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A Model of Caregiving Through the End of Life: Seeking Normal

Janice Penrod¹, Judith E. Hupcey¹, Peggy Z. Shipley¹, Susan J. Loeb¹, and Brenda Baney¹

¹The Pennsylvania State University, University Park

Abstract

Informal family caregivers provide significant contributions to end-of-life (EOL) care. A theoretical model of the phases and transitions of EOL caregiving was explicated using grounded theory methods to explore the experiences of 46 family caregivers of adults suffering a variety of life-limiting conditions. The derived model describes four phases of caregiving spanning prediagnosis through bereavement. Phases are demarcated by key transitions experienced when the illness progression manifestly challenges the established “steady state” achieved by the caregiver. The basic social process was defined as “seeking normal” as caregivers sought reliable patterns of everyday life while meeting the demands of caregiving. Understanding the progression of EOL caregiving enables clinicians to better support family caregivers as both coproviders and corecipients of care.

Keywords

grounded theory; end of life; family caregivers

The term *end-of-life care* traditionally refers to the last phases of an illness, but experiences across the earlier course of the illness (i.e., preterminal phases) are critical to shaping the anticipation, expectations, and preparedness for care during the terminal phases of illness. Research into end-of-life (EOL) care issues has grown exponentially over the past decade, yet the science undergirding clinical practice remains underdeveloped. Several national consensus panels (National Hospice and Palliative Care Organization [NHPCO], 2004; National Institutes of Health [NIH], 2004) have developed strategic initiatives to advance the state of the science, confirming the need for research into the experiences of informal caregivers providing EOL care and the derivation of theory-driven, research-based interventions to meet their needs. Methodologically, ipsative measures (i.e., defined from the individual’s perspective) have been recommended to shift the focus from professional providers’ perspectives toward those of patients and family caregivers (NHPCO). Furthermore, a need to extend understanding to include varied presentations of EOL care trajectories, including both preterminal and terminal phases (NHPCO, NIH), has been asserted. Therefore, the purpose of this study was to explicate a theoretical model of emic perspectives of the phases and transitions of EOL caregiving across complex EOL disease

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Corresponding Author: Janice Penrod, School of Nursing and College of Medicine, 306 Health and Human Development East, University Park, PA 16802 jlp198@psu.edu.

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trajectories, from prediagnosis through bereavement. Since nurses are involved in care delivery across the trajectory of illness that culminates in EOL caregiving, this study provides a useful lens for these frontline providers to interpret the family caregivers' transitions and challenges across the trajectory of care and progressing through EOL care.

Informal Caregiving Through the End of Life

Caring for those living with and dying from life-threatening conditions typically includes both formal care (i.e., paid service by professionals or paraprofessionals) and informal care (i.e., unpaid support by nonprofessionals; Navaie-Waliser et al., 2002; Waldrop, Kramer, Skretny, Milch, & Finn, 2005). Normally, a family member assumes the informal caregiving role and provides a significant contribution to care (Aoun, Kristjanson, Currow, & Hudson, 2005; Fromme et al., 2005; Hauser & Kramer, 2004). The majority of informal caregivers are women; however, demographic and health trends project an increased prevalence of male caregivers (National Consensus Project, 2002). Given the aging of the population and improved survivorship rates for advanced chronic conditions, the overall percentage of adults serving as active caregivers is expected to increase (Hauser & Kramer, 2004; Rabow, Hauser, & Adams, 2004; Sorrell, 2007).

