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A Transactional Model of Cancer Family Caregiving Skill

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Family caregivers of persons receiving treatment of cancer must acquire illness-related skills not usually found among nonprofessional caregivers. Although research is needed to understand the skill acquisition process, no models of family caregiving skill exist to guide such research. The purpose of this study was to develop a model of caregiving skill through qualitative research. Participants were 44 caregiver/patient dyads and 63 individual caregivers. Data were collected using a semi-structured interview. A transactional model of family caregiving skill was developed that includes the concepts of demands of the illness situation, patterns of care, caregiver responses, and patient responses. **Key words:** *cancer*, *family caregiving*, *family caregiving skill*, *grounded theory*, *model development*, *qualitative research*

FAMILY caregiving during treatment of life-threatening illnesses requires an unprecedented level of skill for nonprofessional caregivers.[1-3] Yet, evidence exists that family caregivers feel inadequately prepared.[4] Because families play an essential role during life-threatening illnesses,[5-7] understanding the skills they need and how illness-related skills are acquired by informal caregivers is of utmost importance. However, the conceptual foundation needed for research in this area is in the earliest stages of development and, to our knowledge, no model of family caregiving skill currently exists. Therefore, the purpose of this article is to propose a model of family caregiving skill that was developed in a study of family caregiving during cancer treatment using qualitative research methods.

BACKGROUND

Existing theoretical models of family caregiving

The models used most often in family caregiving research are based on Lazarus and Folkman's cognitive appraisal model of stress and coping.[8] Cognitive appraisal models posit that the meaning of a stressor and the coping resources of an individual mediate the relationship between the objective characteristics of the stressor and the individual's stress response. Researchers have used variations of this model to predict and explain caregiver outcomes in multiple life-threatening illnesses.[9-11] Another model used in family caregiving research is the stress process model developed by Pearlin and colleagues.[12-14] This model highlights the social structural characteristics of the caregiving situation, the relationship between primary and secondary stressors, and concepts related

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to the caregiver's roles and identity. Coping resources are conceptualized as mediating or moderating factors. Both cognitive appraisal and stress process models tend to be individualistic in focus.

The central focus in other models is the caregiving role itself. The model developed by Given et al[15] differs from those described above in that both caregivers and patients are included, as well as their relationship. This model provides a dyadic focus for caregiving research and has at its core the initiation and maintenance of the caregiving role.

Caregiving processes over time are major concepts in the grounded theory model of the "labor of caregiving" developed by Brown and Stetz.[16,17] Processes of the labor of caregiving extend from the beginning of the cancer experience to after the patient's death and include becoming a caregiver, taking care, midwifing the death, and taking the next step.

Finally, a model developed by the author[18] highlights the interactions between caregivers and patients during the transition into the caregiving role. Concepts from symbolic interactionism and structural role theory are included in this model.

Although these models may include concepts potentially related to family caregiving skill, such as self-efficacy,[9] mastery,[10,12,13] and competence,[16,17] none has caregiving skill as a central focus. Thus, researchers have few conceptual resources available to guide studies on how caregiving skill is acquired and developed over time among nonprofessional caregivers. In addition, the lack of models is a limiting factor in the instrument development research on the assessment and evaluation of caregiving skill. Skill-building intervention research also could be facilitated by a more explicit theoretical basis for the development of interventions and the design of clinical trials. In short, model development is an important next step in family caregiving skill research.

Concept development research

Although no model of family caregiving skill currently exists, significant findings in recent caregiving research have laid the groundwork for model development.[16,17,19–21] This research has been conducted in response to the increasing complexity of the skills needed by family and other informal caregivers. As Given and colleagues note, "The role of family caregivers has shifted from one of custodial care to a complex, multifaceted role."[2(p214)] Skills that were once associated with care by health professionals must now be mastered by family caregivers. Accordingly, researchers have begun to describe the demanding clinical activities that family caregivers must now take on and the skills needed to perform these activities.

For example, Wrubel and Folkman[19] described a wide range of challenging skills needed by caregivers of men with AIDS. Included were skills with emotional support, hands-on care, clinical care, high-tech nursing, and healthcare advocacy. Brown and Stetz[16,17] also identified a wide range of caregiving behaviors that comprise the labor of caregiving for individuals with AIDS or cancer. Some behaviors require clinical skills for managing an illness, such as providing physical care, providing comfort and support, and monitoring the illness and responses. Other behaviors included facing and preparing for dying, managing the environment, responding to family relationship issues, and struggling with the healthcare system. Gaining competency was one consequence of this broad range of behaviors.

More recently, Farran and colleagues[20,21] described the skills needed by caregivers of persons with Alzheimer's disease. Their study provided additional evidence of the broad scope of the caregiving role and the skills required of family caregivers. Forty-seven skills across 8 major dimensions of caregiving were identified. Examples of skills included responding to the care receiver in a creative, flexible, and emotionally responsive manner, and using assistive devices to promote safety and support care receiver limitations.

The level of caregiving required of family members today can be deeply satisfying, but can also evoke feelings of uncertainty, inadequacy, fear, anxiety, and even terror[17,19,22] In Wrubel and Folkman's study,[19] caregivers were aware that their care directly affected the person with AIDS' well-being, safety, and comfort. Consequently, they wondered whether they were providing care in the right way, dreaded inflicting pain, worried that they might miss an important clinical sign, and feared making an error that could kill their loved one.

