

Narratives of Family Caregiving: The Process of Making Meaning

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Abstract: Researchers across disciplines have identified meaning as an important influence on family caregivers' responses to caregiving. This paper describes a qualitative inquiry into the process of making meaning used by caregivers. This process includes three interrelated components: expectations, explanations, and strategies. Caregivers used this process to make sense of caregiving in the larger context of their lives, interpreting both the experience of caregiving and their own affective responses. Expectations included predictions for events or behaviors. Explanations incorporated both moral and practical reasoning to account for discrepancies between predicted and actual outcomes. Strategies, actions taken to actualize expectations, were influenced both by desired outcomes and by the presence of an underlying explanation for a given course of action. This paper provides some narrative examples of the process of making meaning to illustrate the components of making meaning and the interrelationships among them. © 2000 John Wiley & Sons, Inc. *Res Nurs Health* 23:424–434, 2000

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Until recently, most published research on family caregiving has described efforts to quantify, describe, predict, or prevent negative outcomes. Negative outcomes were frequently conceptualized as caregiver burden (cf. Given & Given, 1991; Hooyman, Gonyea & Montgomery, 1985; Pruchno, Kleban, Michaels, & Dempsey, 1990; Pruchno & Resch, 1989) or strain (cf. England & Roberts, 1996; Pearlin, Mullan,

Semple, & Skaff, 1990; Vitaliano, Young, & Russo, 1991) and caregiving has been described as “difficult, time-consuming, and emotionally and physically burdensome” (Given & Given, p. 78). This emphasis on the negative aspects of caregiving may be a consequence of the failure of early caregiving instrumentation to discriminate between the experience of caregiving and caregivers' responses to the disabling or fatal illness

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of a loved one, which is the antecedent to caregiving. This decontextualized approach to caregiving may have led researchers to attribute depression, strain, or burden to caregiving rather than to the complex life experiences of which caregiving was a component.

Nolan, Grant, and Ellis (1990), Motenko (1989), and Farran, Keane-Hagerty, Salloway, Kupferer, and Wilkin (1991) suggested that meaning plays a significant role in caregivers' affective responses to caregiving. Nolan et al. found that burden in caregivers was more related to the meaning of particular tasks or events than to the objective features of those events or circumstances, and suggested that caregiving stress was "in the eye of the beholder" (p. 544). Motenko studied the role of gratifications and frustrations in wives of dementia patients and found that wives who described caregiving as a duty experienced less gratification from caregiving than those wives who saw caregiving as reciprocal or nurturing.

Other investigators found that positive meaning mitigated negative responses to caregiving. Farran et al. (1991) used an existential framework to analyze interviews with family caregivers of persons with dementia and found that many of these caregivers were able to find positive meanings in the experience. Farran et al. described this process as "finding meaning through suffering" (p. 483). Folkman (1997) used a stress and coping framework to study spouse and partner caregivers of persons dying from HIV-AIDS. Folkman found that when these caregivers searched for and found meaning, they were able to experience positive psychological states even during this extraordinarily stressful experience.

Several investigators have explored specific expectations or beliefs about caregiving or the caregiving role. Montgomery, Stull, and Borgata (1985) included caregivers' "expectations of care" as a predictor of length of caregiving. Research by Phillips and others (Phillips, Morrison, Steffl, Young, Cromwell, Russell, 1995; Phillips, Rempusheski, & Morrison, 1989) explored the relation between caregivers' beliefs about caregiving, defined as "standards and values... regarding the performance of the caregiving role" (p. 208), and the quality of elder care they provided. In addition, some investigators who used stress and coping theory (Albert, 1992; Braithwaite, 1996; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989) incorporated caregivers' beliefs about caregiving or meanings for caregiving into the construct of caregiving appraisal.

Although there has been some research into caregivers' definitions of or beliefs about caregiving or the care recipient, less is known about the general process by which caregivers make sense of their situations. According to Cartwright, Archbold, Stewart, and Limandri (1994), "knowledge [is] limited about the processes by which families create meaning...in caregiving..." (p. 32). The purpose of this paper is to describe the components of the process of making meaning identified in interviews with 36 family caregivers of physically and/or cognitively disabled adults and teenagers. This paper shows some ways in which the process of making meaning and its components are linked to caregivers' more general ideas about themselves, their lives, and their experiences, and illustrates the ways caregivers make both positive and negative meanings. The analytic methods used to identify the process are described and some stories from within interviews are provided to illustrate positive and negative meanings. The products of the process of making meaning, called story types, are described elsewhere (Ayres, 2000).

