

9-1-2012

Caregivers' Incongruence: Emotional Strain in Caring For Persons With Stroke

Linda L. Pierce

College of Nursing University of Toledo

Teresa L. Thompson

Farmington Hills

Amy L. Govoni

Cleveland State University, A.GOVONI@csuohio.edu

Victoria Steiner

College of Medicine

Follow this and additional works at: https://engagedscholarship.csuohio.edu/nurs_facpub

 Part of the [Nursing Commons](#)

How does access to this work benefit you? Let us know!

Publisher's Statement

This is the accepted version of the following article: Pierce, L. L., Thompson, T. L., Govoni, A. L., & Steiner, V. (2012). Caregivers' incongruence: Emotional strain in caring for persons with stroke. *Rehabilitation Nursing*, 37(5), 258-266. doi:10.1002/rnj.35, which has been published in final form at <http://onlinelibrary.wiley.com/doi/10.1002/rnj.35/full>

Recommended Citation

Pierce, Linda L.; Thompson, Teresa L.; Govoni, Amy L.; and Steiner, Victoria, "Caregivers' Incongruence: Emotional Strain in Caring For Persons With Stroke" (2012). *Nursing Faculty Publications*. 34.
https://engagedscholarship.csuohio.edu/nurs_facpub/34

This Article is brought to you for free and open access by the School of Nursing at EngagedScholarship@CSU. It has been accepted for inclusion in Nursing Faculty Publications by an authorized administrator of EngagedScholarship@CSU. For more information, please contact library.es@csuohio.edu.

Caregivers' Incongruence: Emotional Strain in Caring for Persons with Stroke

Linda L. Pierce, PhD RN CNS CRRN FAHA FAAN • Teresa L. Thompson, PhD RN CRRN • Amy L. Govoni, MSN RN BC RMT • Victoria Steiner, PhD

KEY WORDS

caregivers
caring
incongruence
strain
stroke

Purpose: Guided by Friedemann's framework, the purpose of this study was to examine the dimensions of new family caregivers' emotional strain in caring for persons with stroke.

Method: Seventy-three caregivers who were new to that role participated in an interview every 2 weeks for a year as part of a NIH project. Of these caregivers, 36 participants were randomly assigned and had access to a Web-based intervention and its e-mail discussion. In this secondary data analysis, 2,148 e-mail discussion messages plus 2,455 narrative interview entries were used to examine dimensions of caregivers' emotional strain. Rigorous content analysis was applied to these data.

Results: The majority of these caregivers were white women with an average of 55 years who cared for spouses. Three themes emerged from these data: (1) being worried, (2) running on empty, and (3) losing self.

Discussion: Caregivers worried about themselves and their care recipient, sharing feelings of being just "plain tired." The caregivers felt that their lives were lost to giving care. They described in detail the emotional strain that they felt, as they took on new roles in caring for the person with stroke.

Conclusion: This study informs nurses about new family caregivers' emotional strain, or incongruence in Friedemann's terms, from their viewpoint and provides direction for supportive education interactions.

In the United States, stroke impacts 795,000 people annually, with costs of new or recurring stroke events at \$73.7 billion (American Heart Association [AHA], 2010). Most persons with stroke return to home settings (AHA, 2007). In fact, about 6 million people live with the after effects of stroke, affecting four of five American families (National Stroke Association, 2010). Stroke is a traumatic life altering event not only for the person who survives with a stroke but also for these informal family caregivers, such as relatives, friends, and neighbors. These caregivers are often placed in overwhelming situations, experiencing feelings of burden and depression, decreasing physical and mental health, and declining quality of life (van Excel, Koopmanschap, van den Berg, Brouwer, & van den Bos, 2005; Forester, 2005; McCullagh, Brigstocke, Donaldson, & Kalra, 2005).

This article presents a secondary analysis of data from our National Institutes of Health (NIH) funded project focused on the experience of caring. The purpose of this secondary data analysis is to examine dimensions of new family caregivers' emotional strain in caring for persons with stroke.

Literature

Family Caregivers and Strain

Persons with stroke experience significant functional limitations resulting from decreased mobility, cogni-

tive impairment, depression, and personality changes (AHA, 2010), which require long-term help from family members and other unpaid caregivers (Lutz & Young, 2010). It has been long known that the psychosocial impact of stroke extends to these caregivers who provide the assistance to maintain persons with stroke in the community (Anderson, Linto, & Stewart-Wynne, 1995). Informal care often takes a great amount of time and energy and may cause overwhelming feelings (Ohman & Soderberg, 2004). Some caregivers may not be sufficiently prepared or resilient enough to take on such responsibilities without putting their own health and well-being at risk (Pinqart & Sorensen, 2003). In fact, caregivers worry not only about their loved one or friend but also about what consequences the stroke might have for their own life (ASA, 2010; Kuyper & Wester, 1998). In addition to depression and other forms of psychological distress, reductions in social participation and other indicators of poor quality of life have been found in previous caregiving studies (Boter, Rinkel, & de Haan, 2004; Brummett et al., 2006; Roth, Perkins, Wadley, Temple, & Haley, 2009; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998; Thommessen, Wyller, Bautz-Holter, & Laake, 2001).