Given the responsibilities family caregivers face and the impact of caregiving on both caregiver and patient well-being, a better understanding of how informal caregivers acquire the needed caregiving skills is essential. Unlike skill acquisition among health professionals, which has been well described,[23] little is known about the skill development process among nonprofessionals. Building a conceptual foundation for caregiving skill research is a crucial next step in furthering the science of family caregiving.[20,21] Theoretical models are needed as part of this conceptual foundation.

The study reported here was the next step in a program of research aiming for progressive conceptualization of family caregiving skill during cancer treatment. Patterns of family-based care were identified previously in a grounded theory study[24] and the concept of caregiving skill was elaborated in subsequent concept development research.[25] In this study, we sought to move to model development by beginning to identify relationships between the concept of caregiving skill and other concepts.

METHOD

Design

The qualitative analysis reported here was part of a larger study that aimed to develop a method for systematically assessing family caregiving skill in caregivers of patients receiving treatment of cancer. In the parent study, both conceptual and methodological issues related to assessment were addressed using a cross-sectional, mixed-method research design. Data were collected from 2000 to 2004 through one-time interviews with caregivers (and patients when possible), self-report questionnaires completed by caregivers (and patients), and medical record review by research staff. Only interview data are used for the analysis reported here.

Participants

The study participants consisted of a broad cross-section of cancer family caregivers in order to study caregiving skill under a wide variety of conditions. Caregivers of patients who were receiving chemotherapy, radiation therapy, or surgical treatment of solid tumors or lymphoma were invited to participate. Treatment goals could be cure, control, or palliative care. Patients were also invited to participate if they wished to do so. However, we expected some patients to not feel well enough to participate, so patient involvement in the study was optional. All study participants were aged 18 years or older and spoke English.

The participants consisted of 63 caregivers participating alone and 44 caregiver/patient dyads. Caregivers ranged in age from 23 to 83 years, with a mean of 55.9 (SD = 12.1). Most were women (74%) and white (87%) or African American (10%). One Asian, 1 Native American, and 1 multiracial caregiver participated. Caregivers were related to patients as spouse/partners (73%), adult children (10%), parents (8%), siblings (4%), and other (5%). The patients for whom they were caring averaged 57.2 years (SD = 14.5) and were mostly male (63%) and white (84%) or African American (12%). There was 1 Hispanic, 1 Asian, 1 Native American, and 1 multiracial patient. They had the following types of cancer: lung (7%), breast (8%), colorectal (15%), upper gastrointestinal tract (20%), head and neck (19%), lymphoma (13%), brain (6%), sarcoma (5%), and other (9%). The 44 patients who formally participated in the study averaged 57.3 years (SD = 14.0) and were mostly male (59%) and white (91%).

Procedures

The study was conducted at 3 cancer centers in southeastern Pennsylvania. Permission to conduct the study was obtained from the University of Pennsylvania Institutional Review Board, the Clinical Trials Scientific Review and Monitoring Committee of the Abramson Cancer Center, and the appropriate review panel at each participating clinical site. Participants were recruited in the medical, radiation, and surgical oncology units of the cancer centers. Following informed consent, the interview was scheduled for a location convenient for participants.

Data collection and management

Interview data were collected using the Family Caregiving Skill Interview, a semistructured interview guide designed for this study to assess what caregivers do and how they do it. Patients' participation in interviews provided a valuable perspective on their needs and preferences for care. Interviews were conducted by 4 professional nurses with masters' or doctoral degrees and clinical experience with family caregivers as advanced practice nurses.

Study participants first were asked to provide an overview of their cancer experience, starting at the very beginning and coming forward to the present. This overview provided a context for understanding their current situations. Then they were asked to identify 2 to 3 care issues that were particularly important to them and these issues were explored in depth. Midway through the study, we revised the interview guide on the basis of the concurrent data analysis. We wanted to elicit more specific data about care issues that were affecting patient well-being from patients' perspectives, but were not spontaneously articulated as care priorities by caregivers. For example, some caregivers did not articulate symptom management as a care issue, even when the patient was experiencing significant symptom distress. We wondered if these "sites of silence"[26(p561)] in the data indicated we had not asked the questions that would have helped caregivers articulate the care they were providing or if needed care was missing from the situation.

By the midpoint of the study, we had identified illness demands as an important concept and were able to use the emerging categories of demands to formulate more structured questions. These questions were added to the last part of the interview to elicit specific data about caregivers' experiences with each demand. This change in the interview provided more consistent data across the participants and facilitated comparisons of how caregivers responded to demands.

The data set consisted of 107 interviews, 71 of which were audio taped and transcribed verbatim. Two were not audio taped at caregivers' requests and 8 technical failures with the taping equipment occurred. Toward the end of the study, resources did not allow for verbatim transcription of 26 interviews. Those that were not transcribed were analyzed directly from the audiotape and/or from field notes written during and after the interview.