METHOD

Design

This study used a triangulated design incorporating two complementary qualitative analytic strategies: thematic; across-case analysis and narrative; within-case analysis (Ayres, Kavanaugh, & Knafl, 2000). The two analyses were integrated via the hermeneutic spiral of interpretation (Reason & Rowan, 1981; Tesch, 1990). The hermeneutic spiral is an interpretive strategy designed for the identification and refinement of meaning in narratives. In the hermeneutic spiral, interpretations grow and change as the investigator adds new information, and at the same time previously isolated information takes on meaning as part of the developing whole; thus the interpretation becomes increasingly complex while remaining faithful to the individual accounts that comprise it. This process is similar to the constant comparative method used in the development of grounded theory (Glaser & Strauss, 1967). Hermeneutic interpretations are constantly revisited and revised as the spiral expands. Hermeneutic strategies for narrative analysis have been described by Sandelowski (1991) and by Ayres and Poirier (1996). In addition, a similar strategy was described by Stevens (1994) as the integration of micro and macro narratives.

Sample

The purposive sample comprised 36 caregivers identified by two home health agencies, two health care providers, and by snowball sampling among caregivers. Purposive sampling was used to ensure inclusion of men and African Americans; caregiving researchers have suggested that meanings for caregiving may be different in these two groups (Barer & Johnson, 1990; Miller & Cafasso, 1992; Walker, Pratt, & Eddy, 1995; Young & Kahana, 1995). A total of 36 caregivers of 44 persons with both physical and cognitive impairments were included in the sample. Some caregivers provided care for more than one person. Three care recipients were enrolled in hospice programs. Demographic information about participants' level of education and income were not collected after requests for these data were identified by two early participants as reasons for their withdrawal from the study. Some demographic characteristics of the sample can be found in Table 1.

Procedure

In every case, in accordance with direction from the human subjects protection committee, potential participants were identified first by a familiar health care provider, who approached them and invited them to participate in the study. For potential participants who expressed interest and gave permission for the provider to do so, the provider telephoned me with the participant's contact information. I then telephoned each potential participant, described the study, and answered questions. Most people I talked to made the decision whether or not to be in the study at that time; a few others waited to make a decision until they had received a packet of study materials including a sample consent form, a project information sheet, and a subset of the interview questions. All of the caregivers who were in the study received this packet before the interview.

Participants were interviewed in their homes or other locations of their choice. Interviews were based on a semi-structured interview guide so that each participant responded to the same set of questions, although the language of some questions was clarified after participants early in the study found them confusing. The interview guide provided participants with opportunities to talk about variables of interest from previous caregiving research ("What sorts of things does your family member need help with?"). Use of open-

ended questions ("What was your family member like before s/he got sick?") and neutral probes gave participants the opportunity to illustrate their answers with stories or to provide evidence for particular conclusions they had drawn. After the interview, I gave each participant a sealed envelope containing \$20. All interviews were tape recorded and I transcribed all interviews verbatim.

Data Analysis

Data were analyzed for this paper using a narrative method developed from reader-response theory (Ayres & Poirier, 1996) and the narrative tools for "overreading" described by Poirier and Ayres (1996), which are consistent with reader-response theory. Overreading is a within-case analytic strategy (Ayres, Kavanaugh, & Knafl, 2000) in which the researcher looks for meaning that is implicit rather than explicit in the interview text. Examples of overreading strategies include the identification of repetitions, in which words or themes are mentioned several times in different portions of the interview; omissions, in which salient topics are avoided or evaded, for example by the respondent answering an interview question with a story on another theme; and incongruencies, in which assertions or beliefs stated in one portion of the interview are contradicted in another portion.

Overreading compares text within individual cases. I also compared each individual account with every other. This step in the analysis led to the identification of a process of making meaning that was used by all caregivers: the iterative interaction of expectations, explanations, and strategies illustrated by Figure 1. Although individual caregivers chose different strategies, based on different explanations, and had very different expectations for results, this pattern of expectations, explanations, and strategies occurred within each account. In addition, this same framework could be used by caregivers to make positive meanings, that is, meanings that sustained caregivers, or negative meanings that made caregiving more difficult.

FINDINGS

Overview

The process of making meaning for the caregivers in this study consisted of expectations, explana-

Table 1. Characteristics of the Sample of 36 Family Caregivers and 44 Recipients of Care

