Constructing the reality of recovery: Family home care management strategies

Development of home health care programs for family caregivers is predicated on an understanding of problems caregivers encounter and ways in which they manage those problems. This article describes home care management strategies of family caregivers of stroke survivors. Qualitative analysis of interviews with a purposive sample of family caregivers indicated that caregivers of stroke survivors practice situational vigilance for the stroke survivor, create solutions for problems associated with functional losses of a stroke, construct the reality of recovery for themselves and the stroke survivor, and seek to find personal meaning in the caregiving experience. Implications for practice and future research are proposed. Key words: *family home care, home care management, stroke caregiving*

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FAMILY CAREGIVING and the adaptations that families make when a family member is confronted with a life-threatening illness or injury are recurrent themes in the family research literature. There are few studies that describe ways in which families manage home care for stroke survivors, even though some studies suggest that a stroke survivor's adjustment and recovery will be poor if families are unable to mobilize the necessary resources to cope with the aftermath of the stroke.[1-3] Development of comprehensive, high-quality home care programs for family caregivers is predicated on an understanding of the problems caregivers encounter and the ways in which they manage those problems. This article describes the results of a qualitative study of interviews with family caregivers of stroke survivors during the acute phase of recovery in the home. The purpose of the study was to

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explore the management strategies family caregivers use to solve home care problems. Caregiver problems are identified as the context for understanding the basic social processes that family members of stroke survivors use in successfully managing home care.

STROKES AND FAMILIES

Strokes are the third leading cause of disease-related deaths in the United States, and more than 500,000 individuals each year suffer a stroke.[4,5] Stroke is a major risk factor in some population groups. For example, African Americans have 1½ to 2 times more strokes per 100,000 than white Americans.[6]

Shortened hospital stays mean more stroke survivors will receive the majority of their care in the home, and more family caregivers will manage stroke-related problems ranging from cognitive impairments and perceptual deficits to dysphagia and hemiplegia. While the type of vascular lesion influences a stroke survivor's recovery, a family's management of a stroke survivor's functional losses regarding mobility, eating, elimination, and communication also can have a profound impact on the rehabilitative course of the stroke.[1,7]

DATA COLLECTION AND ANALYSIS

A constructionist perspective of family caregiver interviews

This study was an exploration of family caregiving. The study consisted of qualitative analysis of interviews with eight family caregivers to identify the basic social processes that these caregivers used to manage the complexities of caring for stroke survivors in the home. The study was grounded in social construction theory. A constructionist perspective suggests that the meaning of an experience is essentially a social phenomenon created through interactions with and between family members.[8] When constructionist perspectives are used as the rationale for interviewing family members, the focus is on developing a socially based epistemology of family functioning.[9] Through conversations with family members, their way of knowing and interpreting an experience becomes accessible to the interviewer. For each caregiver, conversation with the interviewer becomes the medium through which home care management strategies are named, classified, and defined.

Family caregivers were selected through a purposive sampling technique. First-time stroke survivors were recruited from acute care hospital settings immediately prior to discharge, from rehabilitation settings, or from outpatient clinics at the time of the initial follow-up visit. Because the literature demonstrates that the majority of functional recovery occurs within the first 6 months after a stroke,[10] only caregivers for first-time stroke survivors who had been discharged 14 weeks or less previously were interviewed. Caregivers were identified by stroke survivors as those individuals who were most closely involved in the day-to-day provision of home care. Caregivers were the spouses, parents, or children of the stroke survivor. Seven of the eight caregivers interviewed were women. All caregivers were English-speaking and -reading adults who gave informed consent to participate in a series of interviews about their home caregiving experiences. The mean ages of the eight stroke survivors and family caregivers were 52 and 50, respectively. Five of the eight stroke survivors were African American. The average length of time since discharge was 59 days (Table 1).