Informal caregiving progressing through the end of life is often protracted (extending over months or years), beginning with diagnosis, continuing through efforts at treatment or curative care, and ultimately, ushering the death of the care recipient with an emphasis on comfort care (Lunney, Lynn, & Hogan, 2002; Lynn, 2001; Waldrop et al., 2005). Over this time, the range of EOL services provided by informal caregivers is a well-documented combination of physical, practical, and emotional care (see, for example, Hauser & Kramer, 2004; Rabow et al., 2004) that shift in focus and escalate over the course of the disease (Hebert & Schulz, 2006; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000; Soothill et al., 2001). Informal caregivers face psychological, physical, spiritual, and financial distress (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Hanratty, Holland, Jacoby, & Whitehead, 2007; Levesque, Ducharme, Zarit, Lachance, & Giroux, 2008; Weitzner, Haley, & Chen, 2000; Zivin & Christakis, 2007). The powerful impact of such distress is reflected in increased mortality rates among informal caregivers (Rhee, Degenholtz, Lo Sasso, & Emanuel, 2009). In fact, spousal caregivers are 63% more likely to die within a 4-year time frame than noncaregivers (Schulz & Beach, 1999). Given the serious risks to the caregivers' well-being, Harding and Higginson (2003) cautioned against conceptualizing informal caregivers solely as coproviders of care and over-looking their unique needs as care recipients.

Although recognition of informal caregivers as corecipients of EOL care has emerged in the literature, strategies to enhance the provision of supportive care to this vulnerable group have not been well articulated. Efforts to extend EOL care to informal caregivers may be thwarted by the caregivers' tendency to focus on the needs of the dying person over their own needs (Lowder, Buzney, & Buzo, 2005; Schulz & Martire, 2004). Caregivers simply do not see themselves as recipients of care (Stajduhar, 2003), and ongoing interactions with formal care providers fail to challenge this perception.

For example, while the Council on Scientific Affairs of the American Medical Association recommended forging care partnerships between formal (i.e., paid providers) and informal caregivers in 1993, this interdependent relationship remains "amorphous" in EOL care, prompting continued efforts to translate discrete clinical strategies for addressing informal caregivers' needs (Rabow et al., 2004, p. 485). Clinical interactions between informal caregivers and health care providers are three times more likely to be oriented toward physical concerns than to psychosocial issues (Detmar, Muller, Wever, Schornagel, &

Aaronson, 2001), thus resulting in a “conspiracy of silence” related to psychosocial concerns (Detmar, Aaronson, Wever, Muller, & Schornagel, 2000, p. 3299). Until clinicians are cognizant of the explicit and implicit challenges to informal caregivers and their expressions of needs, the formulation of theory-guided, research-based strategies to address concerns that are central to the maintenance of the individual caregiver’s health and promote continued care contributions will remain elusive. Therefore, to strategically advance the state of the science undergirding clinical integration of informal caregivers, this study was undertaken to explicate a baseline theoretical model of the phases and transitions of caregiving across complex EOL disease trajectories, from prediagnosis through bereavement.

Method

Grounded theory methods (Glaser, 1978; Glaser & Strauss, 1967) were used to explore preterminal and terminal phases of informal caregiving. The experiences of informal family caregivers providing care across multiple life-limiting disease trajectories were studied to expose the phases and stages of caregiving leading to EOL care. A team approach incorporated two experienced qualitative researchers (i.e., nurse-researchers with funded qualitative projects and methods publications) with four research assistants (RAs) who were nurses with interests in palliative care and hospice. All four RAs completed a graduate course in qualitative methods and were carefully mentored as they participated in all phases of recruitment, data collection, and analysis. Additional clinicians ($n = 4$) from participating agencies assisted with recruitment and were consulted periodically during analysis to clarify agency-specific protocols or educational materials that were cited by participants. Approval of the plan for the protection of human subjects was obtained from a university-based Office for Research Protections. All participants provided written informed consent under principles of full disclosure prior to engagement in the research.

Although sampling, data collection, and analysis are iterative, co-occurring events in grounded theory methods, this discussion will focus on the sample, data collection, and analysis as discrete events for clarity. In reality, the linearity implied in this discussion is quite inaccurate. Starting with the selection of the first participant and the first interview, data were collected and analysis was initiated. Early findings informed subsequent sampling and the decisional audit trail was launched. Researchers functioned as a well-coordinated team across all activities.