Characteristic	<i>n</i>
Caregiver age group	
< 45 years old	6
45–65 years old	20
> 65 years old	10
Minimum reported age: 39	
Maximum reported age: 92	
Caregiver gender	
Male	11
Female	25
Race/ethnicity of caregiving dyad	
African American	9
White	27
Recipient age group	
< 45 years old	6
45–65 years old	12
> 65 years old	26
Minimum reported age: 14 years	
Maximum reported age: 99 years	
Relationship to caregiver of recipient	
Spouse	14
Parent	18
Child	6
In-law	4
Sibling	1
Other	1
Recipient gender	
Male	19
Female	25
Length of caregiving	
1 year or less	8
2–5 years	17
6–10 years	5
11–20 years	2
> 20 years	4
Minimum reported length of caregiving: 6 weeks	
Maximum reported length of caregiving: 50 years	
Recipient diagnoses (some recipients had more than one diagnosis)	
Stroke	9
Mental retardation	9
Alzheimer's disease, dementia	5
Perceptual deficit (blindness, deafness)	4
Arthritis, orthopedic problems	4
Cancer	4
Heart disease	3
Insulin-dependent diabetes	2
Spinal cord injury	2
Chronic mental illness	1
Traumatic brain injury	1
Parkinson's disease	1
Multiple sclerosis	1
Circulatory problems, stasis ulcer	1
Renal failure	1
Huntington's disease	1

tions, and strategies. These components of the process emerged from the data, and were not part of an a priori model of meaning. Although initial coding categories included respondents' expectations for caregiving ("Before you began taking care of your family member, did you have any ideas about what it would be like?") and strategies for providing care ("Tell me about a typical day for you and your family member"), careful examination of the interviews revealed that caregivers had expectations in a variety of situations and used strategies not only to manage caregiving but also to manage their own responses to it (Ayres, 1998). Furthermore, caregivers were eager to share their reasoning for their expectations, for their choices of strategies, and to account for discrepancies between their expectations for events and their actual outcomes. For this reason, explanations were included as the third component of the process of making meaning.

Caregivers used expectations, explanations, and strategies to integrate caregiving with the larger context of their lives. Their expectations grew out of their life experiences. Their explanations were often based on personal philosophies, moral principles, or strongly held impressions about the nature of the world, about themselves, about their families and friends, or about caring. Caregivers identified expectations, developed explanations, and selected strategies as they anticipated care needs, set priorities, organized daily activities, evaluated and managed their own affective responses, and, in some cases, planned for the future. As events unfolded, caregivers made sense of their situations and responded to them, and those responses both rose out of previous expectations and engendered new ones. In the process, caregivers' explanations provided a basis for their expectations and their choice of strategies. Afterward, caregivers used explanations again to account for the success or failure of their choices.

Interrelationships Among Expectations, Explanations, and Strategies

Expectations, explanations, and strategies functioned interdependently in caregivers' stories. Expectations served as predictors; expectations answered the implied question "What will (or should) happen?" Explanations provided reasons for past, present, and future events; explanations answered the questions, "Why did this happen? Why is this happening? Why will this happen?" Strategies were action plans for the fulfillment of

Expectations influence explanations by providing a norm by which events are interpreted.

Expectations influence strategies as strategies are evaluated against expected outcomes.

Explanations influence expectations by specifying the likelihood of various outcomes.

Strategies influence expectations by specifying desired outcomes.

Explanations influence strategies by specifying what actions are acceptable or appropriate.

Strategies influence explanations when moral or practical reasons are needed to justify actions or outcomes.

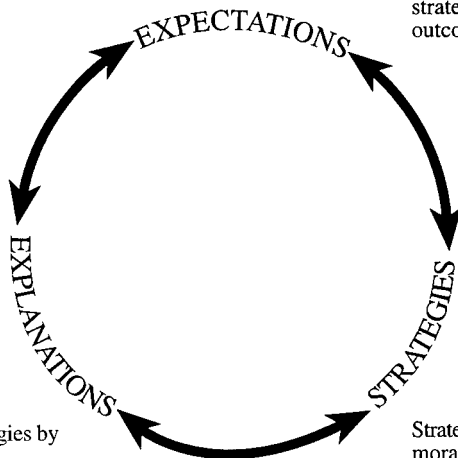


FIGURE 1. Caregivers' process of making meaning. Caregivers used expectations, explanations, and strategies to interpret their circumstances in the context of their lives, to identify those circumstances that required interventions, to select strategies to manage those circumstances, to predict the outcome of a strategy, and to make sense of the events that occurred.

chosen expectations; strategies were developed to answer the question, "How can I accomplish my goal?"

As caregivers made meaning, each of these components influenced the others. That is, expectations influenced explanations by providing a norm against which events were interpreted. At the same time, expectations influenced strategies by providing evaluation standards for outcomes. In the same way, explanations influenced strategies by limiting or increasing the repertoire of possible strategies. Explanations also influenced expectations, since the role of explanations was to account for anticipated or actual outcomes. Finally, expectations served to evaluate the outcomes of strategies as caregivers determined whether particular strategies had been successful. Strategies sometimes influenced explanations after the fact, when caregivers needed a moral or practical justification for a chosen course of action. The following section provides examples of the interactions among expectations, explanations, and strategies in some excerpts from caregiver interviews.