To ensure interviewing consistency, the first three taped interviews were used for research team discussion and training. Interviews were conducted either in the home or the outpatient clinic at the time of the initial follow-up visit. The first interview was conducted with each caregiver to identify the types of problems they had encountered and the strategies they had used to manage those problems since the stroke survivor's discharge from the hospital or rehabilitation facility. One week later, a second interview was conducted by telephone with the caregiver to validate problems and management strategies identified in the initial interview and to explore whether the caregiver had other thoughts over time about the home care experience. Interviewing by telephone also proved useful in that family caregivers frequently identified additional problems or management strategies not cited in the original interview. The telephone interviews also provided an opportunity for caregivers to identify problems or management strategies they did not feel comfortable sharing in the original interview.

During the interviews, caregivers were asked to identify problems encountered since hospital discharge related to caring for the stroke survivor and the ways they had managed those problems. As caregivers identified the postdischarge problems, additional questions such as, "How did you manage that?" or "What did you do to take care of that?" were posed.

All interviews were audiotape recorded and transcribed verbatim. Each transcription was reviewed by the research team member who had conducted the interview and further verified for accuracy with the caregiver at the time of the second interview. Data collection and analysis occurred concurrently. Stroke survivors were recruited and caregivers interviewed until no new problem management strategies were

Table 1. Characteristics of stroke-survivor–caregiver dyad

	Stroke survivor					Caregiver		
Dyad	**Age**	**Race***	**Sex†**	**Stroke-related deficits**	**Days post-discharge**	**Age**	**Sex†**	**Relationship**
1	45	W	M	Right hemiplegia, dysphasia, alexia, hemianopia, memory loss	39	68	F	Mother
2	82	W	F	Right hemiplegia, ataxia, dysphasia	26	55	F	Daughter-in-law
3	78	B	M	Left hemiplegia	21	68	F	Wife
4	69	B	F	Left hemiplegia	80	43	F	Daughter
5	53	B	F	Left hemiplegia	71	32	F	Daughter
6	65	B	F	Right hemiplegia	113	38	F	Daughter
7	59	B	M	Dysphasia, right hemiplegia	80	57	F	Wife
8	48	W	F	Hemianopia	68	38	M	Husband

*W = white, B = black.
†M = male, F = female.

identified. This occurred with the eighth stroke-survivor–caregiver dyad.

Caregiver interview transcriptions were reviewed by three investigators. A constant comparative method of analysis allowed the research team to generate substantive codes for emerging themes in the data and to test, revise, and refine these codes on an ongoing basis. Several steps were involved in this process.

First, phrases were used to describe and code individual management activities that caregivers described in the interviews, such as "monitoring stroke survivor signs and symptoms," " taking action," and "seeking professional assistance." In the first review of transcriptions, more than 85 descriptive codes evolved from analysis of caregiver narratives of their activities for managing home care problems. Similar codes were grouped together and aggregated under a single, inclusive definition for the broader conceptual meaning of the cluster of caregiver management activities, such as "practicing situational vigilance."

In some instances, consultation on codes and conceptual definitions was sought from colleagues with expertise on family behaviors or home care. These content experts were asked to review and independently describe the problems and management strategies they believed to be inherent in the caregiver's narrative response.

Next, the refined conceptual definitions were used in a second review of each transcription to evaluate their adequacy in defining, explaining, and categorizing caregiver strategies. Finally, caregiver narratives, the descriptive codes and conceptual definitions were collated and extracted from the transcriptions with the Martin qualitative text analysis computer software program.[11] This iterative process of describing, defining, coding, analyzing, and reanalyzing data and collating and extracting narrative excerpts took place over 6 months and involved reviewing more than 400 pages of interview transcriptions.

Methodologic safeguards

Lincoln and Guba[12] emphasize the importance of developing safeguards for qualitative analysis so that the investigator ensures the trustworthiness of findings. The following safeguards were used to enhance the trustworthiness of findings from this study. First, individual caregivers were asked to validate the content of their own interviews (member checking). Second, the generalizability (transferability) of the findings was considered trustworthy when codes and definitions were applicable across interviews, despite variations in caregiver age, sex, and relationship to the stroke survivor. Finally, colleagues external to the research team were asked to evaluate the descriptive codes, conceptual definitions, study findings, and conclusions (peer debriefing and auditing).