Sample

Family caregivers were recruited through four different community and hospital-based palliative and hospice care services, and two nurses with independent practices focused on advanced chronic illness/EOL care. Inclusion criteria included the following: above age 18, English speaking, and self-declared as caregiver to a person enrolled in palliative care/hospice services. Nurses who were familiar with the hospice agency or practice caseload assisted with recruitment. These nurses were provided an overview of the study and an information sheet for distribution to potential participants. Identified family caregivers were asked to telephone the researchers or provide written consent for release of contact information (i.e., name and phone number) so that the researchers could make telephone contact. This procedure was highly effective: all contacts resulted in successful recruitment, despite the fact that no incentives were offered.

Early sampling was purposive, targeting recruitment of caregivers whose charge had died while under the care of the palliative care/hospice service. These individuals comprised the majority of the final sample ($n = 38$; 23 of whom experienced the death within 2-12 months of the interview). As the emergent model was articulated and clarified, theoretical sampling

techniques were used to direct the sample to more fully explicate characteristics or variations of the model (Glaser, 1978). Active caregivers ($n = 9$) were recruited later, resulting in a shift toward the variation in life-limiting disease trajectories and phases of the illness experience.

These strategies resulted in a final sample of 46 active or former caregivers. Reflecting demographic trends in caregiving, the sample included 37 females and 9 males. Spousal relationships with the care recipient were the most common (64%), followed by a female relative such as daughter (30%), niece (4%), or sister (2%). The age of the caregivers ranged from 36 to 84 years (mean age = 62 years), whereas the care recipients were slightly older (range = 36-93 years; mean age = 71 years). On average, caregivers reported being involved in caregiving for 28 months from the time of diagnosis until death; however, a wide variation in duration (ranging from a few weeks of intensive activity to years of progressively supportive care) was reported. This variability was related to the range of life-limiting/terminal conditions that were theoretically sampled, including different cancers (53%), organ failure (35%), amyotrophic lateral sclerosis (ALS; 10%), and frailty (2%).

Data collection

Primary data were collected through in-depth, face-to-face interviews ranging from 30 to 90 minutes in duration. Early in the project, interviews were unstructured to explore the phenomenon of providing care that extended into the end of life. The interview opened with a “grand tour” question, such as, “Tell me about your experiences in providing care to ____.” This type of question provided data about the gestalt of the experience, revealing experiential states, primary modes of behavioral responses, perceived outcomes, and meanings assigned to the overall experience. Probes were used to encourage further description or to expand the participants’ initial descriptions to other phases of the illness trajectory, for example, “How did you feel then?” or “What happened after that?”

To build an understanding of key issues prior to engaging active caregivers, early sampling focused on former caregivers. As theoretical insights emerged, interviews became more focused to explicate contextual features and dimensions of the model. Researchers used theoretical sampling to focus participant selection to maximize the utility of the data for refining the emergent theory. For example, as former caregivers’ descriptions of trajectories of care were analyzed, active caregivers were sought to further explore identified phases of the model in varied illness contexts. Multiple interviews were conducted with selected participants based on the nature and quality of their insights ($n = 6$, all active caregivers). These strategies resulted in a rich data set, and data collection was discontinued when a satisfactory degree of saturation was reached.

In addition to interview data, researchers generated field notes. As many interviews took place in the caregivers’ homes, observational field notes captured important aspects of the caregiving scene that further informed the model. Theoretical and methodological field notes also were used to enhance the coordination efforts and in documentation of the decisional path of the project.

Interviews and field notes were audiorecorded and transcribed verbatim. The researcher who conducted the interview (or generated the note) verified the raw transcripts by listening to the recording while checking the transcript word by word. During this process, subject numbers were assigned and all identifiers (e.g., proper nouns) were replaced by descriptors in brackets to protect the participants’ confidentiality (e.g., Dr. Smith replaced by Dr. [Oncologist]). Both clean transcripts and field notes were included in the final data set that was used in analysis.

