

Narratives of Family Caregiving: Four Story Types

Lioness Ayres*

School of Nursing, University of Wisconsin–Madison, Clinical Science Center, 600 Highland Avenue,
Madison, WI 53792-2455

Received 3 March 1999; accepted 15 February 2000

Abstract: Researchers across disciplines have recognized considerable individual variation among caregivers in their response to the experiences of caregiving. One explanation for individual variation is that caregivers make different meanings from caregiving even under externally similar circumstances. This paper describes findings from a study that combined two qualitative strategies, across-case, thematic analysis and within-case, narrative analysis, to investigate meaning in accounts of family caregiving. Themes identified in the across-case analysis were interpreted in the context of patterns identified in the narrative analysis, as well as in the overall framework of caregivers' process of making meaning. Caregivers in this study told four types of stories: stories of ideal lives, stories of ordinary lives, stories of compromised lives, and ambiguous stories. Characteristics of each story type are described, and an example of an ambiguous story is also included as an illustration of the method. Findings suggest a new approach to understanding family caregiving that incorporates the diverse meanings caregivers make of their often similar experiences. © 2000 John Wiley & Sons, Inc. *Res Nurs Health* 23:359–371, 2000

Keywords: narrative; qualitative research; caregivers

Researchers across disciplines have recognized considerable individual variation among caregivers in their response to the experiences of caregiving (cf., Braithwaite, 1990; Davis, 1992; Haley, Levine, Brown & Bartolucci, 1987; Magai & Cohen, 1998). According to Hooker, Monahan, Bowman, Frazier, & Shifren (1998), “[a] consistent theme in caregiving research is the attempt to understand why caregivers under similar circumstances show such great variability in their ability to adapt to the situation” (p. P73). They

proposed that this variability was a result of personality; that is, that “[p]eople assign meaning to a situation through an interactive process in which personality plays a key role...” (p. P73). They studied the influence of personality variables including neuroticism and optimism on caregivers' mental and physical health. According to Hooker et al., personality is important because it influences the meanings people assign to situations. Despite the acknowledged importance of meaning, little research to date has

Grateful acknowledgment is made to the University of Illinois at Chicago, and particularly to the College of Nursing, for facilitating this study. Dr. Kathleen Knafl of the College of Nursing and Dr. Suzanne Poirier of the College of Medicine at the University of Illinois at Chicago were tireless and invaluable mentors. Faculty and postdoctoral fellows of the Oregon Health Sciences University School of Nursing provided additional guidance and support.

Contract grant sponsor: Individual National Research Service Award; contract grant number: NRO6602.

Contract grant sponsor: Clinical Scholars Grant, West Suburban Hospital Medical Center.

Correspondence to: Lioness Ayres.

*Assistant Professor.

offered a systematic description of the meanings caregivers assign to caregiving.

As early as 1966 (Hoenig & Hamilton, 1966), researchers who studied family caregiving recognized the central role of individualized meaning in families' experience. Hoenig and Hamilton urged clinicians to recognize that caregiving "may mean totally different things according to the point of view of the patient and his family or of those outside his kin group" (pp. 106–107), or, as suggested by Archbold and Stewart (1996), according to the point of view of the investigator. Hoenig and Hamilton continued, "A 'burden' taken on in loving care . . . may not be regarded as such . . ." (p. 107). Subsequent investigators have recognized the contribution of individual caregivers' perceptions of their experience to the development of strain or burden (Archbold & Stewart Braithwaite, 1996; Haley et al., 1987; Hooker et al., 1998; Nolan, Grant, & Ellis, 1990; Poulshock & Deimling, 1984). Other investigators have studied beliefs about caregiving (Phillips, Rempusheski, & Morrison, 1989; Phillips et al., 1995) and the influence of beliefs about the caregiving role on the quality of care provided. To date, however, less is known about the diverse meanings caregivers both bring to and make from caregiving. Such research would require both a neutral conceptualization of caregiving and a method that allows participants to describe the experience of caregiving in the context of their own lives. The purpose of this paper is to describe a qualitative study in which individual accounts of family caregiving were interpreted using narrative and thematic analysis in order to explore the variety of meanings caregivers brought to and made from their experiences.

METHOD

SAMPLE

Participants in this mixed methods study were recruited by nurses from two home health agencies, by two private health care providers, and through snowball sampling. A description of the sample of 36 caregivers and 44 care recipients appears in Table 1. The maximum variation sampling strategy described by Patton (1990) was used. Sources of variation included race, gender, length of caregiving, and recipient diagnosis, because caregiving researchers have suggested that meanings for caregiving may be influenced by these characteristics (Barer & Johnson, 1990; Barusch & Spaid, 1989; Connell & Gibson, 1997;

Cox, 1995; Davis, 1992; Given & Given, 1991; Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991; Miller & Cafasso, 1992; Pruchno, Kleban, Michaels, & Dempsey, 1990; Schultz, O'Brien, Bookwala, & Fleissner, 1995; Silliman & Sternberg, 1988; Walker, Pratt, & Eddy, 1995; Vitaliano, Young, & Russo, 1991; Young & Kahana, 1995). For this study, recruiters identified persons as African American or White, and I did not ask participants to specify their race or ethnicity. During the second half of data collection, I also asked recruiters to identify and recruit persons who were especially distressed or troubled, to maximize variation on this characteristic.