HOME CARE PROBLEMS

Functional losses associated with activities of daily living (eg, eating, dressing, bathing, mobility) are the most common

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sequelae of a stroke,[1] and these types of problems were reflected in the majority of caregiver interviews. Findings from intensive interviews with the caregivers of eight stroke survivors revealed that home care problems were related to the nature and scope of functional losses the stroke survivor had experienced. Caregivers cited functional losses resulting in problems with lifting, transferring, and bathing the stroke survivor. Caregiver comments included the following:

> She couldn't bathe herself.... She can't stand up.
>
> Giving him a bath... changing his bed... he is immobile.... He still has this paralysis....
>
> I have to feed him... bathe him... walk him... help with his therapy.

An even more distressing problem for caregivers was the cognitive and emotional losses associated with the stroke. Caregivers recounted these types of problems:

> Her thinking is slower.... She doesn't remember a lot of things.... She has to write things down now....
>
> Her actions are different; her thinking is different; she is not the mother-in-law I had before this stroke. To me, she is a totally different person.
>
> Since the stroke... she has started to say I don't care.... That's not like her....
>
> Since the stroke, I realize he is sick... he says he wants to die.... That's not like him, to give up....

Finally, caregivers cited problems with access to selected services or costs of care. Caregivers reported problems obtaining tangible assistance in caring for the stroke survivor:

> The problem we had was not getting anyone out to help us take care of her... because I was working.... I couldn't stay at the hospital [for the family discharge preparation classes].... I couldn't take off work....
>
> The problem we had was finding nursing services.... Most of the services have contracts... see, we needed a skilled nurse to come out and check him at intervals.
>
> The problem is I was always trying to find somebody to be here with her.... My brother was here but he has no business seeing her like that.... She don't [sic] want her son handling her private parts....
>
> You see, I need some nurses for 12 hours a day.... I need someone for part of the night and early in the morning.... I can't lift him....
>
> The doctor recommended rehab, but without insurance we couldn't afford it....

MANAGEMENT STRATEGIES

Each caregiver was asked how he or she managed the problems associated with home care of the stroke survivor. These management strategies were characterized as practicing situational vigilance, creating solutions to problems, constructing the reality of recovery, and giving meaning to the experience (Fig 1).

Practicing vigilance

Caregivers frequently described functioning as diagnosticians in their efforts to monitor and evaluate the stroke survivor's condition over time. This was manifested in the responses of the caregiver for a family member with alexia and hemianopia:

> He can talk; he never lost the ability to talk.... He has trouble pronouncing words, but he knows what he wants to say.... He cannot see

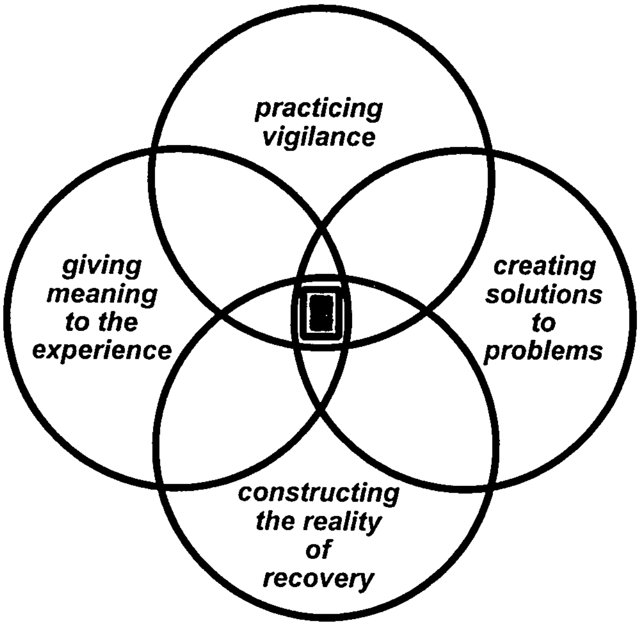

Fig 1. Home care management strategies of family caregivers of stroke survivors.