Analysis

Each team member completed an independent analysis of the same data, using techniques of constant comparison (Glaser, 1978) through which data were compared and contrasted with other data to build a conceptual understanding of the caregivers' experiences. Initial independent analyses were discussed by the research team, and a collaborative process of analysis began to guide subsequent inquiries. As categories, conditions, and linkages were developed, a basic social process (i.e., unifying theme) was identified and the phases and transition of informal caregiving through the end of life was modeled. The team achieved consensus on the model through a process of presenting and reviewing supportive evidence from the data set.

The use of a research team poses some threats to the integrity of a qualitative study as the researcher assumes an active, intellectual role in the unfolding study. These threats were minimized through standard methods of establishing the trustworthiness of qualitative findings (Lincoln & Guba, 1985). Rigor was enhanced by the principal investigator (PI) and coinvestigator (CoI) providing in-depth training for the RAs and critiques of their early interview styles. The research team had frequent interactions during recruitment and data collection (multiple times per week) and weekly analytic meetings. Analytic insights were carefully articulated and subsequently investigated through additional interviews or the literature to confirm, refute, or modify the theoretical contribution to the emergent model. The research team reached consensus regarding all findings, and small group interviews were conducted with clinicians and selected participants to verify the fit of the model with their experiences. All meetings were audiorecorded and transcribed to provide a decisional audit trail.

Results

The Model of Caregiving Through the End of Life describes theoretical formulations of the family caregivers' experiences punctuated by key transitions from prediagnosis through the end of life. In this section, the basic social process of the experience of informal caregiving through the end of life (seeking normal) is presented first. Next, the progressive phases of the model are discussed more fully. Finally, variations in the course and duration of phases in distinct caregiving trajectories are highlighted.

The Basic Social Process: "Seeking Normal"

The primary theme or basic social process of the model is "seeking normal" amid the changing scene of deteriorating health and function of the care recipients. Conceptually, the theme of "seeking normal" cuts across the phases of caregiving. The phases of the caregiving trajectory are patterned transitions in the illness experience of the care recipient that prompts a disruption and, then, a renewed quest for normal. Thus, each phase in the model is labeled to denote the nature of the "seeking normal" during that period of the caregiving trajectory.

"Seeking normal" is a process in which caregivers took in and interpreted evidence related to the situation at hand. This examination often shifted their temporal focus, at times prompting a constrained focus on the present while at other times opening the horizon of the past and future. Ultimately, this processing of evidence influenced caregivers' sense of confidence in being able to fulfill their role and control over the flow of events. A spousal caregiver described the reiterative process of "seeking normal" when challenged by the changing care demands of advanced, progressive illness:

And you may not want to do it [face a challenge], but you do it ... and when you come back, you're just feeling a whole lot better. I mean you can just face it all over again ... you just have to learn how to keep facing it.

"Seeking normal" refers to processing of available information that aims to recreate a sense of pattern in the midst of chaos—a pattern that is comforting, despite the profound demands of caring for a seriously ill or dying loved one. When caregivers were successful in "seeking normal," they were able to manage their complex role demands with a degree of certainty, a sense of confidence, and control. When facing new care demands, a middle-aged caregiver described the process of interpreting evidence in his quest for normal while caring for his dying wife at home:

... listen to what the situation is, find out what the rules and regulations are, where the boundaries are, what I can and can't do, and how I can be a player in this process. What do I need to do to help her get through this?

This man was "seeking normal" by reorganizing available evidence into a new pattern.

However, the changing scene of the illness trajectory drives the caregivers' experiences toward EOL care and continued to challenge the caregivers' sense of normal. The shifting phases of caregiving could not be halted—the disease would not "stand still" and caregivers found themselves responding to a changing landscape of care. Through it all, caregivers were confronted by challenges to their patterned way of life. For example, a caregiving daughter described the dramatic physical and cognitive deterioration of her mother which prompted the daughter to progressively assume responsibility for complete care.

For awhile we were walking her to the bathroom ... and we had some accidents ... We went through the stages with the portable potty next to the bed ... then, shifting mom in bed and trying to get the sheets out without getting her out of bed.