Two Stories from Ms. N

Some caregivers' expectations led to explanations or strategies that increased their options or

widened their outlooks. These stories used explanations and strategies to expand the meaning of caregiving, enabling caregivers to manage new experiences. This story is told by Ms. N, who has cared for her husband since he was disabled by a head injury 7 years ago. As she tells this story, Ms. N interprets events in the context of other expectations and explanations, identified elsewhere in the text: that her husband is not morally accountable for some behaviors because of his injury, that caregiving is an ordinary activity, and that she herself is competent to manage her husband's care in most circumstances. These expectations and explanations enable her to cope successfully with a surprising change in her husband's behavior in a public place.

"I've seen some head-injured people become very combative and try to hit—strike out, at their caregivers. I've never had too many problems with it. But if you provoke him, he will. Which I think in a way is good, because no one's gonna take too much advantage of him. At least when he was a little bit not as involved as he is now. We had one incident when I took him to—I think he was more confused about it than anything else—I took him to the electronics store with me to get a computer part for our daughter's computer. And he simply refused to get back in the car. And I didn't know what to do. And he started swinging at me a little bit. But he moves so slowly, I can just duck, you know. But he just simply didn't understand that I wanted him to

get back in the car and go home. So I didn't know what to do. I called the storekeeper, inside the store, and said "Well, I can't leave him, and I wondered. . ." and he said, "Just call the police. And that'll intimidate him." So the village had THREE squad cars, you know, it was probably their big crime spree of the week. [laughter] So they talked to him and he seemed to be a little intimidated—they understood the problem, he wasn't a criminal or anything, he was just confused, so he told him, he said, "Well, I think I'll get back in the car now." [laughter] So that was our one incident, you know. And they offered to follow me home and everything and I said, "No, I don't think that will be necessary." I was hoping it wouldn't be. I didn't want a trail of cars coming down the street. . . And when I got home, I didn't have any problem, he got out and I've never had another problem with him, you know."

Throughout this interview, Ms. N told a story of caregiving as a normal or ordinary activity of everyday life like raising children or owning a house. She frames this episode as an unexpected event in an ordinary day, not, like some other respondents, as part of a series of management crises, as evidence of her own incapacity to manage caregiving tasks, or as proof of the recipient's unworthiness for care. First, she explains that combative behavior in itself fits within her expectations for her people with head injuries like her husband's: "I've seen some head-injured people become combative." Second, she interprets "combative" behavior as helpful to her husband, because "no one's gonna take too much advantage of him." Then she explains why she did not feel angry or threatened by her husband's outburst, and why she does not blame him. She says that being combative in these circumstances was not aimed at her, and was a symptom of N's disability, not his character: "He didn't understand. . . I think he was more confused. . . than anything else."

Her explanation of his behavior as just another symptom led to her strategies to manage both his behavior and her response to it. First she minimized the severity of the outburst, making exoneration easier: "He started swinging at me *a bit*." Then she explained how easily she managed: "He moves so slowly, I can just duck." Still, having assessed her husband's behavior, she decided that they needed some help: "I didn't know what to do." She never suggests that she was embarrassed or ashamed, either for herself or her husband. Because there was no stigma attached, asking for outside help was easy: "I called the shopkeeper, inside the store." She did not interpret the shopkeeper's response as stigmatizing, either. "Call the police," the preferred strategy, is described not as a sign of failure on her

part but as a part of an overall intervention. She expects the police to "intimidate him." Events fulfilled the expectation: "He seemed to be a little intimidated." The police reinforced her explanation of her husband's behavior as a symptom, not a character flaw: "He wasn't a criminal or anything, he was just confused." As further support for her explanations, she reports success: "He got back in the car." The police offered to follow her home, but that didn't fit with Ms. N's explanation of the source of his confusion (being in the parking lot of the electronics store, a strange place) or her expectations of her own abilities to manage his behavior (able to take care of things on her own turf), so she said no. And her expectations were fulfilled: "When I got home, I didn't have any problem." Furthermore, although she is now prepared for such an eventuality and has added it to her list of expected behaviors and successful strategies, she has never needed to call the police again: "I've never had another problem with him."

On the other hand, this same caregiver did not exonerate everyone she knew from the consequences of their actions. In the following story, another meaning in another context is incorporated: that there is nothing good about her husband's extended family. She expects them to interfere with her caregiving, and for that interference to have bad consequences. She explains their interference and the resulting bad outcomes as consequences of both her extended family's character flaws and their ulterior motives. These expectations and explanations constrain Ms. N's options and color her future expectations, thus reducing Ms. N's ability to make positive meanings out of her situation.