Objective measures of caregiving demand and subjective measures of perceived caregiving strain are both important to consider when examining

quality of life correlates of caregiving (Roth et al., 2009). Studies have found a relationship between emotional distress and caregiver strain, both in stroke and other patient groups (Blake, Lincoln, & Clarke, 2003; Mitchley, Gray & Pentland, 1996; Scholte op Reimer et al., 1998). In addition, spouses who care for individuals whom they perceived as dependent in activities of daily living were more likely to experience strain (Blake et al., 2003; Scholte op Reimer et al., 1998). Structured telephone interviews with participants ($n = 43,099$) in a large national epidemiologic study indicated that caregivers reported more quality of life problems than noncaregivers, but these effects were largely dependent on the perceived level of caregiver strain (Roth et al., 2009). High strain caregivers reported more problems with emotional distress, worse physical functioning, and fewer social contacts than noncaregivers.

In a phenomenological study examining the experiences of spousal caregivers of persons with stroke ($n = 8$), six interrelated themes emerged: experiencing a profound sense of loss, adjusting to a new relationship with a spouse, taking on new responsibilities, feeling the demands of caregiving, having to depend on the support of others, and maintaining hope and optimism (Coombs, 2007). According to a meta-ethnographic review by Greenwood and Mackenzie (2010) of seven qualitative studies, the experience of caring for a person with stroke focuses on change and loss. Change includes changes in roles, relationships, and responsibilities, and loss includes losses of former relationships, autonomy, and "taken-for-granted futures." "Superimposed on this is uncertainty, including fears of another stroke and uncertainty about the future" (Greenwood and Mackenzie, 2010, p. 4). The authors state that acknowledging these issues may be more valuable than attempting to reduce caregiver burden or strain.

Emotional Strain or Incongruence

According to Friedemann (1995, 2011), individuals' behavior patterns to strive toward congruence or balance are acted out in daily life. Congruence is defined as health and well-being as well as compatibility of patterns and rhythms of subsystems, systems of contact in the environment, and the universal order. Although congruence or finding a balance in life is continually attempted, it is never fully realized because changes and conflict continuously threaten the individual's systems operation. Incongruence is the result (Friedemann, 1995). Incongruence or disharmony and incompatibility among systems evoke turmoil and prevent the free flow of energy. This turmoil is evidenced as an indi-

vidual's emotional strain (Friedemann, 1995, 2011). The need for caring often arises from a difficult situation in the family such as stroke and causes caregivers' emotional strain or incongruence that extends throughout the first year of caring or longer.

Research Question

There is a lack of understanding from the viewpoint of caregivers of persons with stroke as to what contributes to or are aspects of their emotional strain or incongruence that resulted in our research question: What are the perceived dimensions of emotional strain expressed by new family caregivers of persons with stroke in the first year of caring?

Methods

Setting and Sample

Family caregivers from four rehabilitation facilities in northern Ohio and southern Michigan were recruited and followed for 1 year for an Institutional Review Board approved, NIH funded project that examined the experience of caring for new caregivers following the care recipients' stroke (Pierce, Steiner, Govoni, Thompson, & Friedemann, 2007; Pierce, Steiner, Khuder, Govoni, & Horn, 2009). Inclusion criteria were that the care recipient had a new diagnosis of stroke and was discharged to home with a caregiver following treatment. The caregiver was the primary person responsible for providing the day-to-day care, was able to read, write, and understand English, and was a novice Internet user. Half of the caregiver participants were randomly assigned to Caring-Web©, a Web-based intervention for education and support (Web users) and the remaining half were in the control group of usual care (non-Web users). Of 144 caregivers screened, 103 ($n = 51$ Web users; 52 non-Web users) caregivers met the inclusion criteria and were enrolled in the project.

Data Collection

Information to describe the caregiver participants' characteristics, such as age, gender, and employment, was collected by a telephone interview. In addition, the participants reported age, gender, and ethnicity/race for their care recipients. Data about the emotional strain in caring were gathered in two ways: e-mail messages and interview data.