> anything to the right . . . he has to be careful because if someone is standing over there—they can get too close and he won't see them.

The wife of an elderly man described monitoring her husband's insomnia:

> At first [when he got home] he had problems sleeping. . . . I got up often during the night to check on him . . . the more active he is during the day, the better he will sleep at night. At first, I considered asking for a light sedative, but I decided he was staying in bed too much and I would keep him active instead. . . . When he sits up now, he doesn't have that problem.

Other caregivers reported monitoring the stroke survivor's environment:

> He gets overbalanced. . . . I took up the throw rugs; I put an extension on the toilet seat. . . . I walk him and balance him so he doesn't lose his balance. . . . I watch him about that.
>
> I know he can't do stairs. . . . I knew he could fall easily; it's a worry I didn't want to have. . . . I just watch him real close . . . so I rearranged the downstairs bathroom.

Some caregivers believed they needed to be vigilant about the care given by others. The daughter-in-law of an elderly stroke survivor with hemiparesis recounts monitoring home visits by physical therapists:

> The therapist comes out and walks her. . . . She has put her on a walker which helped at first. . . . Usually I sit down and watch the therapy. . . . I asked the therapist if she planned to get Mama onto a cane before she quit. She did and that has been helpful. . . .

Creating solutions to problems

In home care situations, all caregivers described their efforts to master the requisite direct care skills, and caregivers frequently described their efforts to create solutions to these problems. Here is a caregiver who described problem solving around her spouse's restricted fat diet:

> I have learned to deal with food by reading about his low-fat diet. I have changed the way I cook. . . . I now read labels very carefully. . . . I try to present him with a well-balanced diet. . . . He doesn't like the food very much, so I have supplemented with fresh fruit and fruit juices . . . that has helped. . . .

A caregiver described learning to make an occupied bed for her paralyzed spouse:

> I've learned to make the bed with him in it. . . . I push the two sheets off; I roll him to his side; I start the fitted sheet from the top and I roll him the other way and finish the bed without help.

The wife of a man who required daily transportation for rehabilitative therapy recounted her efforts to solve a scheduling problem:

> Well I knew that him getting therapy meant he had to be ready early . . . and they [the home health aides] never could get him ready in time. He was missing therapy, so I started getting him up early, bathing and dressing him so he would make that therapy. . . .

Often, caregivers described how they worked with the stroke survivor as a team to solve problems. The wife of a stroke survivor described their joint efforts to manage his hemiparesis:

> I use a belt and transfer board. . . . At times he is able to balance himself better. . . . Since his paralysis is on his left side, he helps me with his right foot and hand and he moves onto the transfer board. . . . I put the belt around him, put the board under him . . . we move when I count to three and he puts his all into it and so do I. . . .

To solve the problems they encountered, caregivers reported using a combination of hope and faith: "It's our faith that gets us through." "We just trust in God and hope for the best. . . ." "We hold onto our hope; we don't give up hope." Most of the caregivers reported seeking and using the support of family, friends, and neighbors. However, caregivers frequently acknowledged limitations in the support provided by others: "There is only so much others can do. . . . " "Others come by and call, but they can't do the things you need." Caregivers also noted their personal responsibility to care for the stroke survivor: "I'm his wife; it's my responsibility. . . ." "I would feel guilty if others did this; it's unnecessary when I can stay home. . . . " "We all have our problems; we do what we need to do. . . ." "This is how it is; she knows I'm there for her." "Others come and sit, but they don't help with the care."

Constructing the reality of recovery

In interviews, care providers regularly verbalized their belief that the stroke survivor was recovering. The daughter of an aged woman with hemiparesis described it by stating the following:

> She was weak as far as coordination is concerned. . . . Since she has been home, she has been steadily improving. . . . I think slowly—but surely—it is coming along . . . it's getting better. I talk to her and she is better.

The daughter of an aged woman with hemiparesis and speech deficits described how her mother was improving:

> Everything is looking up; no needs so far; like I say, she is getting better. . . . So in other words, she is just doing great. . . .