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 choosing. 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 ("How did you come to be the person taking care of your family member?") 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. I transcribed all interviews verbatim.

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 of recipient to caregiver	
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 ^a	
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

^aSome recipients had more than one diagnosis.

Data Analysis

Interview data were analyzed through an iterative process of comparison called the hermeneutic spiral (Reason & Rowan, 1981; Tesch, 1990), a process in which “the analyst moves back and forth between individual elements of the text and the whole text in many cycles” (Tesch, p. 68). Each cycle integrated three kinds of analytic comparisons: comparisons across all accounts to identify particular themes, subthemes, categories, and classes; comparisons within each individual account to identify meanings that were implicit rather than explicit in the text; and comparisons of one whole account with another to identify overall patterns of meaning. The strategy of integrating within-case and across-case approaches to analyze qualitative data has been explained in more detail elsewhere (Ayres, Kavanaugh, & Knafl, 2000).

For across-case comparisons, data were coded using a hierarchical strategy (Richards & Richards, 1995) in order to identify themes and subthemes. Initial coding categories were reorganized into themes and subthemes through iterative comparisons within and across cases. Themes were then arranged in descending order of complexity into subthemes, categories, and classes; this structure was examined for patterns across cases. A similar analytic procedure was previously described by Knafl, Gallo, Zoeller, Breitmayer, and Ayres (1993). Three general themes were identified: definitions, management activities, and motivations and rewards. Some examples of the hierarchical arrangements of themes, subthemes, categories, and classes of responses are shown in Table 2.

Some interviews were difficult to classify on some categories or classes. For example, individual interviews sometimes provided contradictory or conflicting information about a particular classification within a category. A respondent might state explicitly that his or her relationship with the recipient was “good” or “fine” but provide only examples of mutual antagonism. These interviews required a within-case, narrative approach to interpretation. The narrative approach in this study used the “narrative tools” of overreading described by Poirier and Ayres (1996) to refine and contextualize the ways themes varied across cases. Overreading includes attention to characteristics of texts such as repetitions, evasions, omissions, implied endings, and incongruities. When an interview provided strong evidence for two mutually exclusive classes, for example for definitions of the recipient as both

absolved and unworthy, a new class of “ambiguous” was added to the category “Evaluation of the recipient.” In addition, narrative tools were used to distinguish between missing data and evasions or omissions. For example, if I failed to ask a respondent about his or her previous relationship with the recipient, this information was coded as missing. If, on the other hand, I asked the question and the respondent changed the subject or remained silent, this information was classified as an evasion or an omission respectively.

Generally, overreaders interpret repetitions, evasions, omissions, and incongruities as indications of tension within the narrative, what Kermode (1981) referred to as “secrets.” The use of narrative methods cannot resolve those secrets; rather, the identification of repetitions, evasions, omissions, or incongruities offer an additional kind of data, found “between the lines” of the literal text of the interview. Secrets suggest unresolved conflict or confusion regarding particular areas of experience; however, identification of a secret neither condemns the narrator as unreliable nor privileges the reader to resolve the tension with his or her own explanations. The use of narrative tools to inform the thematic analysis is an example of the cyclical and iterative nature of the hermeneutic spiral, through which findings from each analytic strategy inform the other strategies.

FINDINGS

Categories and classes from the thematic analysis, along with representative quotes from each interview that supported the classification, were displayed in a large, handwritten matrix in order to facilitate analytic immersion and to identify patterns across cases. The matrix also included representative quotes identifying expectations, explanations, and strategies (Ayres, in press) and, where present, evidence of the “secrets” described above. This integration of findings from within-case and across-case analysis facilitated the development of a typology of stories in the tradition of Frank (1995) and Hawkins (1993). Three story types had identifiable meanings: stories of ideal lives, stories of normal or ordinary lives, and stories of lives compromised by caregiving. A fourth group of stories was ambiguous. Each of these stories included components of at least two of the three meanings such that it could not be classified further. Table 3 shows the distribution of the sample by gender,

race, and length of caregiving across the four types of stories.

Stories of Ideal Lives

Only two caregivers in this sample told stories of ideal lives. Both were African American men, one in his 20s and the other in his 50s. Both men took care of the women who had raised them. One recipient of care had a long history of chronic mental illness, whereas the other had been recently disabled.

The two caregivers who told stories of ideal lives had very modest expectations and were satisfied with the way those expectations were realized in caregiving. These narrators explained events in terms of how much better their lives were now than they had been before caregiving. They explained their situation as destiny—something meant to be. One man said, “This is what I was put here for, I guess. This is my calling.”

Caregivers with ideal life stories explained their lives as improved, if not saved, by caregiving. Both men described time lived “on the street” before returning home to provide care and both believed that they would not have survived without changing their ways. As evidence, both alluded to people from the street who had died or were in prison. When asked how he thought other people would describe his life now, one man replied, “Grand.”