E mail Data. Data were gathered from the Web users who had access to Caring-Web (<http://caring-web.utoledo.edu/>) during the yearlong project. Caring-Web was developed more than 10 years ago by the first and last author with the assistance of Web designers at the university (Steiner & Pierce, 2002). The purpose of the Caring-Web intervention was

to provide support and education to new caregivers of persons with stroke. The website was constructed with four interrelated components for caregivers: (1) linked websites about stroke and caring; (2) customized educational information or tips specific to caregivers' needs; (3) an e-mail forum to ask a nurse specialist and a rehabilitation team any questions in private; and (4) Caretalk, a nonstructured e-mail discussion among all participants facilitated by the nurse (Steiner & Pierce). Specifically, data for this study were collected from the Caretalk component, e-mail discussion messages concerning emotional strain in caring that caregivers shared among the group participants.

Narrative Interview Data. All participants (Web users and non-Web users) were also queried by trained telephone interviewers every 2 weeks using open-ended questions regarding challenges/problems in caring, with emotional strain emerging as

the dialog unfolded. These questions along with probing statements to clarify these experiences were "what was not working well" ("what was the biggest challenge" and "what were other problems"), "what did that feel like for you," or "tell me more about..." and "what does this mean to you."

Data Management and Results

Profile of Caregivers and Care Recipients

Seventy-three caregivers completed the NIH funded project, and their data were available for this secondary analysis. Presented in **Table 1**, descriptive statistics revealed that 18 (25%) caregiver participants were men and 55 (75%) were women. Of these, there were 34 (47%) wives, 16 (22%) husbands, 13 (18%) daughters, 1 (1%) son, and 9 (12%) other relatives or friends. Sixty-two (85%) participants

Table 1. Demographic Profile of Caregivers for Stroke Survivors ($n = 73$)

Characteristics	Sub-Characteristics	Web User Group ($n = 36$)		Non-Web User Group ($n = 37$)		<i>p</i> -value
		<i>n</i>	%	<i>n</i>	%	
Gender	Male	11	30.6	7	18.9	0.249
	Female	25	69.4	30	81.1	
Relationship	Wife	15	41.7	19	51.4	0.469
	Husband	9	25.0	7	18.9	
	Daughter	6	16.7	7	18.9	
	Son	1	2.8	0	0	
	Other Relatives and Friends	5	13.8	4	10.8	
Race/Ethnicity	American Indian or Alaskan Native	0	0	1	2.7	0.552
	Asian/Pacific Islander	0	0	0	0	
	Black not of Hispanic origin	4	11.1	5	13.5	
	Hispanic	1	2.8	0	0	
	White not of Hispanic origin	31	86.1	31	83.8	
Age (in years)	20 30	0	0	2	5.4	0.738
	31 40	6	16.7	3	8.1	
	41 50	6	16.7	8	21.6	
	51 60	11	30.6	12	32.4	
	61 70	8	22.2	7	18.9	
	71 80	5	13.9	5	13.5	
Education (in years)	None	1	2.8	0	0	0.246
	Grade School (1 8)	4	11.1	1	2.7	
	High School (>8 12)	10	27.8	19	51.4	
	College (>12 16)	15	41.7	15	40.5	
	Graduate School (>16)	6	16.7	2	5.4	

Table 2. Demographic Profile of Stroke Survivors (n = 73)

Characteristics	Sub-Characteristics	Web User Group (n = 36)		Non-Web User Group (n = 37)		p-value
		n	%	n	%	
Gender	Male	20	55.6	22	59.5	0.736
	Female	16	44.4	15	40.5	
Age (in years)	20 30	0	0	0	0	0.819
	31 40	2	5.6	3	8.1	
	41 50	6	16.7	3	8.1	
	51 60	8	22.2	9	24.3	
	61 70	6	16.7	8	21.6	
	71 80	10	27.8	12	32.4	
	81 90	4	11.1	2	5.4	
Race/Ethnicity	American Indian or Alaskan Native	0	0	1	2.7	0.552
	Asian/Pacific Islander	0	0	0	0	
	Black not of Hispanic origin	4	11.1	5	13.5	
	Hispanic	0	0	0	0	
	White not of Hispanic origin	31	86.1	31	83.8	
	Other	1	2.8	0	0	

were White, 9 (12%) were African American, 1 (1%) was Hispanic, and 1 (1%) was American Indian that reflects the areas demographic distribution. The participants' average age was 55 years and the average years of education were 13. Data also revealed that 27 (37%) participants worked full-time, 12 (16%) worked part-time, and 34 (47%) did not work. Described in **Table 2** are the care recipients. Of these, 58% were men and 85% were White. Their mean age was 63 years and most were White Americans.

Data Analysis

The narrative interview entries ($n = 2,455$) and the Caretalk e-mail discussion messages ($n = 2,148$) were entered as text files into QSR N 5 (Richards, 2000), a qualitative software management program, and analyzed using Colaizzi's (1978) rigorous method of content analysis.