Data analysis

Grounded theory methods as described by Strauss and Corbin[27] were used for data analysis. Specifically, our procedures for data analysis included line-by-line coding, extensive memo writing, organization of codes into larger concepts and categories, and conceptualization of relationships between concepts and categories. Data analysis proceeded concurrently with data collection. Ongoing feedback from study participants and discussions among research team members were instrumental in refining the focus of the analysis and contributed to increasing confidence in the credibility of results.[28,29]

The analysis reflects multiple perspectives. Both caregiver and patient perspectives were present in the data set, and a nursing perspective influenced our interpretation of the data as we engaged reflexively with the analysis and in ongoing interviews with study participants. As nurse researchers, our ultimate purpose was to understand how to better assess family caregiving skill so that skill-building interventions could be provided when needed. Caregivers repeatedly voiced the need for more nursing support than they had received, thus sharpening our focus on instances in which additional caregiving skills were needed but not yet available in a caregiver's repertoire.

This study did not generate an initial grounded theory, but rather elaborated and modified an existing grounded theory based on new data, as described by Strauss and Corbin.[30(p273)] The concept of family caregiving skill, which was identified in the original grounded theory study and explored in depth in a subsequent qualitative concept development study,[25] was the focal concept for this analysis. This study also included further analysis of patterns of family-based care, which had been identified in the original grounded theory study but not explicitly integrated with caregiving skill.[24] Thus, we began this study equipped with the results of earlier studies and used these results as an initial coding framework (Table 1). On the basis of new data, the coding framework was revised and expanded. Through analysis of relationships between caregiving skill and other concepts, we moved from a descriptive to a theoretical level.

At the outset of this study, the subprocesses listed in Table 1 were conceptualized as indicators of caregiving skill, based on the concept development study. We found wide variability in caregivers' use of these "skills." In some interviews, almost every one was present. In others, very few were present. Reasons for this variability were a focus of research team discussions. It became clear that whether caregivers used or did not use a particular skill had little meaning independent of the context. We realized that perhaps skill needed to be conceptualized in a different way. In some contexts, a particular caregiving process was needed to effectively respond to a care issue. In other contexts, the same process was not needed and its absence did not indicate a lack of skill. For example, in the context of an acute illness episode, recognizing a deviation from normal and judging its seriousness were needed and their absence led to delays in seeking care. However, if no deviation from normal occurred, recognizing deviations was not a relevant caregiving process. We found that the meaning of the use or nonuse of particular caregiving processes was inextricably linked to the context.

This early analysis suggested that the fit between the caregiving processes used and the context for caregiving was a key consideration needing in-depth exploration. Accordingly, an analytic focus became the identification of specific aspects of the context that shaped the use of caregiving processes. Ultimately, as described below, we redefined caregiving skill to take into account the context in which caregiving processes were used. In this article, we focus on 2 aspects of the context for caregiving that are important: the demands of the illness situation and patterns of care of caregiver/patient dyads. We also address individual qualities of caregivers and patients that influenced their abilities to effectively use needed caregiving processes.

RESULTS

Caregiving processes

Family caregiving encompasses a wide array of cognitive, behavioral, and interpersonal processes and subprocesses, which are listed in Table 1. Caregivers engaged in these processes to a greater or lesser extent when a family member was diagnosed with cancer. The subprocesses in the table were conceptualized as the relatively observable manifestations of the broader, more abstract processes of monitoring, interpreting, making decisions, etc. The subprocesses denote specific aspects of caregiving that caregivers may use to respond to the demands of the illness situation and the dyad's pattern of care (Fig 1). Considerable variability existed in caregivers' use of these subprocesses, and understanding this variability and its implications for theory about family caregiving skill

Table 1. Family caregiving processes and subprocesses

Monitoring

1. Noticing symptoms/illness behaviors
2. Attending to multiple symptoms/illness behaviors
3. Making appropriately specific observations
4. Noticing subtle changes
5. Noticing verbal and nonverbal indicators of patient well-being
6. Confirming observations verbally
7. Making distinctions between closely related symptoms
8. Keeping a written record of observations when appropriate
9. Using instruments for monitoring when appropriate
10. Using an appropriate degree of vigilance
11. Noticing patterns

Interpreting

1. Recognizing deviations from normal or expected clinical course
2. Recognizing that something is "different" or that something is "wrong"
3. Judging seriousness of a deviation from normal/expected course
4. Seeking explanations for new signs and symptoms
5. Recognizing relationships among symptoms and/or behaviors
6. Making correct attributions
7. Using a reference point in making sense of observations
8. Considering multiple explanations for an observation

Making decisions

1. Taking into account multiple cancer-related care issues when deciding what to do
2. Taking into account care demands for illnesses other than cancer
3. Weighing competing illness care demands
4. Weighing advantages and disadvantages of alternative strategies
5. Attending to multiple care issues at once
6. Thinking ahead about possible consequences of a given action
7. Planning ahead about needed care
8. Acknowledging limits of own abilities

Taking action

1. Taking recurrent actions at effective intervals
2. Timing actions with respect to the pattern of patients' responses to treatment
3. Timing actions with respect to patients' daily pattern of activity
4. Maintaining continuity in daily routines and meaningful activities when possible
5. Balancing multiple role demands
6. Developing a systematic approach to organizing multiple role demands
7. Using a system for remembering when actions are due
8. Developing routines to manage multiple and/or complex illness care actions
9. Involving patient in illness care if he/she wishes and is able
10. Taking action appropriately on one issue to facilitate resolution of another
11. Recording actions when appropriate