Rewards in ideal life stories came from love between caregiver and recipient, and these caregivers interpreted events in a way that emphasized the positives in the recipient’s situation while minimizing or ignoring the negatives. Both tellers of ideal life stories described the importance of the lifelong relationship each had with the recipient of care. Both of these narrators also exonerated the recipient from remarks or behaviors that they would otherwise have found objectionable. For example, one man explained, “You have to be this type of person where you’re gonna say ‘Well, I can put up with this . . . because this is how this person is feeling right now.’” In both cases, caregivers explained that both their love of the recipient and the recipient’s frail health made otherwise unacceptable behaviors tolerable. Consistent with an expectation that sometimes care recipients will not behave as well as they might, and an explanation that these behaviors are due to ill health and thus not to be taken personally, caregivers negotiated care strategies with the recipient and sometimes chose to omit treatments or medications that the

Table 2. Examples of Themes, Subthemes, Categories, and Classes of Responses

Theme	Subtheme	Category	Class
Definitions	Oneself and one's own life	Self as caregiver	Active agent
			Thwarted agent
		Life changed by caregiving	Victim
			Ambiguous
			Life better
	Recipient and relationship	Evaluation of recipient	Life the same
			Life worse
			Ambiguous
		Current relationship	Normal and ordinary
			Absolved
Management activities	Caregiving	Own view	Unworthy
			Ambiguous
			Reciprocal
			Role reversal
			Antagonistic
	Managing care	Priorities	Custodial
			Ambiguous
			Pleasure
			Normal responsibility
			Challenge
	Day to day care		Identity
			Burden
			Ambiguous
	Managing own affect	Positive strategies	
Motivations and rewards	Motivations	Negative strategies	
		Ambiguous responses	
		Duty	Justice
			Relationship
		Affection	
		Other reasons	Destiny
			Appeasement
			Compulsion
			Ambiguous

Table 3. Story Types of 36 Caregivers by Race, Gender, And Length of Caregiving

Story type	Males	Females	Total Caregivers	African American	White	Length of Caregiving
Stories of ideal lives	2		2	2		< 1 year = 1 > 20 years = 1
Stories of normal or ordinary lives	5	12	17	3	14	< 1 year = 2 2–5 years = 11 6–10 years = 2 10–20 years = 1 > 20 years = 1
Stories of lives compromised by caregiving	2	6	8	1	7	< 1 year = 2 2–5 years = 2 6–10 years = 3 > 20 years = 1
Ambiguous stories	2	7	9	3	6	< 1 year = 4 2–5 years = 5

recipient found objectionable. Finally, these caregivers took what appeared to be a short view of the future, because they expected their lives to continue to get better. Neither teller of an ideal story suggested that caregiving might end.

Stories of Normal or Ordinary Lives

Caregivers who told stories of ordinary lives made up the largest group in the sample. Ordinary stories varied widely in the range of difficulties caregivers encountered, the degree of stress they felt outside of caregiving, and the ways in which they responded to those stresses. Diagnoses of care recipients included Huntington's disease, traumatic brain injury, Alzheimer's disease, cardiovascular disease, multiple sclerosis, cancer, mental retardation, and stroke.

Caregivers with stories of ordinary lives had flexible expectations. If strategies failed to succeed on the first try, these caregivers described either revising their strategies or reframing their expectations. Reframing strategies included both explaining outcomes in new ways so they fulfilled expectations and also modifying expectations to match actual outcomes. In either case, caregivers with ordinary life stories constantly identified, executed, and evaluated strategies to manage both the needs of the recipient and their own emotional responses to care. More than any other respondents, this group of caregivers described utilizing community resources to help them manage care responsibilities, and those who did so were unanimously satisfied with the results.

Although caregivers in this group of stories showed considerable flexibility toward the demands of caregiving, such generosity was not always extended to others outside the caregiving dyad. Some tellers of ordinary stories held others, for example family members or health care providers, to stricter standards of accountability, and were quick to condemn coldness, selfishness, or carelessness. Thus in stories of caregiving as an ordinary life the choice to blame or excuse was a deliberate explanation, not a habit of mind. In these stories, caregivers' motivations all included affection for the recipient, and this affection combined with a strong sense of the recipient's point of view to inspire strategies and decisions in which recipients participated as actively as they were able in making decisions about their care.

Caregivers with stories of ordinary lives rejected the word "burden" when applied to their situations, although they acknowledged that "other people" might think caregiving was burdensome. Caregivers with ordinary life stories expected change, both positive and negative; they explained change as a normal characteristic of family life. In this context, caregiving was described as routine, and even crises were minimized and managed. For example, an 83-year old man who took care of his comatose wife said, "People usually say, 'It's pretty bad, isn't it?' I always tell them it's just routine as far as I'm concerned."