These narrative descriptions of the participants experience in caring were then read to obtain a sense for the whole. Significant statements and phrases pertaining directly to the phenomenon, emotional strain, were replete throughout these entries, and early signs of clustering were evident. Using a coding categorization, based on Friedemann's (1995) framework of systemic organization that was previously developed, piloted, and confirmed by

the theorist and investigators (Pierce et al., 2003; Thompson et al., 2004), statements were coded. Patterns of responses were found in their recorded statements, and phrases were clustered from which the themes emerged. Finally, the results were integrated into an exhaustive description of caregivers' incongruence. With over 4,600 entries from the narrative interviews and the e-mail discussion messages, these data are saturated and expand the knowledge of caregivers' incongruence or emotional strain in caring for persons with stroke.

Trustworthiness of the data and interpretations were further enhanced in the following ways. The interviewers were trained in asking the questions and read literature and attended presentations by the investigators and the theorist, Friedemann. The e-mail discussion group leader was an advanced practice psychiatric nurse with years of experience in dealing with caregivers and their issues. The biweekly narrative, interview entries and the e-mail discussion messages provided a vast amount of data from the caregivers, which added to the trustworthiness of the overall findings. Finally, although the researcher is part and parcel of the qualitative research process, the added dimension of having all authors/investigators involved for content clarification, refinement, and concurrence enhanced the data interpretation. Coded data and themes emerging from the analysis identified by the investigators

were shared with the interviewers for confirmation, which also helped to establish the credibility of these data.

Findings

These participants reported emotional strain with day-to-day situations involved in caregiving. Three themes emerged from these data: (1) being worried, (2) running on empty, and (3) losing self. Although these themes stand on their own presenting different dimensions of emotional strain, there are connecting threads running through them as well.

Theme One: Being Worried. The caregiver participants said that they were worried about self and the care recipient. Some caregivers worried about their health and if something happened to them, asked who would be there for the care recipient. One spousal caregiver exemplified this feeling. She said:

My health isn't that great! I have Cogan Syndrome [recurrent inflammation of the cornea and often fever, fatigue, and weight loss; episodes of dizziness; and hearing loss]. I've been dealing with it for over twenty years. Some days it's hard to get out of bed, but somehow I do. Also, my husband has suffered a major depression not long ago [before his stroke]. I worry more about us sometimes... all the stress in the family.

Still other caregivers shared more concerns, stating that they "worried about the care recipient having another stroke" and about "real or imagined symptoms" or "if the doctor should be called or if it is something inconsequential." For many caregivers, another stroke was not only a "worry" but seen as going backwards, and "to have to go backwards is the scariest thing." Caregivers told of "worrying about how far he [or she] could come back from the serious brain hemorrhages" and if they would be "incapacitated and not function much at all." They shared that they worried about "personality changes" such as anger or/and if these changes would be permanent, making "their lives together emotionally more difficult."

One caregiver related a personal story of family upheaval shortly after her husband's stroke and told how she dealt with those issues. She shared, "...and had to leave my husband by himself, [and she was] full of worry." She went on to say how this bothered her. However, there was another side of being worried that emerged. Caregivers shared that as time went on, they were "able to leave the house for short spells and not worry" about the care recipient, noting that the more that they left, the better

they found it got, i.e., the worry lessened. Caregivers told that worry was just a part of the caring process and led to growth or reestablishing "normal." Worry was now seen as valuable. A woman caregiver told others that she would still have concerns even after being told by the doctor that her husband's "heart looks very good..." She said, "I will probably still worry. As far as the doctor is concerned, he [husband] can go back to a physically 'normal' life." A male caregiver said,

You will always hold that doubt if it is really all right not to worry, that is known as caring and I hope for me that I never lose the concern. I just hope I can do my best for my wife, letting her reach out to do things that she is comfortable with and being there to catch her if something goes wrong.

Another male spouse suggested to others in an e-mail message that he did not worry about the future, saying "don't worry be happy." Another man summed it up and his statements are reflective of many caregivers. He said that after months of caring, he was aware of how stroke had changed their lives. He shared that caregiving equaled "emotional strain" that denoted "worry," but that worry leads to "celebrating big and small things. Like a drum roll please: August 9th was our 30th wedding anniversary." However, he also noted that he was "very, very tired all the time and wanting to sleep late without the worry that his wife will try to boil an egg and burn herself..."

Theme Two: Running on Empty. Many caregivers said that they felt "exhausted," "overwhelmed," "irritable," "worn out," "worn down," and just plain "tired." These caregivers knew they were running on adrenalin at times and at others times they shared "I'm operating on only half my cylinders." They talked about becoming ill, being too tired to make good decisions or even dying before their loved one. All this drained their energy and resulted in feelings of fatigue or inability to sleep and feel rested. A woman caregiver shared, "I don't sleep well lately. I jump at every move he [husband] makes. This is not good. I have to take care of me so I can take care of him." Others shared the changes in former ways of intimacy resulting in changes in their sleeping. "We used to snuggle a lot but he has a dead side now and when he rolls over, he hits me with his arm. I am not getting enough sleep because of it." They were sleeping but always aware of the potential of being needed or called on for assistance.