Making adjustments

1. Adjusting amount of food, medication, rest, exercise, etc until optimum comfort and symptom management achieved
2. Adjusting timing of actions for maximum effectiveness
3. Modifying long-standing routines to accommodate illness situation
4. Modifying environment to accommodate illness situation
5. Generating multiple strategies for problem-solving
6. Trying multiple strategies until a solution to care problems found
7. Using creativity in problem-solving

(*continues*)

Table 1. Family caregiving processes and subprocesses (*Continued*)

Accessing resources
1. Seeking resources widely; casts a broad net
2. Taking initiative in seeking resources
3. Using resources available
4. Making own needs known
5. Seeking authoritative resources
6. Coordinating resources when multiple agencies, services, or people are involved
7. Continuing to seek resources until what is really needed is found

Providing hands-on care
1. Performing procedures safely
2. Performing procedures gently
3. Attending to ill person's comfort
4. Taking the time needed with procedures to get the best results
5. Creating aesthetically pleasing results

Working together with the ill person
1. Sensing when to take a more active role in illness care
2. Sensing when to step back
3. Planning care jointly with patient when possible
4. Negotiating caregiving roles so that own needs are taken into account
5. Maintaining patient's dignity
6. Providing care in a way that is meaningful in the context of the patient's personal history and identity
7. Communicating constructively about illness with patient
8. Communicating constructively about illness with family

Navigating the healthcare system
1. Evaluating care received in the healthcare system
2. Figuring out which healthcare providers are most accessible, helpful, and knowledgeable
3. Gathering information broadly
4. Clarifying information when necessary
5. Advocating for patient and/or self when necessary
6. Coordinating care among multiple healthcare providers
7. Organizing schedule systematically
8. Seeking assistance from healthcare providers in a timely way
9. Organizing healthcare bills, reimbursement, and correspondence

was the central focus for the analysis reported here.

Demands of the illness situation

The *demands of the illness situation* were defined as the care needs presented by cancer and its treatment. Illness demands were organized into 9 categories, which are listed in Table 2 along with illustrative subcategories. The demands of the illness situation varied greatly across the study participants. For example, the need for interpersonal care and navigation of the healthcare system were the main demands for one caregiver. Her situation presented few symptom management needs and no need for nursing procedures or management of acute illness episodes. Other caregivers were presented with every demand listed.

Variation in the demands of the illness situation influenced the caregiving processes used in response. Situations with fewer demands tended to elicit fewer caregiving processes. For example, situations in which patients were not experiencing symptoms called for

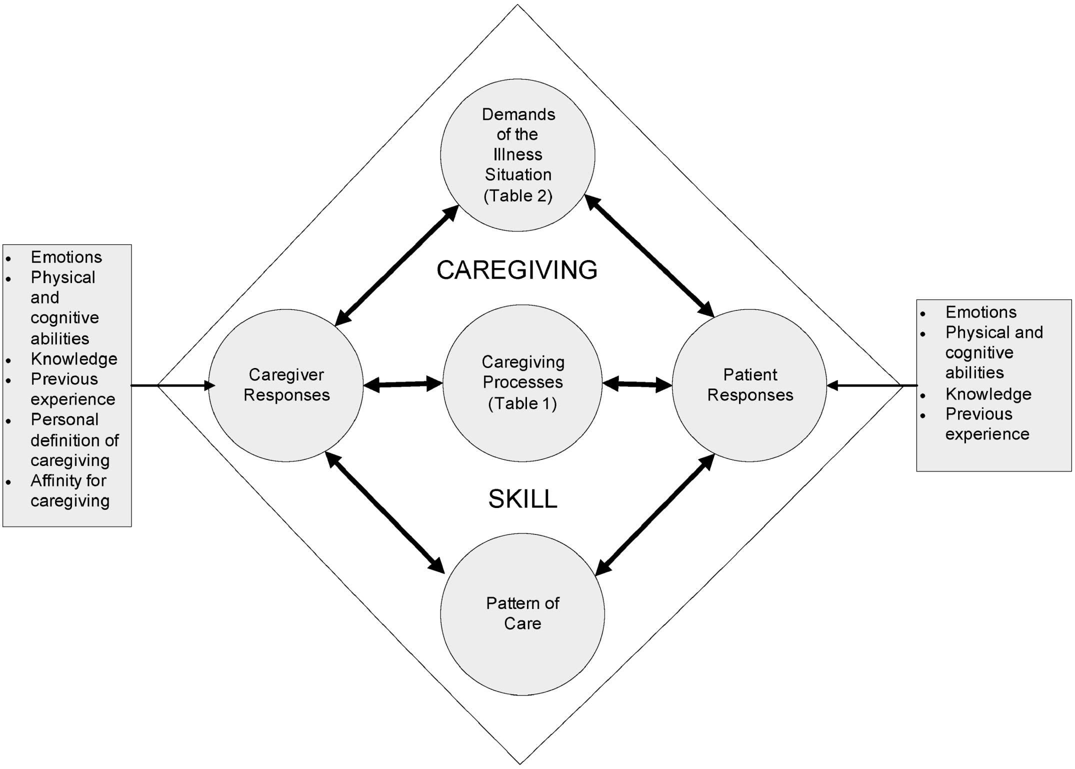

Figure 1. A transactional model of family caregiving skill.

less monitoring than situations in which patients were experiencing many symptoms. Some situations called for responses that caregivers did not provide and patients' needs went unmet. For example, one caregiver did not respond to the confusion and somnolence caused by an opioid analgesic and the patient experienced a fall. This caregiver was so overwhelmed that she was not able to respond fully to a very demanding illness situation and needed assistance.

