.7
Employment						
Full Time	27	37.0	15	40.5	12	33.3
Part Time	12	16.4	4	10.8	8	22.2
None	34	46.6	18	48.7	16	44.4

Table 2
Emotional Support Ratings by Caregivers of Stroke Survivors
Non-Web User Group (n= 37) Rating, %

Time Period	Not at all	Somewhat	A lot
Baseline	8.1	35.1	56.8
3 months	2.7	56.8	40.5
6 months	2.7	51.4	45.9
12 months	10.8	54.1	35.1

Note. Shaded boxes signify most frequently reported responses.

Web User Group (n= 36) Rating, %
Not at all
5.6
8.3
11.1
5.6
Somewhat
27.8
36.1
47.2
55.6
A lot
66.7
55.6
41.7
38.9

Table 3

Physical Help Ratings by Caregivers of Stroke Survivors

Non-Web User Group (n= 37) Rating, %

Time Period	Not at all	Somewhat	A lot
Baseline	27.0	32.4	40.5
3 months	24.3	51.4	24.3
6 months	43.2	35.1	21.6
12 months	51.4	32.4	16.2

Note. Shaded boxes signify most frequently reported responses.

Web User Group (n= 36) Rating, %

Not At all	Somewhat	A lot
30.6	41.7	27.8
27.8	47.2	25.0
41.7	47.2	11.1
36.1	52.8	11.1

Table 4

Health Ratings by Caregivers of Stroke Survivors

Time Period	Non-Web User Group (n = 37)					Web User Group (n = 36)				
	Poor	Fair	Good	Very Good	Excellent	Poor	Fair	Good	Very Good	Excellent
Baseline	2.7	5.4	54.1	24.3	13.5	2.8	13.9	44.4	33.3	5.6
3 months	5.4	16.2	40.5	35.1	2.7	0	11.1	63.9	19.4	5.6
6 months	0	13.5	43.2	35.1	8.1	0	8.3	55.6	25.0	11.1
12 months	2.7	18.9	40.5	32.4	5.4	0	8.3	63.9	27.8	0

Note. Shaded boxes signify most frequently reported responses.

Table 5Spearman Rho Correlation Results for Caregivers as One Group ($N = 73$)

Relationships	Baseline	3 Months	6 Months	12 Months
EmotionalSupport/Physical Help	.403**	.342**	.222	.294*
Emotional Support/Caregiver Health	.081	.124	.377**	.249*
Physical Help/Caregiver Health	.100	-.084	.110	.012

* Correlation is significant at the .05 level two-tailed.

** Correlation is significant at the .01 level two-tailed.