The caregivers were so fatigued at times that they described how they fell asleep at the computer

trying to catch up with life. Or they shared with others in the project, "It took me a while to get started 'talking' at first I was so tired and stressed that I just read what others were saying." Many e-mail messages in the project were typed late into the night, the only time the caregivers had to take for themselves and get on the computer to share. Caregivers reported in interviews that they slept through alarms or appointments which gave them concern about what they had not done or what if something had happened. Another caregiver shared a story about falling asleep while their loved one was in therapy and had to be awakened to drive home.

At times, caregivers shared that they were just tired of being tired and were forced by fatigue to seek out medical advice for themselves or their care recipient. They described discussing their feelings of fatigue with their healthcare providers. One provider asked why the caregiver waited so long to talk about her lack of energy and prescribed medication that helped her to sleep. Some caregivers shared that they were on antidepressants, or took sleeping pills or Tylenol® (Acetaminophen) before going to bed. The caregivers knew they were not taking care of themselves. One caregiver noted, "It is also much harder to maintain a positive attitude when you are tired and hungry (even if you don't realize for awhile that may be the reason)."

It wasn't always the physical work of caring that caused fatigue but it was also the emotional feelings that added to that tiredness. One caregiver shared, it isn't the "doing for" that is tiring but "being with." As one caregiver described, "... later that night, and ever since during his waking hours, he has been calling me over and over worrying about this and that, past and present and future. It is exhausting." Another shared,

It is hard to be so emotionally on guard all the time and to have to try editing things (what you say). As a result, I guess, I seem to be more distracted ... my thinking is not as sharp as usual a lot of the time, and I get sleepy too early in the evening, which also upsets me.

Overwhelmed and exhausted, one caregiver shared in a message that at times, she "wakes up with dread of caregiving for another day." Another caregiver said in an interview, "Sometimes, you just feel like you want a truck to hit you but you don't want to leave someone else with the mess." Along with these strong feelings of exhaustion, caregivers would come back with statements of how they were still hanging in there or shared the next day that they were feeling better.

Theme Three: Losing Self. Loss of self is exemplified by loss of time to be yourself. One caregiver described it as: "I am tired of donating all my free time to hubby...." This frequently coincided with descriptions of extreme exhaustion and lack of time for necessary things as well as alone time for self. Escaping into anything else describes the need by the caregivers to have support outside of their caregiving experience, and find some time for themselves to be the person they were before they started on the caregiving journey. One caregiver shared, "I want to do nothing that has to do with caregiving for a change!"

The feeling of being controlled by another represents losing self for another. This is expressed by caregivers sharing, "he just wants my undivided attention only when he wants it. Am I making sense? I guess my attitude is he is being unfair to me" and "a lot of things are messed up right now. I think he [husband] likes to drive me nuts. Some days I just don't know if I want to get out of bed or not." Another person described the need for energy to be able to do things for self. She stated "It's like having kids again and always needing to find a sitter or not being able to go anywhere because you have no one to watch them." For another, even having surgery was a treat, "I am looking forward to having my surgery so that I will not have to care for mother. I know that sounds bad, but it is true."

Comparisons with life before caregiving were expressed wistfully. For example, "I was thinking about how infrequently these days, compared to our 'prestroke' life, that I actually have a good conversation with someone other than a family member with problems, or who is constantly repeating the same things." Looking for support and expressing their frustrations and lack of being perfect to the others allowed the caregivers opportunities to reduce their emotional strain while trying to hang on to their true selves. There is an unspoken fear within these quotes that the person they were before the stroke is no longer present; they have disappeared under the strain of caregiving. Humor and prayers were seen as possible supports that they hoped would be able to help them through the challenges that they were presented daily.

Discussion and Implications

It is an ongoing balancing act with worry, running on empty and loss of self all pulling the caregivers down in one direction and pushing the caregivers away from any sense of congruence within their life (Friedemann, 1995, 2011). These three themes exemplify the idea that the experience of caring for a person with stroke focuses on change and loss,

overlaid with uncertainty (Greenwood & Mackenzie, 2010), and are consistent with the interrelated themes found by Coombs (2007). The caregivers described in great detail the emotional strain that they felt as they took on these new roles in caring for the person with stroke and learned just what caregiving entailed. These feelings were interspersed in the narrative interview entries and e-mail discussion messages and represent incongruence. This was not just a time to share their complaints about caring for the care recipient; that was not the tenor of what they shared in this secondary data analysis. They simply wanted to tell about the experience of caring for the person with stroke and what it meant to them. As pictured in the figure, these caregivers are trying to balance on a teeter tauter as they strive toward some level of congruence in their lives (Figure 1).