The wife of a man with hemiparesis stated,

> I stand by and help him . . . I don't let him go on his own. . . . He is doing so much better . . . since he went to his last exam. . . . I talk to him and tell him we are going to work together to make it better and I stay with him . . . . It is not as bad as it used to be. . . . He is doing good, oh yes, he is doing much better.

The daughter of a woman with hemiparesis recounted this:

> Well, we are just working . . . and she is coming a long way from doing what she did last week. . . . She is opening the refrigerator; she can bend over . . . after she does it one time—she knows how for the next time. It didn't work out the way [we expected it to], but we are working on it. . . . She wants to be back to herself again. That is what she is working toward. I think we are doing fine . . . and I think she has gone a long way. . . . It just seems like every day, you can see how much better she is and how much more confidence she has in herself.

Caregivers also reported describing the recovery progress to the stroke survivor: "I told him he is doing better. . . ." "She knows she is getting stronger. . . ." "He doesn't always agree, but I tell him he is doing good. . . ." "When she says she can't manage it, I tell her she is coming along. . . ."

Giving meaning to the experience

When asked how they managed problems, caregivers reported finding personal meaning in the caregiving experience:

> I'm old fashioned; I do all I can for him . . . sometimes I do too much. . . . I still assist him. . . . I watched him from where he was to where he is now and that is good to me.

> I'm glad she is here . . . the positive for me is the fact that she got through this without it being even more serious. . . . She could have gone altogether. . . . So it is positive from my point of view that she is home. . . . She is afraid that she will end up a burden. . . . I told her, look, that is part of it. I'm not going anywhere . . . perhaps we can, it can be controlled.

> I feel like I am giving back to her and it is when I am taking care of her that I don't have to worry if she is being mistreated, or whether things are being done properly . . . because I know she is being cared for.

In caring for a stroke survivor at home, caregivers must make daily decisions about the changing health status of a family member with significant physical and cognitive limitations and take appropriate action.

DISCUSSION

Sims, Boland, and O'Neill[13] observed that family members who provide home care are expected to take responsibility for activities traditionally done by professionals. In caring for a stroke survivor at home, caregivers must make daily decisions about the changing health status of a family member with significant physical and cognitive limitations and take appropriate action. To successfully manage home care, the findings from this study indicate that caregivers of stroke survivors use four types of management strategies.

First, the strategy of practicing situational vigilance is one of the central activities of family members in the home care setting. Caregivers practiced situational vigilance in monitoring the stroke survivor's condition and environment. This process of patient monitoring by the family caregiver has been noted in previous studies. Kuhn[14] observed that family caregivers of an elderly relative regularly reported assessing the patient's symptoms. Dura, Haywood-Niler, and Kiecolt-Glaser[15] noted that spousal caregivers closely follow symptom changes in elderly individuals with cognitive impairments.

Second, caregivers regularly reported creating solutions to problems. They identified their most important problems as those concerned with the stroke survivor's physical and functional losses. Caregivers often reported managing problems alone or with the help of the stroke survivor. Further, they frequently noted limitations or a mismatch between specific available resources and their needs. Sims, Boland, and O'Neill[13] also noted that home care solutions evolve from the ways in which family members frame, or give meaning to, a problem. These caregivers framed their problems as being solvable only by themselves. Caregiver reluctance to seek or use assistance from others has been described previously in the literature.[16,17] Collins and colleagues[18] reported that spousal caregivers believe themselves to be exclusively responsible for their disabled relative and often are unable to accept available community services. In the current study, the comments by these caregivers that others could not help, would not help, or were unable to provide the appropriate services likely reflect these caregivers' conclusions that they alone must retain ultimate responsibility for the care of the vulnerable family member with severe cognitive and communication deficits. Phillips and Rempusheski[19] noted that successful family caregiving is predicated on an individual's acceptance of a caregiver role. In this study, the strategies caregivers described to reassure the stroke survivors that they "will be there for them" may well represent their efforts to justify their decision to take on the primary caregiver role.