A reciprocal, mutually influencing relationship was found between the caregiving processes used and the demands of the illness situation. The effective use of caregiving processes in response to illness demands could lessen demands, and, in turn, lessen the need for caregiving. For example, one patient's pain called for the processes of monitoring, interpreting, making decisions, taking action, making adjustments, and navigating the healthcare system. The effective use of these processes not only reduced the pain but also lessened additional demands resulting from unrelieved pain, including social withdrawal and decreased functional ability. As the patient felt better, he resumed more usual activities and needed less caregiving.

Pattern of care

Another influence on caregivers' responses was the pattern of care developed by each dyad. *Pattern of care* refers to the nature of the shared involvement in illness-related care by caregivers and patients. As depicted in Figure 1, patients as well as caregivers responded to the demands of the illness situation. Thus, caregiving potentially included both family caregiving by family members and self-caregiving by patients.

Three patterns of care, identified in the earlier grounded theory study,[24] were also

Table 2. Demands of the illness situation

- Symptom management
  - Pain
  - Fatigue
  - Dyspnea
  - Weakness
- Nutrition support
  - Weight maintenance
  - Nutritional supplements
  - Tube feedings
- Response to illness behaviors
  - Discouragement
  - Irritability
  - Anger
- Modification of usual activities for the illness situation
  - Social and recreational activities
  - Family events (eg, weddings, holidays)
  - Household responsibilities
  - Personal care
  - Work
- Interpersonal care
  - Promoting emotional well-being
  - Working together with the ill person
  - Maintaining patient's sense of self
  - Communicating with extended family
- Implementation of a treatment regimen
  - Hands-on procedures
  - Making/keeping appointment (including transportation)
  - Medication regimen
- Management of acute illness episodes
  - Fever
  - Vomiting
  - Diarrhea
- Use of community resources and informal support
  - Community agencies
  - Neighbors, coworkers
  - Complementary and alternative therapies
- Navigation of the healthcare system
  - Transfers of care
  - Coordination of care
  - Information acquisition and management
  - Reimbursement
  - Advocacy (for self and patient)
  - Communication with healthcare professionals

evident in this study: the self-caregiving pattern, the collaborative care pattern, and the family caregiving pattern. In the self-caregiving pattern, patients were mostly independent with their own care and family members took a "standby" role. This pattern required only limited family caregiving in response to illness demands because patients were meeting the demands through self-care. In the collaborative care pattern, patients and caregivers shared care activities and responded together to the demands of the illness situation. In the family caregiving pattern, patients were unable to independently perform needed care activities, and more extensive caregiver involvement was needed.

Patients' preferences and abilities were often the driving force in determining the pattern of care. Patients who preferred to be independent with their care (and were able to be independent) tended to have caregivers who took a standby role. On the other hand, patients who were able to do their own care, but preferred to have their caregivers actively involved too, tended toward a collaborative pattern. The family caregiving pattern usually was associated with a steep decline in a patient's ability to be involved in his or her own care. While the family caregiving pattern was needed in some situations, it was usually not the preferred pattern when self-care or collaborative care was possible.

Proximity, or how close caregivers lived to patients, also influenced patterns of care. Caregivers with less proximity tended to have fewer opportunities for involvement than those who lived in the same household. Sometimes caregivers who lived at a distance lacked the awareness of caregiving demands that regular, close contact facilitates. For example, a caregiver who provided transportation and helped with errands, but did not live with her sister, was unaware of the severity of her sister's pain. Without an awareness of the pain, caregiving processes to respond to it were not called into play.

When we analyzed relationships between caregiver responses and patterns of care, we found reciprocal relationships here as well. Caregivers' responses to a pattern of care could alter the pattern, which in turn altered the responses needed. For example, one patient was so deconditioned that he was unable to do his own care and a caregiving pattern was needed. The caregiver modified the bathroom environment to increase the patient's independence with personal care, thereby shifting the caregiving pattern to a collaborative pattern. Potentially, the increased activity with daily personal care could increase the patient's stamina and result in an increase in physical abilities, which could then reciprocally result in a further shift toward a self-care pattern. Since we did not follow dyads over time, we were unable to determine whether this whole sequence of reciprocal influences actually took place, although the caregiver hoped that it would. Longitudinal research could better tease out the nature of these reciprocal relationships over time.

Caregiver responses

Caregiver responses were defined as the use of specific caregiving processes in response to demands of the illness situation and the dyad's pattern of care. As described above, caregiver responses varied in relation to illness demands and patterns of care. Responses were also shaped by personal qualities of caregivers. We identified 6 personal qualities that influenced the way caregivers acquired and used the cognitive, behavioral, and interpersonal processes of caregiving.