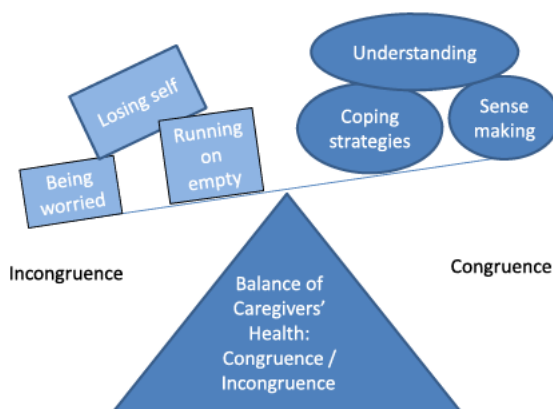
Friedemann (1995, 2011) noted that congruence or health is an ideal that one strives for. In the case of caring for another, there is emotional strain that leads to incongruence, e.g., decreasing physical and mental health and declining quality of life (van Excel et al., 2005; Forester, 2005; McCullagh et al., 2005). The caregivers' personal systems were changing and their ability to feel a sense of control was lost. These caregivers, nonetheless, continued to try to make sense of their experiences, understand ways in which they could worry less, feel less tired, and find themselves, and implement these coping strategies to achieve some new tenuous balance and control (Friedemann, 1995, 2011). Assessment of caregivers' needs and helping them to understand their role and legitimize their concerns leads to effective adjustment and success in the recovery process not only for the person with stroke but also for family caregivers.

The first theme, being worried, is a real feeling for caregivers. Simple consolation or minimization does not give the caregiver what they need to understand their worry. Assessment questions that nurses may ask to build coping strategies upon include the following: What is that worry? How can that worry be better understood, compensated for, or eliminated? Is there factual information which would help the caregiver realistically understand the worry? Although the caregivers' worry lessened over time, this study revealed that they worried about their health and that of the care recipient and especially in leaving the person with stroke alone. Providing education to caregivers may help them understand their situation and worry less. Being connected to therapists, peers, family, and friends who have worked with others or who have experienced similar situations may also prevent feelings of worry. Professional counseling for the caregiver is another strategy that may be beneficial to deal with behavioral issues, as they strive for life to be "normal" again. Additional strategies that may be of help is a plan for respite care enlisting other family members and friends as sitters and care partners and establishing a long-term care plan for future caregivers if the current family member becomes incapacitated.

Worry depletes energy and can contribute to the second theme of running on empty. Emotional energy is depleted through worry as is physical energy. The participants were fatigued, not sleeping, and doing physical as well as intellectual tasks that they were not used to trying. They did not have the time or opportunity to replenish their emotional and physical strength. Recognizing this, the nurse can help caregivers understand time-saving strategies, resources, assistance, and ways to lessen the strain of the caregiver experience. For example, a portable monthly calendar to keep track of days for, times of, and places of appointments and also to schedule family members and friends for assistance can be an important aid. Taking care of the caregivers is also important, and they should visit their healthcare provider regularly. Nurses can recommend adequate nutritional intake, as well as exercise and sleep regimens, to help lessen strain and bring congruence/balance to caregivers' lives.

The third theme of losing self can also be linked to the earlier themes of being worried and running on empty. Being consumed in the caregiver experience relates directly to the loss of self. Caregivers need to get some "time away" and do things that they used to do before assuming their new caregiving role. Nurses may encourage caregivers to read a book, play games, resume old hobbies, attend

Figure 1. Balance of Health: Incongruence and Congruence in Caregivers' Life



religious services, pamper themselves, i.e., do anything they enjoy. Caregivers may also find themselves and gain comfort in reaching out to others in the family or to friends through face-to-face, telephone, or Web-based interactions. Finally, in an effort to make sense of their caregiving situation, nurses can help caregivers through educational and supportive strategies to find a new sense of “normal” and come to a fresh balance in their lives and appreciation for what they have.

Although data for this analysis were derived from a large number of e-mail messages and narrative interview entries, there are several methodological limitations. The sample was composed of caregivers from two Midwest states, and thus, the results may not be transferred to other populations of caregivers or settings. Although all participants were interviewed, of this sample only 36 of the 73 caregiver participants had access to and wrote messages in the e-mail discussion. In addition, the e-mail data were from a free flowing online discussion, while the interview data were in response to specific questions on what was not working well for the caregivers in caring for the person with stroke. Although not all the same caregivers spoke of or wrote entries related to all three themes, there is indeed commonality in the outcome of these findings. The nurse can share in the acute, subacute, or home care venues with caregivers the best ways to use time and energy, how to get rest, support, and relief or respite. Nurses need to recognize and encourage caregivers to share their feelings about this experience. Caregivers have a right to grieve what was, as they move forward to what is. Ultimately, the nurse can help caregivers identify coping strategies. As pictured in the figure, it is only through coping, understanding, and sense making of the situation that these issues do not become the emotional strain that would limit their ability to be effective in their new caregiver role.