Although these caregivers did not worry about the future, they did recognize that there were likely to be disappointments ahead and used this possible darker future as a downward comparison

to improve their appreciation of the present. In general, caregivers who told ordinary stories deliberately chose not to worry about the future, which they called "dwelling." These caregivers felt that dwelling would undermine their emotional well-being, and so they avoided it, sometimes to the extent that they avoided thinking about the future at all except in the most general terms. One woman explained, "You know, I don't know that you dwell on the long term part of it . . . If you begin to sit and think and worry about what's—you don't KNOW what's going to happen."

Stories of Lives Compromised by Caregiving

Diagnoses of care recipients in stories of lives compromised by caregiving included Alzheimer's disease, mental retardation, arthritis, cardiovascular disease, diabetes, spinal cord injury, and cancer. Five of these caregivers were recruited as part of a purposive sampling strategy during the second half of data collection.

Stories of compromised lives were characterized by predictable patterns of inconsistency. Caregivers who felt their lives had been compromised by caregiving described unrealistically high expectations both for themselves and for others. When these expectations were unmet, these stories often revealed a second expectation, of failure. Common explanations of unmet expectations were, "Nothing that I can do is good enough" or "There isn't anything that will help." Such explanations were usually personalized and failure was attributed to flaws in either the recipient's character or the caregiver's own. For example, one unhappy caregiver described herself as "mean" and "stupid" and her mother as "vindictive" and "nasty." Explanations in stories of lives compromised by caregiving evaded or omitted the possibility of unlikely expectations or unworkable strategies. In sharp contrast to stories of caregiving as an ordinary life, caregivers who told stories of lives compromised by caregiving described "dwelling" both on the difficulties of the present and the anticipation of worse things to come. In these stories, even when daily life was relatively free of strain, caregivers "borrowed trouble," anticipating future difficulties. For example, one caregiver said of her elderly father, "Either he'll break a hip at home, or he'll break a hip in a nursing home. Either way I'll feel guilty."

Stories of lives compromised by caregiving were unbalanced. Sometimes narrators so effaced

themselves that only the recipient's version of events seemed to matter; these caregivers saw themselves as victims and sought always to meet the recipient's or other family member's expectations. Other narrators described recipients, other family members, and health care professionals only as illustrations of the multiple ways the narrator's attempts to provide care were thwarted by others. Stories of compromised lives were characterized by evasions, omissions, and misdirections that emphasized only one point of view, most often the caregiver's own but occasionally the recipient's.

Strategies described in these stories were similarly unbalanced and seldom successful, consistent with explanations based on character flaws. Strategies frequently omitted either acknowledgment of the recipient's autonomy or the legitimacy of the caregiver's own well-being. Caregivers who told stories of compromised lives had expectations that seemed impossible to achieve. Some caregivers expected to control all of the recipient's activities and decisions; in other instances stories of lives compromised by caregiving described caregivers who acted against their own better judgment in acceding to the recipient's wishes. The two caregivers in this group who had been providing care for less than 1 year were both finding nursing home placement for the care receivers; other caregivers said that they often thought about institutionalization but at the same time were unable to find an explanation that could rationalize their expectations for themselves as caregivers with this decision. One woman, who would have liked to put her disabled parent in a nursing home, said she was "waiting for a fax from God" because she felt unable to make the decision on her own (Ayres, *in press*).

Many caregivers who talked about compromised lives seemed desperate for attention, acknowledgment, and affirmation, perhaps because their lives seemed to provide so few satisfactions. Yet, consistent with their expectations, they dismissed offers of support by explaining that no one could understand them or their experiences, or by explaining themselves as undeserving. The close relationship between expectation, explanation, and experience in these stories illustrates the difficulty of separating the responsibilities of caregiving from the meaning of caregiving responsibilities, further complicating the measurement task of separating meaning from the caregiver's affective response to those meanings. It was not possible to know, based on evidence in the text, to what degree caregivers'

lives were compromised by external circumstances or the meanings they made of those circumstances.

Ambiguous Stories

The final nine stories in this sample were too ambiguous to classify further. In general, caregivers in this group had been providing care for less time than caregivers in other groups. Diagnoses of care recipients in this group included cancer, perceptual deficits, mental retardation, spinal cord injury, renal failure, and cardiovascular disease.

Like stories of compromised lives, ambiguous stories were difficult to read. As stories, they lacked coherence, offered incomplete explanations, described strategies whose rationales I could never quite understand. They held too many secrets, provided too little evidence, made too many unsupported assertions. In addition, like stories of compromised lives, ambiguous narratives were unbalanced. Narrators of ambiguous stories kept the focus on themselves and rarely acknowledged other points of view, including the recipient's.

In ambiguous stories, the expectations, explanations, and strategies did not fit together. Narrators of ambiguous stories might describe flexible expectations in the context of very controlling strategies, or alternately blame and exonerate recipients of care for the same behaviors. Narrators sometimes described their lives as ideal in one part of a story and as compromised in another. Although literature scholars would describe these narrators as "unreliable," such a description suggests a deliberate deceptiveness that was generally absent from tellers of ambiguous stories. I believe ambiguous stories represent a stage in the process of "getting the story straight," that is, of making meaning in lives that had recently been disrupted by the serious—sometimes terminal—illness of a close family member. Tellers of ambiguous stories seemed to be trying out various combinations of expectations, explanations, and strategies, testing the fit of each version until a story emerged that made sense of their changed circumstances. In ambiguous narratives the frequent inconsistencies, omissions, repetitions, and evasions reflect the attempt to master these changes, both narratively and literally. Ambiguous stories had important secrets, hidden not just from me but from the narrator as well. Because ambiguous stories are the most complex both to describe and to genera-

lize, an example of an ambiguous story is provided here.