[His parents] went to the daycare once and the social worker said they were some of the most obnoxious people she'd ever met in her life. And one summer he—I was working, I had to work most of that summer—and the in-laws said, "Why don't you bring N out and we'll keep him for a couple of days." And I had to take our car in to be fixed and it turned out that they had to keep it for a lot longer than they thought they were going to keep it cause they had to get a part from Detroit. Fortunately, it didn't cost us anything, but the car didn't work for awhile. So that was OK, and I was able to get to work by bus, and they had my kids with them and they had N. For a couple days. He apparently thought I'd deserted him. Even though I talked to him every night. He thought I had deserted him and he tried to commit suicide. It wasn't a real serious attempt but. . . And one of them said, they said to me at that point, "We didn't realize how much he depended on you." I think they were trying to see if they could just take him. You know. What he would do

if they did. And the one [aunt], she called me at work, she was in a panic, and she said, "I have to take responsibility," she said, basically, "I laughed at him when he told me he was depressed." You know. She said, "I didn't pay attention." And then our daughter found him and that was really kind of bad, and they felt bad about that. It didn't seem to have a big effect on him—I don't think it was a real serious attempt—but still, it could have. But fortunately he wasn't hurt at all. But we did take him to the doctor the next day, you know, the psychiatrist, and that's when they started the stellazine. They gave him an anti-depressant, too, and that seemed to help. But I think the in-laws, at that point, they realized I'm not gonna be shoved out of the situation.

This story actually contains two sets of expectations and explanations. The first set condemns "the in-laws." Ms. N offers expert evidence that they are "obnoxious" people, who want to take over care for Mr. N but are neither worthy nor qualified to do so. During the course of the interview, Ms. N told many stories about Mr. N's family, all with this same set of expectations and explanations, all more or less condemnatory. The second set of expectations and explanations involves Mr. N, the object of their dispute. As previously noted, Mr. N is not responsible for his actions by virtue of his injury. Ms. N uses dramatic language ("...he tried to commit suicide") in the context of his family's inadequate care but reduces the intensity ("...not a real serious attempt," stated twice) when describing Mr. N's actions in the context of his illness. Ms. N used similar minimizing language for the parking lot story told above ("...he started swinging at me *a bit*"). Only the expectations for "the in-laws" are discussed in this section.

This might have been an ordinary story of family cooperation. Ms. N's car had broken down. She needed the car to get her children to school and her husband to daycare and herself to work. Without a car, her carefully organized schedule was no longer possible, so she needed a different strategy. One plan might be that Ms. N could accomplish all of her goals by getting some outside help, in the same way that she got Mr. N back in the car with the aid of the shopkeeper and the police. But, as Ms. N has explained previously in the interview, neither she nor her husband can expect to benefit from her in-laws' interventions, both because "the in-laws" are less competent than she and because they have ulterior, less honorable motives.

Ms. N has an ongoing dispute with her in-laws about who can and should provide the best care for Mr. N. Ms. N believes her in-laws want control over her husband so they can control his

money; she, on the other hand, cares for him out of affection and "to keep our family together." The meaning Ms. N makes from the in-law story, and the explanation for which this story provides evidence, is that the in-laws are unworthy to care for Mr. N, whose best interests concern them less than his net worth (an explanation offered, with evidence, in other parts of the interview). Ms. N expects that her husband would suffer emotionally, as he did in this instance, because he needs his wife: "He though I had deserted him." Ms. N, unlike her in-laws, had anticipated (expected) that the change in his routine might upset him. She explained this upset as Mr. N missing her, although she does not offer evidence for this explanation. She describes her strategy to prevent him from thinking she had deserted him—"I talked to him every night"—but this strategy was not successful. Ms. N explains her husband's upset as a consequence of his family's careless planning: "We didn't realize how much he depended on you." Furthermore, Ms. N explains the whole incident in terms of an unworthy motive: "I think they were trying to see if they could just take him [from me]." For Ms. N, this was not a story about the unfortunate results of Mr. N's confusion in a strange place exacerbated by inexperienced caregivers who misinterpreted his behavior; rather, this is a story about the successful prevention of a coup.

Ms. N makes one meaning of this story: "I think they realized...I'm not gonna be shoved out of the situation." She reports additional evidence against "the in-laws," quoting the aunt who said, "I laughed at him when he was depressed." Not only that, Ms. N's own children were put at risk: "Our daughter found him, and that was really kind of bad."

Once Ms. N was back in charge, she was able to bring the story to a successful conclusion. Despite her situational explanation of her husband's behavior, that he thought she had deserted him, her strategy is based on a medical model of depression. "But we did take him to the [psychiatrist] the next day...and that's when they started the stellazine...[and] an antidepressant." She never returns to the subject of the effect of this event on her daughter, nor does she question the adequacy of her strategy of calling her husband every night, or suggest that she might instead have made regular visits during their separation.