Conclusions

There were three major dimensions of emotional strain that emerged from these new caregivers during the first year of caring: being worried, running on empty, and losing self. They wondered if there would ever be a normal life again, what would happen if they were not around for their loved one or were consumed with worry. Fears of the “what if’s,” the incredible fatigue, lack of intimacy, lack of caring for themselves, and constant vigilance were common. There was concern that the care recipient would not recover or would have another stroke. Caregivers feared that they have disappeared under the strain of caregiving.

The implications for nursing begin with the understanding of the impact of caregiving on the caregiver. From early in the rehabilitation process through homecare and follow-up, nurses have the opportunity to identify the caregiver as well as the patient as the focus of nursing care. Teaching of procedures and strategies are commonplace to the rehabilitation nurse. The impact of caregiving and strategies to assist caregivers must be added to this teaching to balance out the caregivers’ needs and resources to increase the congruence they experience in their lives. Being surrounded by family members and friends and doing enjoyable activities are coping strategies that nurses can suggest. Caregivers should be reminded to take care of themselves, including asking for assistance, eating and drinking to nourish and hydrate, getting adequate sleep, and using humor, a positive attitude, and/or prayers. As the caregiving process goes on, other strategies may be suggested by the home care nurse or case manager. The need for respite, ways to manage time, and escape from the unrelenting caregiver tasks are important. For nurses, knowledge about the dimensions of caregivers’ emotional strain will help in the understanding of family caregivers new to the role, anticipate their needs in dealing with the myriad of problems that they will face in that first year, and provide strategies that have been identified to assist in caring for the person with stroke. It is through the nurse’s understanding of the caregiving experiences of worry, loss of self, and feelings of depleted energy that preventive and supportive strategies can be given.

The need for future research centers on the ongoing evolution of social media resources that have exploded in the past decade. From the time of listservs and discussion boards, there have emerged new mechanisms that can be used therapeutically in dealing with emotional strain. Their efficacy needs to be ascertained through controlled studies that identify the degree to which they can be seen as credibly supportive. The second area of research should focus on the themes identified here and interventions that can impact on the caregivers feeling of control and sense of congruence. Finally, would these themes differ if the sample was divided into subgroups? Demographic characteristics, such as employment status, ethnicity, and relationships to the person with stroke, could be analyzed with a larger sample regarding their impact on caregivers’ e-mail messages and/or interview responses.

Acknowledgments

This secondary data analysis was taken from a yearlong project that was supported through a National Institute of Nursing Research, National

Institutes of Health Grant #RO1 NR007650. The authors thank the research team members and all caregivers for their participation in that project.

About the Authors

Linda L. Pierce, PhD RN CNS CRRN FAHA FAAN, is a professor at College of Nursing, University of Toledo (UT), Toledo, OH. Address correspondence to l.pierce@utoledo.edu.

Teresa L. Thompson, PhD RN CRRN, is a dean and professor at College of Nursing and Health, Madonna University, Livonia, MI.

Amy L. Govoni, MSN RN BC RMT, is an associate professor at School of Nursing, Cleveland State University, Cleveland, OH.

Victoria Steiner, PhD, is an assistant professor at the UT College of Medicine, Toledo, OH.