The ambiguous story of Ms. A and her husband SA. Ms. A and her husband, S, have survived one horrible year, but Ms. A explains her story as coming at what she calls a plateau. The ambiguity of Ms. A's story comes from her attempts to integrate the story of the horrible year, a story about lives compromised by serious, possibly fatal, illness with the ordinary or even ideal life story Ms. A envisions for them now. In the latter version, the As live happily ever after, leaving behind the horror of S's illness. The challenges of integrating the mutually exclusive possibilities of S dying and S surviving, of putting S's illness behind them, and of finding a happy ending produce the ambiguity in this story.

The As had been married for 20 years when S began to have indigestion, which he ignored. Ms. A says S can be "passive resistive in some ways." S's indigestion turned out to be caused by a tumor. S's responses to treatment were not encouraging: he developed respiratory failure and septicemia. Then, as if to add insult to injury, a CAT scan found widespread metastases. The situation was grave; S talked about suicide. Then, remarkably, he rallied. With hospice support, S was able to go home. At the time of the interview, S was sleeping in his own bedroom, eating at his own kitchen table. Life seemed to be back to normal, a happy ending to a scary story.

Ms. A's narrative, on the surface, is a heroic story of triumph over great odds. In it, Ms. A is the protagonist and other characters play minor roles as they help or hinder her quest to rescue S both from illness and from despair. Ms. A describes the physicians who, without her persistence, might have abandoned S; the nurses who danced the macarena when S felt low; the neighbor who recommended hospice. In this heroic story, even S himself plays an essentially supporting role, the object of actions and reactions by others. In order for this story to make sense, S needs to stay rescued, to be safe not just for now but ever after.

Ms. A is an intelligent woman, and a realist, and she recognizes the improbability of a fairy-tale ending to the story of S's illness. Cancer, the real antagonist, is seldom mentioned. Instead, Ms. A tells the story of epic struggles in which S is delivered safely from a succession of life-threatening complications: respiratory failure, infection, depression. Ms. A offers plenty of evidence for the kind of happy ending she would prefer, and hopes to have found, in which she and S enjoy normal and ordinary lives. She describes

her pleasure in the meal she served to S on the night of the interview: "... turkey and mashed potatoes and gravy and creamed cauliflower and a salad that was mango and cantaloup and cranberries on it and for dessert later he'll have strawberry pie with a little whipped cream. I mean, it's a wonderful diet." A few months ago, such a dinner seemed forever beyond S's reach; until recently, S's nutrients dripped into his stomach through a gastrostomy tube, and frequently came right back out of his mouth, although this last detail was omitted in Ms. A's account and was added instead by S himself. Ms. A, with a little self-mockery, refers to an article she found in a medical journal that has raised her hopes. In this case report, a patient somewhat like S was found not to have metastases at all; the CAT scan was proved wrong. Ms. A tells a story of hope, and provides ample evidence for optimism.

There are signs that perhaps S's expectations are less positive. S has steadfastly refused to dress in the clothes he wore before his illness, although she has urged him to do so. In addition, although they share the same bedroom, S still sleeps in his hospital bed, where his suction machine and infusion pump wait nearby, silently reminding us all of the bad time. The suction machine and infusion pump, like the wheelchair collapsed in the hall, play a very small role in Ms. A's account. Of the wheelchair she says only that they no longer need it but... Here her explanation trails off. Another artifact of the bad time is S's antidepressant medication. S does not think he necessarily needs it, but Ms. A insists. It is very important to Ms. A that S not get depressed again.

Before S was discharged to home, Ms. A managed her negative affect in part by redecorating. In their beautiful modern bedroom, S's little corner is visually astonishing, a grim souvenir of the recent past that Ms. A might prefer, at least for now, to forget. Although I did not usually talk to recipients of care, Ms. A insisted that I meet S, to hear firsthand about the good life they now share. In this, Ms. A's expectation was not met. S's story fit the hospital bed and suction pump, not the beautiful room. When I entered the bedroom, where S was sitting up in his hospital bed watching television, he gestured immediately to the suction machine. "I used to throw up horrible black stuff," he said without preamble. "It used to clog up the tube. I just stuck this in my mouth to suck it up." Part of the complexity of Ms. A's narrative comes from these divergent stories. Ms. A's story is about their current normal, perhaps even ideal, life. S's story is about the horrible

black stuff. Additional ambiguity is introduced by the uncertainty of S's future.