Listeners or readers may be uncomfortable with stories that integrate expectations of bad behavior, illustrated with evidence that confirms those expectations and supported by explanations

that seem to omit other points of view. Such stories often contain inconsistencies, such as the apparent double standard that exonerates Ms. N from any responsibility for Mr. N's distress while making serious accusations about the values and competence of his extended family. A reader, outside the situation, might wonder about the motives attributed to Ms. N's in-laws—is it possible that they might not share Ms. N's evaluation of the care she provides, or of their own desire to care for Mr. N? One-sided stories restrict the narrator's possible expectations and explanations, and the absence of other points of view alerts the interpreter to unresolved tension in the narrative. At the same time, such stories limit the strategic options of the narrator. As long as Ms. N continues to expect her in-laws to work against her, their offers of help will be met with suspicion and their strategies will be rejected, or perhaps even sabotaged. This example can be contrasted to Ms. N's story about the parking lot, in which Ms. N made positive meanings. The meaning of this story, at least as regards Ms. N's in-laws, is negative, and Ms. N may use the meanings from this story to justify future negative expectations of the in-laws or to explain future strategies that distance Mr. and Ms. N from Mr. N's family.

Ms. C's Story

Negative expectations about the recipient of care combined with rule-based expectations that are difficult to adapt to changing situations narrow options even further. Ms. C, a woman who cares for her disabled father, describes her struggles to care for her father, placed in the specific context of finding a new way to bathe him:

The only thing we don't have is the shower. So that's my question now at the end is I've got to figure out what I'm doing, you know? Do I put him in a home, do I get someone to come in and help me, because we're gonna have to haul him upstairs—he should take a shower. You need a shower. You see, HE doesn't think so. And I wash him up everyday, I sponge bathe him every day, you know, so that's fine. So that's the rock and the hard place now of where we're gonna be. So fortunately or unfortunately—you see, I've been asking—I pray a lot and I've been asking God for a fax or for something to tell me what to do.

She has an expectation. "He should take a shower." Her expectation is linked by the word "should" to her explanation about the overall importance of showers: "You need a shower." One of the more general expectations Ms. C has for her father, which she illustrated with a number

of examples, is that since her father has been disabled, he has "given up" on taking care of himself. She sees his disinterest in showering as another example of his giving up, saying here, "HE doesn't think so." Ms. C has a choice of strategies. "Do I put him in a home or do I get someone to come in and help me, because we're gonna have to haul him upstairs." The stairs in question are a steep flight of 14 steps to the second floor of her home, which her father in his walker is unable to manage, even with help. Now she is searching desperately for an explanation—"a fax" from God—to justify the two strategies she describes: to "put him in a home" or "get someone to come in and help me."

Although she describes expectations about hygiene, the larger context of her problem is not how to keep her father clean, but whether or not she must continue to care for him, the real object of her hoped-for "fax." Her desired strategy, as she repeats many times throughout the interview, is to institutionalize her father or, failing that, to find some home help. Her desire for these strategies prevents Ms. C from changing her expectations. Another caregiver might give up on "He should take a shower" and choose instead a new expectation: "Now that he can't manage the stairs, he needs another way to stay clean." Other explanations, such as "A sponge bath is just as good as a shower at this age," justify bathing strategies that Ms. C could accomplish without outside help, strategies that fail to resolve the tension in her story around whether or not she should continue to care for her father at home. This example illustrates the force a chosen plan of action exerts on the caregiver's range of explanations.

DISCUSSION

Cartwright et al. (1994) identified biography as an important influence on meaning in family caregiving. Corbin and Strauss (1988) described biographical work, a process of making meaning, as a component of living with chronic illness. Biographical work is a process by which persons living with chronic illness make sense of their experience by "recapturing the past, examining the present, and projecting into the future—all interpreted in the light of the present" (1988, p. 70). Biographical work demonstrates the integration of a particular circumstance, chronic illness, within a larger context, "the past. . .present. . .and future." It may be that caregivers, too, are doing biographical work as they make sense of the

changes that the illness and disability of a loved one have made in their lives.

Other investigators have addressed particular components of the process of making meaning, particularly expectations and strategies. A number of investigators have identified or alluded to caregivers' expectations of caregiving as influential in caregivers' experience of burden or strain (Archbold, Stewart, Greenlick, & Harvath, 1990; Archbold et al., 1995; Cossette & Levesque, 1993; Kurtz, Kurtz, Given, & Given, 1995; Pagel, Becker, & Coppel, 1985; Pallett, 1990; Phillips et al., 1995; Williams, Oberst, Bjorklund, & Hughes, 1996). In general, these investigators have considered only expectations directly related to the work of caregiving or the caregiving role. For example, Archbold et al. (1995) conceptualized expectations for caregiving as "preparedness" and found that caregivers whose expectations for caregiving did not match their experiences demonstrated greater role strain than caregivers whose expectations were realized in caregiving.