In the final days, she was answering her mother's calls every 2 hr, noting, "But you know, you keep thinking, 'Well, we did it 5 days, why couldn't we do it 6 days?'"

Accommodating the phase-specific challenges resulted in a sense of "having things under control," even for a short period of time, despite dynamic changes in the care recipient's condition. This restructured sense of normal was dramatically different from "what *used* to be normal life" and is marked by the caregivers' sense of being able to interpret the situation with some degree of confidence and to influence the outcome of the situation. Achieving a sense of normal fosters a sense of being in a steady state marked by minimal uncertainty and is a highly desirable state for caregivers transitioning through EOL care. Even in the face of new and exceptionally challenging experiences (e.g., comprehending the certainty of imminent death of a spouse or parent), caregivers described a sense of normal in how they managed their care of the dying. A wife described caring for her husband for the weeks prior to his death at home:

You know, you just had to take it as it came that's all ... and not react to it, just make it routine. Just say, "Let's not worry about it" ... You just have to get on the bandwagon and get into the routine. And there's a lot to do ... managing a house and keeping everything up and taking care of dogs, ... keeping other family members' spirits up and all that ... Have the routine and that's comforting. You know what you have to do and you don't have to imagine what's gonna' happen. That's real important.

Phases of Caregiving Through the End of Life

All caregivers in the study expressed conceptually congruent experiences related to caregiving from prediagnosis through bereavement. Four phases of caregiving through the

end of life, punctuated by three transitions, were identified. The Model of Caregiving Through the End of Life is illustrated in Figure 1. In this section, each phase is presented to highlight phase-specific experiences and the key transitions marking movement into the next phase.

Sensing a disruption—Participants described the prelude to caregiving as “something’s not right.” During this phase of *sensing a disruption*, symptoms or complaints brought to light a change in the loved one’s health. Although this phase varied in duration, it ended when the care recipient received a diagnosis of a life-limiting/terminal condition at the juncture named *confirming suspicions*, described as “getting the bad news.” The variability of the duration of this phase (*sensing a disruption*, ending at *confirming suspicions*) is illustrated in the following two quotes from wives:

He had some symptoms [2 years before diagnosis with ALS] but we didn’t know what he had. He was just very weak and having trouble with the left side of his body ... he saw doctors, they kept saying the blood work’s coming back normal and everything’s fine ... we saw he was getting worse and we knew something was seriously wrong with him. We went to a neurologist who diagnosed him and then after that he just progressively got worse ...

Another wife describes a short course of her husband experiencing symptoms described as indigestion. They sought medical advice, and he was diagnosed with pancreatic cancer: “It was just a real shocker. And then, we went to [major medical center] for a little test [endoscopy] and that’s when we found out for sure. So that date is just like emblazoned into your memory.”

Challenging normal—After diagnosis at the juncture called *confirming suspicions*, the next phase *challenging normal* ensued as the caregiver joined forces with the care recipient as they sought treatment in hopes of curing the condition or at least achieving a long remission. Throughout this phase, caregivers described “hoping for the best” as they made meaning of their loved one’s illness and integrated treatment into their everyday lives. Control was relinquished into the hands of perceived experts. They “followed doctors’ orders” meticulously. Home care, office visits, treatments, and diagnostic exams were fit into hectic schedules. The emphasis on maintaining a sense of normal everyday life, despite the changing health status of the care recipient, is evident in the following quote by a husband who maintained full-time employment amid a new caregiving role:

I would go in [to work], you know in the morning for a little bit. It was a seesaw ride up and down and, uh, going back and forth to [regional medical center]. I mean ‘cause that’s a 100 miles each way back and forth. But I was just determined that that’s where she had to be.

Another woman’s quest to maintain normal everyday life while fulfilling her caregiving role was expressed as follows:

You know I remember being angry a lot and what had happened to us and at him a lot of times because you know I had to make him a special milkshake in the morning and you know and I’d be running late to work all the time.