Third, when asked how they managed selected problems, all caregivers engaged in conversations with the interviewers to describe the stroke survivor's rehabilitative progress. A social constructionist perspective suggests that caregivers were constructing the reality of recovery for themselves. Caregivers consistently began with negative statements on the current health status of the stroke survivor, such as "Well, she is still weak. . . ." They then ended with positive statements about the stroke survivor's progress, such as ". . . but she is getting better. . . ." This finding indicates the caregiver's effort to construct the reality of recovery by projecting beyond the context of the stroke survivor's current limitations.

Johnson and Morse[20] described the efforts myocardial infarction survivors make to regain personal control of their lives after a coronary episode. Keller[21] noted similar efforts on the part of postcardiac surgery patients and classified this phenomenon as seeking normalcy. The repeated efforts of caregivers of stroke survivors to identify and describe convalescent progress during this acute phase of stroke recovery were construed to represent their own tentative first steps toward regaining control and seeking normalcy in their life and the life of their families.

A fourth type of management strategy, giving meaning to the experience, was evident in caregivers' discussions about the value and significance of their caregiving—

both for themselves and the stroke survivors. Farran and Keane-Hagerty[22] hypothesized two stages for finding meaning in experiences. The search for provisional meaning reflects an individual's effort to find personal meaning and purpose in an experience (eg, "something good will result from this experience"), and the search for ultimate meaning reflects an effort to relate the experience to a larger, philosophical, spiritual, or religious meaning (eg, "My Christian beliefs support my doing this"). In the current study, caregivers' comments on the value of caregiving for themselves and for the stroke survivor during the acute stages of recovery reflected their conclusions about the provisional meaning of the caregiving experience. It is likely that the stroke episode was too recent for caregivers to have incorporated the ultimate meaning of the experience into their lives.

The finding that caregivers often reported that they felt they had little choice but to solve problems without the assistance of others demonstrates the crucial need to integrate hospital discharge planning programs and transitional and home care nursing services. A good example of lack of communication between a hospital discharge planning program and home care services was noted in the response of one family caregiver who reported the hospital discharge planner, without performing a home environment assessment, had ordered an assistive lifting device to aid in transferring her hemiplegic spouse from the wheelchair to the tub. When the lift arrived, it could not be used because it was too large for the bathroom.

Findings from this study support additional exploration of the management strategies of family caregivers. For example, the next phase of the current study includes 1-year poststroke follow-up interviews with these eight caregivers to explore the ultimate meanings they construct for the caregiving experience. Because this study focused on caregiving for stroke survivors who were recovering, future research is needed on how families manage home caregiving when they must construct a terminal reality. In such situations, home care nursing support would be useful to enable families to find meaning in the family caregiving experience. Currently, interviews are in progress to explore the management strategies of caregivers for stroke survivors who have a history of repeated stroke episodes and a poor prognosis.

The current study used interviews with caregivers of stroke survivors as a means of exploring the management strategies they used to solve the home care problems they encountered. Social construction theory suggests that these interviews were social interventions that helped families construct the changing reality of their world. Long-term follow-up also is anticipated to explore how these interviews and conversations were helpful to these caregivers.

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The management strategies reported by family caregivers of stroke survivors have implications for hospital discharge planners and home care providers. Given that family caregivers spend time in assessing and evaluating the ill family member's symptoms as well as functioning as the primary home care problem solver, more attention should be placed on helping families to develop, refine, and expand their repertoire of problem-solving skills. For example, in addition to family education on stroke risk factors, family caregivers of stroke survivors might be familiarized with simple techniques for assessing changes in level of consciousness and muscle strength.

Finally, the literature suggests that family caregiver management strategies are created through social interactions and conversations between the caregiver and stroke survivor, other family members, and health professionals. In that caregivers reported management strategies to construct the reality of recovery for themselves and the stroke survivor as well as to find meaning in the experience, the most valuable component of discharge planning, transitional, and home care services may be the provision of regular opportunities (eg, through weekly telephone access or periodic home visits) for caregiver–provider conversations around the nature and meaning of caregiving. Such conversations could be crucial to the development of successful family home care management strategies.

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