References

- American Heart Association [AHA] (2007). *Let's Talk About Living at Home After Stroke*. Retrieved January 12, 2011, from <http://www.strokeassociation.org/>
- American Heart Association [AHA] (2010). *Heart Disease and Stroke Statistics*. Retrieved January 12, 2011, from <http://www.americanheart.org/>
- American Stroke Association [ASA] (2010). *Recovery and Support*. Retrieved January 12, 2011, from <http://www.strokeassociation.org/>
- Anderson, C. S., Linto, J., & Stewart Wynne, E. G. (1995). A population based assessment of the impact and burden of care giving for long term stroke survivors. *Stroke*, 26, 843-849.
- Blake, H., Lincoln, N. B., & Clarke, D. D. (2003). Caregiver strain in spouses of stroke patients. *Clinical Rehabilitation*, 17(3), 312-317.
- Boter, H., Rinkel, G. J. E., & de Haan, R. J. (2004). Outreach nurse support after stroke: A descriptive study on patients' and carers' needs, and applied nursing interventions. *Clinical Rehabilitation*, 18(2), 156-163.
- Brummett, B. H., Babyak, M. A., Siegler, I. C., Vitaliano, P. P., Ballard, E. L., Gwyther, L. P. et al. (2006). Associations among perceptions of social support, negative affect, and quality of sleep in caregivers and noncaregivers. *Health Psychology*, 25(2), 220-225.
- Colaizzi, P. (1978). Psychological research as the phenomenologist views it. In R. Valle, & M. King (Eds.), *Existential phenomenological alternatives for psychology* (pp. 48-71). New York: Oxford University Press.
- Coombs, U. E. (2007). Spousal caregiving for stroke survivors. *Journal of Neuroscience Nursing*, 39(2), 112-119.
- van Excel, N., Koopmanschap, M., van den Berg, B., Brouwer, W., & van den Bos, G. (2005). Burden of informal caregiving for stroke patients. Identification of caregivers at risk of adverse health effects. *Cerebrovascular Disease*, 19(1), 11-17.
- Forester, A. (2005). Caregiver burden in stroke. *Stroke Review*, 9(1), 127-131.
- Friedemann, M. L. (1995). *The Framework of Systemic Organization: A Conceptual Approach to Practice and Research with Families and Family Members*. Thousand Oaks, CA: Sage.
- Friedemann, M. L. (2011). *The Framework of Systemic Organization*. Retrieved January 12, 2011, from <http://www.angel-fire.com/ak3/Friedemann/Framework11.htm>
- Greenwood, N., & Mackenzie, A. (2010). Informal caring for stroke survivors: Meta ethnographic review of qualitative literature. *Maturitas*, 66(3), 268-276.
- Kuyper, M. B., & Wester, F. (1998). In the shadow: The impact of chronic illness on the patient's partner. *Qualitative Health Research*, 8(2), 237-253.
- Lutz, B., & Young, M. (2010). Rethinking intervention strategies in stroke family caregiving. *Rehabilitation Nursing*, 36(4), 152-160.
- McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiver burden and quality of life in caregivers of stroke patients. *Stroke*, 36(10), 2181-2186.
- Mitchley, N., Gray, J. M., & Pentland, B. (1996). Burden and coping among the relatives and carers of brain injured survivors. *Clinical Rehabilitation*, 10(1), 3-8.
- National Stroke Association (2010). *Caregivers and Families*. Retrieved January 12, 2011, from <http://www.stroke.org/site/PageServer?pagename=care>
- Ohman, M., & Soderberg, S. (2004). The experiences of close relatives living with a person with serious chronic illness. *Qualitative Health Research*, 14(3), 396-410.
- Pierce, L., Steiner, V., Govoni, A., Hicks, B., Thompson, T., & Friedemann, M. (2003). Caregivers pull together and feel connected in caring for persons with stroke. *Neuroscience Nursing*, 36(1), 32-39.
- Pierce, L., Steiner, V., Govoni, A., Thompson, T., & Friedemann, M. (2007). Two sides to the caregiving story. *Topics in Stroke Rehabilitation*, 14(2), 13-20.
- Pierce, L., Steiner, V., Khuder, S., Govoni, A., & Horn, L. (2009). The effect of a web based stroke intervention on carers' well being and survivors' use of healthcare services. *Disability and Rehabilitation*, May 21, 1-9. [Epub ahead of print]. Retrieved from <http://www.informaworld.com/smpp/content-db/all-content/a911800154>
- Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta analysis. *Psychology and Aging*, 18(2), 250-267.
- Richards, L. (2000). *N 5 Reference Guide*. Bundoora, Australia: QSR International Pty. Ltd.
- Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: Associations with quality of life in a large national sample of middle aged and older adults. *Quality of Life Research*, 18(6), 679-688.
- Scholte op Reimer, W. J. M., de Haan, R. J., Rijnders, P. T., Limburg, M., & van den Bos, G. A. M. (1998). The burden of caregiving in partners of long term stroke survivors. *Stroke*, 29, 1605-1611.
- Steiner, V., & Pierce, L. (2002). Building a Web of support for caregivers of persons with stroke. *Topics in Stroke Rehabilitation*, 9(3), 102-111.
- Thommessen, B., Wyller, T. B., Bautz Holter, E., & Laake, K. (2001). Acute phase predictors of subsequent psychosocial burden in carers of elderly stroke patients. *Cerebrovascular Disease*, 11, 201-206.
- Thompson, T., Pierce, L., Steiner, V., Govoni, A., Hicks, B., & Friedemann, M. L. (2004). What happened to normal? Learning the role of caregiver. *Online Journal of Nursing Informatics*, 8(2). Retrieved January 12, 2011, from http://www.eaa-knowledge.com/ojni/ni/8_2/caregiver.htm