Over time, it became clear that the “old normal” way of everyday life could no longer be maintained. Caregivers perceived the futility of new life prolonging care, that is, they were “out of options.” Thus, the juncture that marked the end of this phase of caregiving was *acknowledging the end of life*, a point at which the caregivers described perceptions of receiving the message that “there’s nothing more we can do.” At this transition, the illness was regarded to be terminal. The certainty of death permeated the world of the caregiver;

death was now anticipated. The goals of the caregiver shifted toward providing comfort within a milieu of quality of life (QOL). *Acknowledging the end of life* was manifested in different ways by caregivers.

The wife of a patient with ALS faced the certainty of his death from this terminal condition very close to the point of diagnosis. Understanding the progressive deterioration of her husband smoothed her transition through *acknowledging the end of life*: “They [the ALS clinic staff] were very helpful in educating us and helping us to know how to deal with things and kind of be ahead of it.” In contrast, the wife of a patient with cancer had a very different experience, referencing when they determined it was “time for hospice”:

That was the day he got his hospital bed and all that lovely stuff ... the beginning of the end; it was just another 2 weeks. That’s when we really knew—it was just real difficult. The decision for him to accept hospice totally meant that I’m giving up, he’s giving up.

Building a new normal—Acknowledging that the care recipient’s condition is terminal is the preamble to transitioning into the third phase of the trajectory, *building a new normal*. This phase is marked by descriptions of “active caregiving—a new routine.” During this phase, caregiving demands escalated and a much more active role was assumed in providing ongoing care for their loved ones. For many, this phase included a prolonged period of “24/7 care” during which they felt “on duty” every moment. Even those caregivers who had supportive care through paid services (e.g., home care or private duty) or family support perceived themselves as “the only one” responsible for facilitating optimal care of their dying loved ones. During this phase, the caregivers became intensely present-focused on the here and now or the immediate task, to maintain some sense of control in the midst of this extremely difficult life situation. One wife described the demands of caregiving, as the disease progressed, creating new caregiving demands that upset the established routine that she had achieved earlier in the trajectory:

As time went on, I felt very tired all the time and stressed. I felt halfway. I felt so grateful that I could do stuff for him and the other half of me was like felt burdened and exhausted ... When his speech was gone that was the worst ... when they can’t even tell you what they need and when it takes 20 min to figure it out, that’s the most frustrating thing. They feel helpless, you feel helpless.

This phase (*building a new normal*) ended at the death of the care recipient, a significant *loss of normal*, a transition expressed by caregivers as “it’s over.” The nature of death experienced by the caregivers ranged from a peaceful “letting go” to agonizing scenes of “fighting until the end.” One husband described being “shocked that we lost her.” Another husband said, “There was nothing more we could do but keep her comfortable. I was right there with her when she died.”

Reinventing normal—The death of the care recipient brought a rush of often-conflictive emotions that extended into the next phase of *reinventing normal*, described by caregivers as “finding a new life.” These emotions were manifest in sporadic episodes of intense grief as the caregivers mourned their loss while questioning their caregiving—“Did I do enough?” “Is this what he would have wanted?” As well, they pondered, “What will I do with my time now?” Over time, caregivers established a new relationship with the deceased through the processes of mourning and bereavement. Their patterns of caregiving were replaced with reformulated patterns of normal everyday life. Eventually, they reinvented a sense of normal, assimilating in their new roles as survivors, replete with memories:

I miss my husband, but I feel at peace. I feel I’m okay. I did what I knew what I could at the time, and I don’t beat myself up about it anymore. But when I think

about it, I feel like I'm back over there again, but I know that I did the best that I could and my husband did reassure me of that at times, so that was nice.

However, old patterns are hard to break. Two years following the death of her husband, one participant still maintains routines from her caregiving days. She sleeps beside the sofa where her husband laid and falls asleep each night with the television on. She has gained weight and describes feelings of guilt ("I should have done more") that still creep into her consciousness. Finding a new life is still elusive; she has not been able to reinvent a new sense of normal.