The narrative ambiguity in this story can be seen in the incongruity between the literal text, in which everything is fine and getting better all the time, and the story "between the lines," in which the A's current happiness is only a respite between horror and loss, a story in which their lives have unquestionably been compromised, not by caregiving but by illness. At the same time she is telling her heroic rescue story, Ms. A told bits of a story with a different ending, in which she lives on alone. "We're riding the plateau," she says of S's current well-being, in a comment inconsistent with her hope for a mistake in the CAT scan:

You know, it is a lot of responsibility, and because S has leveled off and I just try to look at him and think—for the day when this is maybe gonna change and it's gonna be downhill—we're riding on the plateau. And we're enjoying that very much. But I try and think when these are gonna be dark days, how is it going to be? And I guess I'll go back to where I'm feeling anxious and apprehensive and hope that I'll still be able to make all the right decisions that are gonna be important for him. You know, I was a grown woman when I married S, and I knew then that I would be probably a widow for a long time, and so I—I never deluded myself into thinking that he was gonna be there. I had lived an independent life, I paid all my bills—and that is very different than the person who's never had that experience, so, you know, I think that if S starts to decline, I think I'll be able to make those kinds of decisions for him.

Ms. A has already begun to plan for S's decline. Ms. A describes her contingency plan to hire a live-in caregiver to supplant S's home health aide, who now provides all of S's personal care. Although she never explicitly acknowledges it, Ms. A does not provide any of S's physical care. She will gladly make him wonderful dinners, entertain his friends when they come to visit, search the medical literature for advances in cancer care, chase the gastroenterology team into the elevator for a straight answer about a CAT scan, but as for that horrible black stuff, Ms. A is silent. Whether this is not her expectation for herself, or whether she had expected it of herself and been disappointed, remains a secret. If S had expectations for her, these, too, remain undisclosed.

Ms. A's story is ambiguous because it is a work in progress. The ambiguity arises from confusion about the end, and helps to illustrate the force endings exert over meaning. Ms. A's two stories are both about survival, but one story is about her rescue of her husband and the other story is about

her relentless agency on his behalf and then her ability, afterward, to go on without him. In order for either story to be meaningful, S must fulfill his role: to prosper, both physically and psychologically, until the end. Such a story cannot accommodate S suffering or afraid, which may explain Ms. A's insistence on the antidepressants. In addition, Ms. A's story is incompatible with the compromised life story S might choose to tell about his recent experiences and uncertain future. Ms. A's two stories make meanings that sustain her, but this sustenance might come at the expense of S's story to which, as a nurse, I found my sympathies most drawn.

For these reasons, Ms. A made me angry at first, and that anger made it harder for me to interpret her narrative. In addition, as previously noted, ambiguous stories do not lend themselves to definitive interpretations; they are works in progress. Neither Ms. A nor I know yet what taking care of S will mean in Ms. A's life. It is clear that Ms. A's collection of meanings sustain her, and perhaps S as well, in a situation that might easily defeat a less resourceful narrator. Furthermore, the strategies she has chosen are necessary to her well-being, which in turn is necessary to S. Ms. A never describes S as having chosen to come home, one of many omissions and evasions in this, as in all of the ambiguous narratives; nevertheless, if home is where S wants to be, then Ms. A is doing all she can to keep him there. And if only Ms. A will remain at the end of this story, she is also doing all she can to have a story that can sustain her own meaning after S's story ends.

DISCUSSION

Caregivers who told ideal, ordinary, compromised, and ambiguous story types were not strikingly different from one another in age, gender, race, or in the relationship of the caregiver to the care recipient, as shown in Table 3. The two tellers of ideal stories, both of whom were African American, might represent a unique perspective on caregiving. Connell and Gibson (1997) described African American caregivers as feeling more satisfied with caregiving, expressing more mastery, and experiencing less burden than White caregivers; this description suits the two tellers of ideal stories in this study. Contrariwise, Connell and Gibson (1997) also described African American caregivers as typically female, older, and widowed, unlike the two caregivers in this study who told stories of ideal lives. Cox (1995)

described African American caregivers as expressing less of a sense of competence than White caregivers, perhaps because African American caregivers set higher standards for themselves than their White counterparts. This, too, differed from the men in this sample who told stories of ideal lives. Thus there is still more to be learned about the experience of African American caregivers. In addition, there appears to be a need for additional narrative research with other ethnic populations conducted by researchers who are highly competent in the narrative and meaning making traditions in those populations.

More than half (19 out of 36) of the caregivers in this study told stories in which caregiving was described in a positive way, either as an ideal life or as a normal or ordinary life. It may be that at least until recently "the disproportionate emphasis in the literature on burden and depression has deflected our attention from significant positive outcomes" (Walter, Acock, Bowman, & Li, 1996). It appears that caregivers themselves often see caregiving as part of normal family life, as suggested by Brody (1985). Even among caregivers for whom the disabling event was sudden or unexpected, as in the case of traumatic brain injury, cancer, or multiple sclerosis, many respondents did not describe caregiving responsibilities as threatening or extraordinary. Rather, as described by family researchers such as Thorne (1985), Knafl and Deatrick (1986), and Knafl, Breitmayer, Gallo, and Zoeller (1996), many caregivers worked hard to view themselves and their lives as normal. Research would be helpful to extend the concept of normalization, if applicable, to family caregivers.