Emotions

Caregivers' emotional reactions to the diagnosis of a life-threatening illness and the beginning of treatment created a challenging context in which to take on the complexities of caregiving. Caregivers expressed feeling devastated by the cancer diagnosis and the threatened loss it represented. Experiencing the array of emotional responses and marshalling their coping resources tended to dominate the early experience of caregiving. Many caregivers called their early cancer experience a "nightmare" and described feeling overwhelmed.

However, caregivers varied in their emotional reactions. Some quickly used coping strategies to manage their emotions and began responding to the demands of the situation. Other caregivers felt so emotionally overwhelmed that they had difficulty engaging in caregiving. For example, one caregiver was so upset with her extended family that she was initially unable to respond to the many care demands present in the illness situation. Consequently, the patient had unmet needs and was hospitalized several times for symptom management and hydration.

Physical and cognitive abilities

Caregivers also varied greatly in their physical and cognitive abilities. *Physical abilities* included the manual dexterity needed to carry out technical procedures, the physical stamina needed for long hours of travel to treatment sites or provision of round-the-clock care, and the strength needed to assist patients with movement or ambulation. High levels of physical ability were needed especially to provide postoperative care and end-of-life care at home. The physical demands of caregiving sometimes were underestimated by health professionals, who then failed to insure adequate assistance for the caregiver. For example, one patient needed round-the-clock bedside care, including frequent suctioning of his tracheostomy. His caregiver tried to provide this level of care, but eventually collapsed from exhaustion and was hospitalized.

The *cognitive abilities* required for family caregiving included the ability to process and retain large amounts of new information, a good memory, and the ability to concentrate. Caregivers sometimes acknowledged cognitive limitations and sought help from visiting nurses or other family members. For example, one caregiver said, "I can't understand that, so the visiting nurse takes care of it." Mild cognitive impairment resulting from stress and sleep deprivation seemed to play a role in caregivers' abilities to engage in the caregiving processes called for by the situation.

The feeling of being overwhelmed that so many expressed may have resulted from their emotional reactions to the cancer situation in combination with reaching the limit of their cognitive ability to take in and process large amounts of information with life and death significance.

Knowledge about caregiving

The emphasis on patient/family education in the study's clinical settings plus the information about cancer on the Internet, which increased tremendously during the period of data collection, provided unprecedented resources for knowledge about cancer-related care. However, gaps between having information and being able to put it into practice as caregiving were evident. For example, a caregiver had detailed information about each of a patient's many medications. However, she had difficulty developing a routine for managing the complex medication regimen and remembering when each medication was due. Caregivers often became saturated with information, while lacking guidance in how to use it. When an interviewer asked whether a coach, mentor, or expert guide would have been helpful as they began to put their new knowledge into practice, caregivers almost unanimously responded with an emphatic "yes!"

Previous experience

Caregivers' previous life experience was another personal characteristic that influenced their use of caregiving processes. Many types of life experiences were influential. Perhaps, most obvious were previous experiences with caregiving in an occupational role, or with the patient in another illness situation, or with another family member. However, the particular ways in which previous experience influenced the present situation varied greatly. For example, caring previously for an older family member who needed some assistance with activities of daily living did not necessarily prepare one for caring for an acutely symptomatic younger adult receiving concurrent chemotherapy and radiation. Some caregiving behaviors learned in the earlier experience, such as involving the ill person in her care as much as possible, were used again in the current situation, while others, such as recognizing a deviation from the expected clinical course during chemotherapy and judging its seriousness, were new.

Caregivers' responses to illness demands could be related to previous life experiences in surprising ways. For example, the interviewer commented on one caregiver's systematic problem-solving skills and asked whether he had experience as a health professional. He replied, "No," but added that the critical thinking skills he learned as a pilot were helpful in his caregiving role.

Personal definitions of caregiving

Caregivers' personal definitions of caregiving were how they mentally constructed the nature of the caregiving role. Caregivers' personal definitions of caregiving seemed to determine where they directed their attention and actions. Some caregivers thought of caregiving only in terms of hands-on care and did not attend to issues like symptom management, or the challenges of providing optimal nutrition during cancer treatment. In some instances, considerable inconsistency existed between caregivers' personal definitions of caregiving and the caregiving processes needed to meet patients' needs.

For example, one caregiver described her role only in terms of assistance with meals, bathing, and giving prescribed medications. She responded to the patient's postoperative symptoms of pain, dyspnea, and weakness with emotional distress, but not with caregiving behaviors. Because of his symptoms, the patient was reluctant to get out of bed. Eventually, a professional nursing assessment resulted in the patient's rehospitalization for symptom management. The caregiver was extremely attentive and concerned, but did not think of the caregiving implications of the patient's symptoms. There were numerous instances in the data in which a caregiver's personal definition of caregiving was more limited in scope than the patient's needs. In these instances, caregivers' definitions of caregiving tended to be based on familiar household and personal care activities. It was when unfamiliar care in the clinical realm was needed that gaps between the caregiving provided and the care needed appeared.