Variations in the Course and Duration of Phases

It was not surprising to find that the key transitions in the caregiving trajectory corresponded with benchmarks of the clinical progression of life-limiting or terminal disease trajectories. Although the caregivers had theoretically congruent experiences, the course and duration of phases of the caregiving trajectory varied in dynamic response to the death trajectory of the care recipient. That is, how the care recipient progresses toward death shapes the caregiving experience.

Superimposing the Model of Caregiving Through the End of Life onto varied death trajectories demonstrates marked variations in the course and duration of the phases of EOL caregiving (Penrod, Hupcey, Baney, & Loeb, 2011). As shown in Figure 2, from an EOL perspective, the most critical feature shaping the caregiving experience is the certainty of death. Communication of the certainty of death presents strong evidence to the caregiver, predisposing the acknowledgment of death and transition into the phase of *building a new normal*.

First, consider the mixed death trajectory. The course of care starts with a focus on cure or resolution of the illness (e.g., Stage III/IV lung cancer) and care focuses on avoiding death through reiterative treatment cycles. However, when options for curative treatment are exhausted, the certainty of death overshadows the experience. Typically, this is an abrupt shift as care is refocused toward comfort care and may be discharged to specialty EOL services (e.g., hospice care). At this shift, the caregiver is thrust into *building a new normal* for the duration of life until death.

In an expected death trajectory, the certainty of death is expressed on diagnosis of a terminal condition. Progressive downward deterioration toward death (e.g., ALS) is anticipated. Still, the caregivers experienced a very short phase of *challenging normal*, hoping for a change in course of illness while treatment regimens were initiated. However, the course of caregiving progresses with a prolonged phase of *building a new normal* as the caregivers acknowledge the impending end of life.

In sharp contrast, in an unexpected death trajectory (e.g., heart failure), the course of illness is framed as a progressive series of health challenges with an unanticipated or very late acknowledgment of the certainty of death. Caregivers providing care across the unexpected death trajectory of heart failure experienced reiterative cycles of looping back through phases of *challenged normal* in response to each exacerbation in the patient's condition. For these caregivers, *building a new normal* was of very short duration, as the caregivers did not acknowledge the impending end of life until this reality was thrust on them, typically during the terminal hospitalization.

Discussion

A theoretical model of the trajectory of caregiving by family members through the end of life was derived through a grounded theory study of 46 current and former informal

caregivers of dying family members. Most significantly, this research demonstrated how junctures at which cardinal events markedly shaped perceptions (i.e., key transitions) resulted in challenges to the caregivers' perceptions of achieving a sense of normal and, therefore, predisposing them to distressed states. These peaks of disruption marked transitions to new phases of caregiving, each focused on "seeking normal." The processes described by caregivers as "seeking normal" are akin to cognitive restructuring, defined as thinking or tallying evidence to reframe the interpretation of one's world and negate negative emotions such as distress (Ellis & Harper, 1975). When "seeking normal," caregivers were reorganizing available evidence into a new way of thinking or view of their world that promoted a sense of pattern or reliable expectations of the flow of events. The new steady state was evident in the caregivers' linguistics and behaviors, indicating a renewed sense of confidence and control and a lessening of uncertainty (and distress) as they transitioned through the disruption toward a new sense of normal in their changed caregiving role.

Two recent review articles have noted that cognitive restructuring is associated with enhanced QOL in patients coping with chronic conditions such as tinnitus (Martinez-Devesa, Waddell, Perera, & Theodoulou, 2007) and potentially life-limiting conditions such as breast cancer (Al-Azri, Al-Awisi, & Al-Moundhri, 2009). The current study further acknowledges the utility of cognitive restructuring as a supportive strategy for informal caregivers providing EOL care and informs future research addressing McMillan's (2005) call for intervention trials focused on relieving the distress of primary caregivers of patients nearing the end of life.