For those caregivers whose stories were less positive, the group who told stories of caregiving as a compromised life most closely resembled a model of caregiving characterized by burden, depression, and strain. In this study, 8 caregivers out of 36 told stories of compromised lives, although this number should be interpreted with caution, since more than half of these (5) were recruited purposively in order to expand and clarify the developing analytic framework. Caregivers in this group had expectations and explanations that were consistent with poor quality caregiving strategies as described by Phillips et al. (1989, 1995). In particular caregivers who told stories of compromised lives used reasoning similar to Phillips et al.'s (1995) construct of Caregiving Dogmatism, in which caregivers' reasoning was based on "a priori truth or assumptions rather than empirical evidence" (p. 208). In addition, Phillips et al.'s description

of a monitoring role definition, in which caregivers perceive their dominant role as "to control behavior by whatever means necessary," (p. 208) was very similar to the class of management strategies called "policing" in this study, which were most commonly described by caregivers who told stories of compromised lives. Dogmatism and monitoring care priorities were all associated with potentially poor quality care (Phillips et al., 1989). Unfortunately, the present study lacked a measure of the quality of caregiving. Further research is urgently needed to measure caregiving quality and explore links between meaning and the quality of the care provided.

Ambiguous stories of caregiving have not previously been reported in the literature; this group of stories provides the most scope for further research and, potentially, for nursing intervention. It may be that all caregivers go through a process of "getting their stories straight," progressing slower or faster toward an integration of definitions, management strategies, motives, beliefs, reasoning, and expectations into a coherent whole. If these ambiguous stories represent a stage in a process that ends in the development of the story of an ideal, an ordinary, or a compromised life, it is in the interest of nurses to encourage the development of stories of ordinary lives and avert, if possible, stories of compromised lives. Thus further research is indicated to increase knowledge about these ambiguous stories. Researchers may need for a time to use qualitative or observational methods, since the inherent contradictions in ambiguous stories undermine the usefulness of self-report measures with these caregivers. At the same time, a better understanding of stories of normal or ordinary lives may provide nurses with the tools to help caregivers who are engaged in getting their stories straight to develop meanings that are both inherently satisfying and consistent with high quality care.

Narrative methods have particular strengths and weaknesses. Because narrative is always a moral undertaking (Fisher, 1987), researchers and clinicians using narrative methods run particular risks of bias. As an interpretive researcher, I struggled with some of the stories in this sample, and I sometimes found myself using the evidence in them to condemn or exonerate certain narrators based less on their circumstances than on the quality of the stories they told. The notion that interpretation of meaning includes license of investigators or clinicians to turn literary judgments into moral judgments is a troubling one,

and demands considerable reflexivity from readers or listeners. For this study, I used strategies recommended by Poirier and Ayres (1996) as appropriate to reader-response theory, including an exhaustive audit trail and consultation with content and methods experts, to identify bias and to ensure internal consistency of interpretation.

The narrative method used in this study, and in particular the development of both story types and exemplar stories, has implications for research utilization. Hunter (1991) has found that, among physicians, medical knowledge is often transmitted through stories. If this is also the case for nursing, the use of stories could enhance information exchange among researchers and clinicians. Since one of the barriers to research utilization is the language used by researchers (Phillips, 1986; Sandelowski, 1998), the use of stories told in ordinary language may help to bridge this gap.

In conclusion, this study used a combination of across-case, thematic analysis and within-case, narrative analysis to develop a typology of stories for family caregivers. Four story types were described: stories of ideal lives, stories of ordinary lives, stories of compromised lives, and ambiguous stories. Both researchers and clinicians can benefit from interpretive methods that offer access into the processes and products of making meaning through stories. It is often easier to see the possibilities for reinterpretation from outside a story than from within it. Because nurses are uniquely privileged to hear so many stories, it may be that nurses will also be uniquely able to help clients who are in the process of "getting the story straight" to find new, more sustaining meanings and even to live more happily ever after.

REFERENCES

- Archbold, P.G., & Stewart, B. (1996). The nature of the caregiving role and nursing interventions for caregiving families. In E.A. Swanson & T. Tripp-Reimer (Eds.), *Advances in Gerontological Nursing* (pp. 133-157). New York: Springer.
- Ayres, L. (in press). Narratives of family caregiving: The process of making meaning. *Research in Nursing & Health*.
- Ayres, L., Kavanaugh, K., & Knafl, K.A. (2000). Within- and across-case approaches to qualitative data analysis. Manuscript submitted for publication.
- Barer, B.M., & Johnson, C.J. (1990). A critique of the caregiving literature. *The Gerontologist*, 30, 26-29.