Other researchers, notably Phillips et al. (1989, 1995), have explored the relationship between caregivers' expectations and strategies as part of a systematic investigation of poor quality family caregiving for elders. The construct of Caregiving Dogmatism, defined as "beliefs...that are based on a priori truth and assumptions rather than empirical evidence" seems to underlie the negative expectations, explanations, and strategies described in Ms. C's story. Ms. C's desired strategies, either to find someone to help her bathe her father or to institutionalize him, grow out of the situational expectation that "he needs a shower." This expectation in turn is justified by the more universal explanation that "you" need to shower. The identification of the framework of expectations, explanations, and strategies builds on the work of Phillips et al. by explicitly identifying the role of explanations as a link to both expectations, for example a priori truths and assumptions, and strategies. In their research, Phillips et al. described the relation of caregivers' beliefs to the provision of good or poor quality caregiving.

Explanations play a crucial role in caregivers' construction of meaning. Explanations are important when caregivers' expectations are not met or when rigid, negative explanations such as dishonorable motive or bad character limit caregivers' strategies. Conversely, explanations of caregiving as an ordinary activity that the caregiver is competent to manage allow the caregiver to be more flexible in response to new situations.

In this regard, explanations resemble appraisals in that, when caregivers explain events as normal or ordinary, such events are not perceived as threats to the caregiver's sense of safety or well-being and thus reduce stress (Braithwaite, 1996). Explanations, however, are broader than appraisals. Explanations go beyond evaluations of events as threatening or benign, because they serve to integrate particular experiences with caregivers' more general meanings, for example that "you need a shower" or that sometimes combative behavior is useful. Combined with caregivers' expectations for action in particular circumstances and the more general inferences about the world and its inhabitants by which caregivers evaluate meaningfulness in their lives, explanations bring caregivers' moral as well as practical reasoning to bear on their situations, and thus strongly influence both choice of strategy and likelihood of success. There is no doubt that some caregivers interpret their experiences as extraordinary, difficult, and burdensome. On the other hand, caregivers whose explanations emphasize manageability and ordinariness might find very different meanings, even in externally similar circumstances.

For these reasons, further research is clearly indicated to measure, rather than just describe, the components of caregivers' expectations, explanations, and strategies. Such research could identify explanations associated with flexible expectations and successful, good quality strategies, as well as provide clinicians with tools to predict those caregivers at risk for difficulty. Knowledge about caregivers with positive meanings could then be incorporated into interventions or other services for caregivers at risk. Nursing interventions could help caregivers discover new expectations, explain their situations more positively, or find new strategies that both provide more satisfaction and are more consistent with good quality care.

In conclusion, as caregiving becomes a common experience for families, researchers on caregiving have begun to incorporate meaning in their investigations of caregivers' experiences. It may be that for many, caregiving is an ordinary circumstance like marriage or parenting, in which individuals assume substantial responsibilities whose meanings are more complex than, although related to, the responsibilities themselves. Because nurses also choose to care for others in the context of meanings that may be more complex than their everyday responsibilities, nursing research has particular promise in illuminating this point of view.