Furthermore, while all caregivers had theoretically congruent experiences, the transitions among the four phases (i.e., sensing a disruption → challenging normal → building a new normal → reinventing normal) pivoted on the care recipients' progression across benchmarks of the disease/death trajectory. A study by Lunney, Lynn, Foley, Lipson, and Guralnik (2003) described the variability among disease/dying trajectories. Overlaying the Model of Caregiving Through the End of Life on established disease/death trajectories has resulted in further delineation of three distinct forms of EOL caregiving trajectories that are predicated on the anticipation of death: expected, unexpected, and mixed (Penrod et al., 2011). Confirming the findings of Waldrop and colleagues (2005), the certainty of death in each trajectory profoundly influences the course and duration of phases of the Model of Caregiving Through the End of Life. These variations in the caregiving trajectory are significant to understanding caregivers' experiences longitudinally and to developing supportive phase-specific interventions for family caregivers.

The use of a trajectory framework for understanding illness experiences is not new; however, the Model of Caregiving Through the End of Life advances nursing science by focusing exclusively on the family caregivers' experiences. In contrast, the Nursing Model for Chronic Illness Management (Corbin, 1998) was based on a chronic illness trajectory framework (Corbin & Strauss, 1991) that includes informal caregivers, but it fails to specify their experiences as unique from the illness experience. Still, the key phases of illness (e.g., recognition of new symptoms, diagnosis of disease, exacerbation of disease symptoms, and times of stability and instability during the progression of the disease) drive the experiences of the care recipient and caregiver in both models. From a process perspective, "comeback" as described by Corbin and Strauss (1988) is when the care recipient (and, implicitly, the family caregiver) works through rehabilitation to "return to an acceptable way of life" (Corbin, 1998, p. 36, Table 2). In the current study, caregivers described multiple phases of coming back to an acceptable (or normal) way of life across the trajectory of illness, beyond chronic care and into EOL care. This evidence supports theoretical congruence in phases and processes of the two models; however, the Model of Caregiving Through the End of

Life makes explicit the nuances of the caregiving experience while supportive caregivers are implicitly addressed in the Corbin model.

The identification of discrete phases of a caregiving trajectory that are theoretically congruent across varied disease/death trajectories provides a framework for nurses to better understand this complex, often protracted phenomenon. Since the seminal EOL work by Glaser and Strauss (1965, 1967), nurses have launched numerous investigations of chronic illness and EOL issues and have been instrumental in asserting the importance of considering the experiences of both the ill individual and the supportive others surrounding them. The Model of Caregiving Through the End of Life provides a new lens for such inquiries.

For example, Kim and Given (2008) reported that the QOL for family caregivers of cancer patients varies across three phases of the illness trajectory spanning diagnosis through bereavement. The findings of the reported study extend understanding of variations in QOL by specifying the unique challenges faced during different phases of the trajectory. Disruptions to everyday life, prompted by the illness experience, challenge caregivers and threaten their QOL. Those caregivers who achieved a comforting pattern of normal through processes of “seeking normal” expressed a solid sense of confidence and control—a state that is congruent within Ferrell’s (1995) conceptualization of QOL.

Based on a comprehensive review of caregiver literature and expert consensus, Grande and colleagues (2009) called for more adequate conceptual models for planning and studying proactive interventions that support caregivers providing EOL care. Although the theory described herein does not yield direct interventions, conceptual understanding of EOL caregiving can promote praxis as nurses encounter caregivers in their clinical settings. Understanding the trajectory of caregiving provides nurses with an awareness of the experiences of caregivers and opens the door for enhanced, proactive supportive care. Further research is underway to determine effective strategies for reaching these vulnerable partners in care by recognizing their expressions of distress and tailoring phase-specific intervention to support their sustained participation in one of life’s most difficult journeys—ushering the death of a loved one. The need is great, as described by a caregiver’s posting on a community bulletin board in a cancer treatment center:

Please try and remember to help the patient’s spouse. I’ve never felt so alone and lonely in my life. I don’t want anyone else to go through this ... It’s too late for me. But *know* their needs and talk to them.

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Figure 1.
The model of caregiving through the EOL

Figure 2.
Variations in the course and duration of phases of the model of caregiving through the end of life