Affinity for caregiving

Affinity for caregiving was the natural appeal that caregiving had for a caregiver. Some caregivers expressed a strong preexisting interest in caregiving while others did not. Some had chosen a caregiving occupation, such as professional or technical nursing, while others had consciously avoided these occupations. As one caregiver said, "I never in my life wanted to be a nurse, and I can't believe I'm doing this now. I still don't want to be a nurse." Others expressed a previous, unrealized ambition to be a nurse and had an interest in developing caregiving skills that preceded their current situations. Caregivers with a natural affinity for caregiving seemed to engage in the needed caregiving processes more easily, even when they were distressed about the cancer diagnosis, while those who said that they were "not cut out for this" struggled more with caregiving.

Patient responses

As depicted in Figure 1, our model includes patient responses. When patients were able, most preferred to be actively involved in their own care. Although the original purpose of the study did not include investigation of patients' self-care skills, the interviews indicated that patients used an array of self-care behaviors that were similar to the processes of family caregiving. Furthermore, the data suggested several personal qualities that influenced how patients used these processes to respond to illness demands. Although we have fewer data on patient responses and personal qualities, we include them in the model because the analysis indicated the importance of dyadic involvement in care.

Emotions

Patients' emotional reactions to the diagnosis of a life-threatening illness and the beginning of treatment affected how they responded to the demands of the situation, as did caregivers' emotional responses. During times of heightened emotional distress, patients were less able to respond to illness demands. In fact, patients' emotional responses sometimes became illness demands for the family caregiver, exemplifying the complex relationships between demands, patient responses, patterns of care, and caregiver responses. For example, patient depression could turn a self-care pattern into a caregiving pattern and create an illness demand that required a range of caregiving processes in response. This kind of intricate relationship between the components of the model was found often in the data.

Physical and cognitive abilities

Patients' physical and cognitive abilities, referred to as functional status in many studies, influenced their responses to the demands of the situation and often were a strong determinate of the pattern of care. As noted above, patients tended to prefer a self-care or collaborative pattern of care and to reject the family caregiving pattern. However, patients' physical and cognitive abilities varied greatly over the course of the illness experience, so their abilities for self-care tended to wax and wane. Also, the presence of other chronic conditions, such as diabetes or kidney disease, complicated both the demands of the illness situation and patients' abilities to respond to them. Patients' physical and cognitive abilities were more dynamic than caregivers', so their responses to illness demands and pattern of care tended to be dynamic as well.

Knowledge about self-care

Patients' knowledge level about cancer-related care at home also affected their responses. In many dyads, the person who responded to a particular care demand was the one who had the most knowledge in that area. For example, when acquisition of information was an important care demand, the person most knowledgeable about using the Internet often took on that aspect of care. Areas of particular knowledge were often the basis for task-specific specialization in the collaborative care pattern, as patients and caregivers took on the activities with which they were most familiar.

Previous experience with self-care

Patients' previous experience with other chronic illnesses also influenced their cancer-related self-care. For example, patients with a chronic condition that required symptom management, organization of a medication regimen, or nursing procedures at home (ie, injection, ostomy care, etc) often were able to use this experience in the cancer situation. For example, a caregiver of a patient with heart disease said, "Oh, yes, he's used to keeping track of his medications himself. He just had to add a few new ones." Management of a complex medication regimen was not difficult for this patient, because he had already developed skills in that area. Patients with previously acquired self-caregiving skills sometime needed less involvement by their family caregiver.

Summary and integration of the model

To integrate the emerging theory, we defined *family caregiving* as a family process that occurs in response to an illness and encompasses multiple cognitive, behavioral, and interpersonal processes. Each of these processes has relatively observable manifestations or subprocesses. Family caregivers use these processes to respond to the demands of an illness situation, taking into account the patient/caregiver dyad's pattern of care.

We defined *family caregiving skill* as the ability to respond effectively and smoothly to the demands of the illness and pattern of care using these processes. This definition revises the previous definition of caregiving skill, which was "the ability to effectively and smoothly engage in nine caregiving processes."[25] Our revised definition incorporates 2 aspects of the caregiving context that proved to be important in the conceptualization of caregiving skill, that is, demands of the illness situation and the dyadic pattern of care. *Skill* is a property of caregiving that varies among caregivers and within caregivers over time.[25]

Caregivers' abilities to provide care smoothly and effectively were influenced by several personal qualities. These qualities could facilitate or hinder effective responses to the illness context.

The relationships of caregiving processes to the demands of the illness situation and to the dyad's pattern of care were very complex. To reflect their complexity, we propose a transactional model in which the relationships among these major concepts are reciprocal or mutually influencing. To effectively and smoothly respond to illness demands and pattern of care, caregivers essentially had to manage these transactions well. Therefore, caregiving skill is not a context-free concept, but rather a transaction between the caregiving processes used and the context for caregiving. When care is skillfully provided, the caregiving processes used fit with both demands and care pattern.

A complementary set of relationships was found between patients' use of self-caregiving processes and personal qualities of the patient, illness demands, and pattern of care. However, an in-depth exploration of self-caregiving skills was beyond the scope of this study.

In short, *family caregiving skill* was conceptualized as a property of family caregiving that is manifested in the transactions between a caregiver's use of a wide array of caregiving processes and the illness care context.