REFERENCES

- Albert, S.M. (1992). Psychometric investigation of a belief system: Caregiving to the chronically ill parent. *Social Science & Medicine*, 35, 699–709.
- Archbold, P.G., Stewart, B.J., Greenlick, M.R., & Harvath, T.A. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health*, 12, 375–384.
- Archbold, P.G., Stewart, B.J., Miller, L.L., Harvath, T.A., Greenlick, M.R., Van Buren, L., Kirschling, J.M., Valanis, B.G., Brody, K.K., Schook, J.E., & Hagan, J.M. (1995). The PREP system of nursing interventions: A pilot test with families caring for older members. *Research in Nursing & Health*, 18, 3–16.
- Ayres, L. (1998, March). "I just say, Help me, Lord:" Family caregivers' strategies to manage emotional distress. Midwest Nursing Research Society 22nd Annual Conference, Columbus, OH.
- Ayres, L. (2000). Narratives of family caregiving: Four story types. *Research in Nursing & Health*, 23, 359–371.
- Ayres, L., Kavanaugh, K., & Knafl, K.A. (2000). Within- and across-case approaches to qualitative data analysis. Manuscript submitted for publication.
- Ayres, L., & Poirier, S. (1996). Virtual text and the growth of meaning in qualitative analysis. *Research in Nursing & Health*, 19, 163–169.
- Barer, B.M., & Johnson, C.J. (1990). A critique of the caregiving literature. *The Gerontologist*, 30, 26–29.
- Braithwaite, V. (1996). Between stressors and outcomes: Can we simplify caregiving process variables? *The Gerontologist*, 36, 42–53.
- Cartwright, J.C., Archbold, P.A., Stewart, B.J., & Limandri, B. (1994). Enrichment processes in family caregiving to frail elders. *ANS: Advances in Nursing Science*, 17, 31–34.
- Corbin, J.M., & Strauss, A. (1988). *Unending work and care*. San Francisco: Jossey Bass.
- Cossette, S., & Levesque, L. (1993). Caregiving tasks as predictors of mental health of wife caregivers of men with chronic obstructive pulmonary disease. *Research in Nursing & Health*, 16, 251–263.
- England, M., & Roberts, B.L. (1996). Theoretical and psychometric analysis of caregiver strain. *Research in Nursing & Health*, 19, 499–510.
- Farran, C.J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilkin, C.S. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. *The Gerontologist*, 31, 175–183.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science & Medicine*, 45, 1207–1221.
- Given, B.A., & Given, C.W. (1991). Family caregiving for the elderly. In J.J. Fitzpatrick, R.L. Taunton, & A.K. Jacox (Eds.), *Annual review of nursing research* Vol. 9, pp. 77–101. New York: Springer Publishing Co.
- Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory*. New York: Aldine de Gruyter.
- Hooyman, N., Gonyea, J., & Montgomery, R. (1985). The impact of in-home services termination on family caregivers. *The Gerontologist*, 25, 612–617.
- Kurtz, M.E., Kurtz, J.C., Given, C.W., & Given, B. (1995). Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states, and depression. *Social Science & Medicine*, 6, 837–846.
- Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology: Psychological Sciences*, 44, 61–71.
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *Gerontologist*, 32, 498–507.
- Montgomery, R., Stull, D., & Borgatta, E. (1985). Measurement and analysis of caregiver burden. *Research on Aging*, 7, 137–152.
- Motenko, A.K. (1989). The frustrations, gratifications and well-being of dementia caregivers. *The Gerontologist*, 29, 166–172.
- Nolan, M.R., Grant, G., & Ellis, N.C. (1990). Stress is in the eye of the beholder: Reconceptualizing the measurement of caregiver burden. *Journal of Advanced Nursing*, 15, 544–555.
- Pagel, M.D., Becker, J., & Coppel, D.B. (1985). Loss of control, self-blame, and depression: An investigation of spouse caregivers of Alzheimer's disease patients. *Journal of Abnormal Psychology*, 2, 169–182.
- Pallet, P.J. (1990). A conceptual framework for studying family caregiver burden in Alzheimer's-type dementia. *Image: Journal of Nursing Scholarship*, 22, 52–58.
- Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583–594.
- Phillips, L.R., Morrison, E., Steffl, B., Young, M.C., Cromwell, S.L., & Russell, C.K. (1995). Effects of situational context and interactional process on the quality of family caregiving. *Research in Nursing & Health*, 18, 205–216.
- Phillips, L.R., Rempusheski, V., & Morrison, E. (1989). Developing and testing the beliefs about caregiving scale. *Research in Nursing & Health*, 12, 207–220.
- Poirier, S., & Ayres, L. (1997). Endings, secrets, and silences: Overreading in narrative inquiry. *Research in Nursing & Health*, 20, 551–557.
- Pruchno, R.A., Kleban, M.H., Michaels, J.E., & Dempsey, N.P. (1990). Mental and physical health of caregiving spouses: Development of a causal model. *Journal of Gerontology: Psychological Sciences*, 45, 192–199.
- Pruchno, R.A., & Resch, N. (1989). Husbands and wives as caregivers: Antecedents of depression and burden. *The Gerontologist*, 29, 159–165.

- Reason, P., & Rowan, J. (1981). *Human inquiry: A sourcebook of new paradigm research*. Chichester, NY: Wiley.
- Sandelowski, M. (1991). Telling stories: Narrative approaches in qualitative research. *Image: Journal of Nursing Scholarship*, 23, 161–166.
- Stevens, P.E. (1994). Lesbians' health-related experiences of care and noncare. *Western Journal of Nursing Research*, 16, 639–659.
- Tesch, R. (1990). *Qualitative research*. New York: The Falmer Press.
- Vitaliano, P.P., Young, H.M., & Russo, J. (1991). Burden: A review of measures used among caregivers of individuals with dementia. *The Gerontologist*, 31, 67–75.
- Walker, A.J., Pratt, C.C., & Eddy, L. (1995). Informal caregiving to family members: A critical review. *Family Relations*, 44, 402–411.
- Williams, M.A., Oberst, M.T., Bjorklund, B.C., & Hughes, S.H. (1996). Family caregiving in cases of hip fracture. *Rehabilitation Nursing*, 21, 124–131.
- Young, R.F., & Kahana, E. (1995). The context of caregiving and well-being outcomes among African and Caucasian Americans. *The Gerontologist*, 35, 225–232.