- Barusch, A.S., & Spaid, W.M. (1989). Gender differences in caregiving: Why do wives report greater burden? *The Gerontologist*, 29, 667-676.
- Braithwaite, V. (1996). Between stressors and outcomes: Can we simplify caregiving process variables? *The Gerontologist*, 36, 42-53.
- Brody, E.M. (1985). Parent care as a normative family stress. *The Gerontologist*, 25, 19-29.
- Connell, C.M., & Gibson, G.D. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist*, 37, 355-364.
- Cox, C. (1995). Comparing the experiences of black and white caregivers of dementia patients. *Social Work*, 44, 343-349.
- Davis, L.L. (1992). Building a science of caregiving for caregivers. *Family and Community Health*, 15(2), 1-9.
- Fisher, W.R. (1987). *Human communication as narration: Toward a philosophy of reason, value, and action*. Columbia, SC: University of South Carolina Press.
- Frank, A.W. (1995). *The wounded storyteller*. Chicago: University of Chicago Press.
- 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.
- Haley, W., Levine, E., Brown, S., & Bartolucci, A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*, 2, 323-330.
- Hawkins, A.H. (1993). *Reconstructing illness: Studies in pathography*. West Lafayette, IN: Purdue University Press.
- Hoening, J., & Hamilton, M. (1966). Elderly psychiatric patients and the burden on the household. *Psychiatric Neurology (Basel)*, 152, 281-294.
- Hooker, K., Monahan, D.J., Bowman, S.R., Frazier, L.D., & Shifren, K. (1998). Personality counts for a lot: Predictors of mental and physical health of spouse caregivers in two disease groups. *Journals of Gerontology: Psychological Sciences*, 2, P73-P85.
- Hunter, K.M. (1991). *Doctor's stories: The narrative structure of medical knowledge*. Princeton, NJ: Princeton University Press.
- Kermode, F. (1981). Secrets and narrative sequence. In W.J.T. Mitchell (Ed.), *On narrative* (pp. 79-98). Chicago: University of Chicago Press.
- Knafl, K.A., Breitmayer, B.J., Gallo, A.M., & Zoeller, L.H. (1996). Family response to childhood chronic illness: Description of management styles. *Journal of Pediatric Nursing*, 11, 315-326.
- Knafl, K.A., & Deatricks, J.A. (1986). How families manage chronic conditions: An analysis of the concept of normalization. *Research in Nursing and Health*, 9, 215-222.
- Knafl, K., Gallo, A., Zoeller, L., Breitmayer, B., & Ayres, L. (1993). One approach to conceptualizing family response to illness. In S. Feetham, J. Bell, S. Meister, & K. Gilliss (Eds.), *The cutting edge of family nursing* (Vol. 2, pp. 70-78). Newbury Park, CA: Sage.
- Kuhlman, G.J., Wilson, H.S., Hutchinson, S.A., & Wallhagen, M. (1991). Alzheimer's disease and family caregiving: Critical synthesis of the literature and research agenda. *Nursing Research*, 6, 331-337.
- Magai, C., & Cohen, C.I. (1998). Attachment style and emotional regulation in dementia patients and their relation to caregiver burden. *Journals of Gerontology: Psychological Sciences*, 53B, P147-P154.
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *Gerontologist*, 32, 498-507.
- 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.
- Patton, M.Q. (1990). *Qualitative evaluation and research methods*. Newbury Park: Sage.
- Phillips, L.R. (1986). *A clinician's guide to the critique and utilization of nursing research*. Norwalk, CT: Appleton, Century, Crofts.
- 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. (1996). Endings, secrets, and silences: Overreading in narrative inquiry. *Research in Nursing & Health*, 20, 551-557.
- Poulshock, S., & Diemling, G. (1984). Families caring for elders in residence: Issues in the measurement of burden. *Journal of Gerontology*, 39, 230-239.
- 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, P192-P199.
- Reason, P., & Rowan, J. (1981). *Human inquiry: A sourcebook of new paradigm research*. Chichester, New York: Wiley.
- Richards, T., & Richards, L. (1995). Using hierarchical categories in qualitative data analysis. In U. Kelle (Ed.), *Computer aided qualitative data analysis* (pp. 81-95). Thousand Oaks, CA: Sage.
- Sandelowski, M. (1999). Writing a good read: Strategies for re-presenting qualitative data. *Research in Nursing & Health*, 21, 375-382.
- Schultz, R., O'Brien, A.T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35, 771-791.
- Silliman, R.A., & Sternberg, I. (1988). Family caregiving: Impact of patient functioning and underlying causes of dependency. *The Gerontologist*, 28, 377-382.

- Tesch, R. (1990). *Qualitative research*. New York: The Falmer Press.
- Thorne, S. (1985). The family cancer experience. *Cancer Nursing*, 8, 285–291.
- Walker, A.J., Pratt, C.C., & Eddy, L. (1995). Informal caregiving to family members: A critical review. *Family Relations*, 44, 402–411.
- Walter, A.J., Acock, A.C., Bowman, S.R., & Li, F. (1996). Amount of care given and caregiving satisfaction: A latent growth curve analysis. *Journal of Gerontology: Psychological Sciences*, 51B, P130–142.
- 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.
- Young, R.F., & Kahana, E. (1995). The context of caregiving and well-being outcomes among African and Caucasian Americans. *The Gerontologist*, 35, 225–232.