DISCUSSION

Family caregivers' and patients' accounts of caregiving during treatment of cancer allowed us to redefine family caregiving skill and propose theoretical relationships with other concepts relevant to family-based care, thus refining and extending the results of an earlier study.[25] Identification of relationships among multiple concepts moved the research from concept development to model development. The use of grounded theory methods enabled us to base the model in the actual experiences of family caregivers and patients.

Although models of family caregiving for cancer patients have been published,[11,16,17,31,32] none have caregiving skill as their main focus. Rather, caregiving skill (or competency) has been one concept among several in models that represent the caregiving experience broadly. Our model contributes to knowledge development by providing an in-depth focus on one aspect of the broader caregiving experience. Key features of the model include its focus on caregivers and patients both as individuals and as dyads, and the transactional nature of the relationships among the major components of the model. This is our initial attempt at model development and we consider it a work in progress. Further research is needed to confirm, refute, revise, and extend the results of this study.

The demands of the illness situation, a major concept in our model, have also been described by other researchers.[11,31-34] Our study provides yet another confirmation of the broad scope of demands experienced by caregivers of people with cancer. The study extends previous research by conceptualizing demands not as stressors but as aspects of the illness context that require a skilled response. In this respect, demands are "care needs" rather than stressors. Models that explain coping responses to stressors and caregiving responses to illness demands are both needed to further the science of family caregiving.

Another key feature of the model is dyadic patterns of care. Researchers have long studied patients and family members as dyads and have explored the reciprocal influence of their individual responses to the cancer situation.[34-39] Less well developed is the conceptual and research base for understanding how patients and their family members respond individually and jointly to care demands. Our analysis revealed again 3 patterns of care that had been identified earlier in this program of research.[24] These patterns could provide a way to categorize the respective involvement of patients and family members in research on family-based care in the future. A method for describing and categorizing patterns of care is needed, especially for research on how patient and caregiver involvement changes over time. A limitation of this study is that potential additional patterns were not explored. Specifically, a network pattern involving multiple family members and/or friends was not explored, nor were collaborative care patterns involving health professionals. Our data indicated that such patterns exist, but we did not have sufficient data to explore them in depth. This is another area in which future research is needed.

We identified a number of personal qualities caregivers and patients brought to the cancer situation that influenced their responses. These qualities suggest both strengths that facilitate skill acquisition and challenges creating less than ideal conditions for skill acquisition. Further exploration of skill acquisition is needed, in both qualitative research and model testing and intervention research. From the perspective of patient/family education, it is vital to understand how skill acquisition occurs when the need for rapid acquisition of caregiving skill is great, yet overwhelming emotional and cognitive reactions to the situation create less than ideal conditions for learning.

The bidirectional relationships depicted in Figure 1 make the model complex, but the data seemed to indicate this complexity. Longitudinal research is needed to better tease out the nature of the relationships between model components over time. Newer methods of data analysis that can address changes over time in both members of a dyad[40] may help to tease out some of the complex, fluid relationships that this qualitative analysis suggested.

The transactional nature of situational demands, caregiver responses, patient responses, and patterns of care has other implications for research. Our findings suggest that efforts to assess or quantify caregivers' skillfulness as a variable should take into account the fit between the demands of the situation, the caregiver's level of involvement in care, and the caregiving processes used. The absolute number of caregiving processes and the frequency with which they were used did not appear in this analysis to have meaning independent of the demands of the situation and pattern of care.

Clinical implications include the need for careful, complete, and accurate assessments of patients' and family members' situations. As indicated in the examples, caregivers and patients both experienced distress when their responses could not match the demands they faced. Our model suggests specific areas for assessment, including caregiving responses needed and used, illness demands, the dyad's pattern of care, and individual qualities of caregivers and patients. Anticipation of potential demands caregivers may face is also needed in clinical practice. When illness demands exceed a caregiver's ability to respond, the caregiver should have ready access to a health professional for assistance.

Given the context-specific nature of the caregiving processes used, our model may have limited generalizability to other life-threatening conditions. The demands of caregiving differ in important ways across clinical populations. Also, patients' abilities to participate in their own care differ across clinical populations. Previous research suggests that the skills needed to respond to behavioral issues in advanced Alzheimer's disease have both similarities and differences with cancer-related skills.[20,21,25] However, additional research is needed to identify the unique and common features of models of caregiving skill across populations.

A limitation of the study was the low participation rate of patients. Because the original purpose of the study was to investigate family caregiving skills, patient participation was optional. Although we welcomed and encouraged patient participation, we chose not to require it for caregiver eligibility, because we did not want to exclude caregivers of patients who were too ill to participate. However, especially for interviews conducted in the treatment setting, we found that some patients chose not to participate so they could sleep during their treatment, rather than because they were too ill. In the future, we will explore ways to make study participation more convenient for more patients.

A strength of the study was the number of interviews available for analysis. Although the data were time consuming and labor intensive to collect and analyze, we conducted interviews with every participant in this mixed-method study. The number of interviews generated contributed to our confidence that the components of the model are important for understanding skillful caregiving behaviors.

In conclusion, this model provides a new theoretical lens through which to view caregiving skill. It contributes to a conceptual foundation for future research by proposing that caregiving skill involves a transactional relationship between multiple cognitive, behavioral, and interpersonal processes and the context for care.

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