

*Résumé*

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**Les filles de patients cardiaques :  
le processus de prestation de soins**

**Donna-Michelle Gage-Rancœur et Margaret A. Purden**

Cette étude prospective et exploratoire examine le rôle de soignante joué par des femmes ayant un parent hospitalisé pour des problèmes cardiaques. De façon plus précise, l'étude se penche sur l'élaboration et l'évolution du rôle de soignante pendant la période d'hospitalisation et durant la période suivant l'hospitalisation. Des données ont été recueillies auprès de neuf femmes par le biais de commentaires émis par les participantes et d'entrevues non structurées et semi-structurées. La prestation de soins exécutée par des femmes ayant un parent cardiaque était caractérisée par un processus non linéaire d'acquisition de « compétences », lequel incluait la recherche de connaissances, la consolidation des connaissances et les interventions menées à partir de ces connaissances. Dans un processus secondaire d'auto-évaluation de leurs connaissances, les participantes circulaient d'une dimension à l'autre. De plus, leur degré d'engagement reflétait quatre styles distincts de soins, qui relevaient de la culture familiale en matière de prestation de soins. Les infirmières peuvent être plus efficaces dans leurs interventions auprès des femmes qui prennent soin d'un parent en déterminant la position de celles-ci dans le processus d'acquisition de « compétences » et en agissant en fonction de cette position. Les infirmières doivent également tenir compte des opinions et des traditions familiales face à la prestation de soins.

Mots clés : maladie cardiaque, prestation de soins, femmes prenant soin d'un parent, processus de prestation de soins, famille, prestation de soins par un membre de la famille, différences liées aux rapports sociaux entre les sexes, soins informels

# **Daughters of Cardiac Patients: The Process of Caregiving**

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This prospective, exploratory study examined the caregiving role that adult daughters play when a parent is hospitalized for a cardiac condition. Specifically, the study addressed the development and evolution of the caregiving role during the hospital stay and in the post-discharge period. Data were collected from 9 daughters using participant observation and unstructured and semi-structured interviews. Daughters' caregiving was characterized by a non-linear process of "knowing" that included knowledge seeking, consolidation of knowledge, and acting on the knowledge. In a secondary process of self-assessment concerning their knowledge, the participants moved back and forth among the 3 dimensions. In addition, their level of involvement was defined by 4 different caregiving styles, based on the family's caregiving culture. Nurses might collaborate more effectively with women caring for a parent by determining their position in the "knowing" process and tailoring the intervention accordingly. Nurses should also be sensitive to families' opinions and traditions regarding caregiving.

Keywords: cardiac illness, caregiving, caregiving daughters, caregiving process, family, family caregiving, gender differences, informal care

## **Introduction**

The percentage of the population that is 65 years and older is on the rise, and it is midlife daughters who provide much of the informal care to this ageing population (Robinson, 1997). While age-related changes increase an elderly parent's need for support, the presence of a chronic illness such as heart disease necessitates even greater involvement on the part of the family caregiver. It often entails helping the parent adjust to hospitalization for an acute exacerbation of their condition. Indeed, hospitalization for cardiac disease is increasing in Canada, with elderly persons accounting for more than 75% of the patient population (Health Canada, 2000). The high incidence of coronary-related disease in the elderly and the prevalence of daughters in caregiving roles point to the need for research on the caregiver-care recipient dyad. Previous studies on family caregiving for the elderly have focused on either daughter-parent caregiving in the community (Bull & Jarvis, 1997; King, 1993) or the experiences of the spouses of cardiac patients (Biegel, Sales, & Schulz, 1991). There is a paucity of research on the role of adult daughters caring for parents hospitalized with heart disease.

For caregiving situations in general, Merrill (1996) found that children either volunteered to be caregivers or were chosen by the parent. In contrast, Brody, Litvin, Hoffman, and Kleban (1995) found that daughters often became caregivers by default: other family members either were unwilling to provide care or were unable to due to poor health or full-time employment, while in 23% of cases the daughter was the only remaining child. King (1993) reports that crises such as illness in the other parent or in a caregiving sibling precede daughters' caregiving involvement. Guberman, Maheu, and Maillé (1992) identify love, family ties, the need to help others, and the needs of the care recipient as influential factors in the decision to become a caregiver. Cicirelli (1993) also describes daughters' caregiving behaviour as motivated by obligation or attachment to the parent. Crawford, Bond, and Balshaw (1994) and Stoller (1983) found that daughters provide more care to parents than sons even when employment, marital and child status, and geographic location are controlled for. Crawford et al. also report that gender differences increase when the functional ability of the parent is perceived as low. Thus, daughters appear to play a greater role than sons in parental caregiving.

In cardiac disease, motivation for spousal caregiving appears to be focused on protecting the partner from stress, physical exertion, or unhealthy activities that might bring on an attack (Biegel et al., 1991; Coyne & Smith, 1991). Spouses who are highly involved in caregiving have been found to experience poor vocational, domestic, social, psychological, and global adjustment (Purden & Frasure-Smith, 1994). However, women's reasons for becoming caregivers to parents with a cardiac condition and their experiences in caring for them have not been addressed.

Bowers (1987), in her study of caregiving, was the first to go beyond the tasks of caregiving to identify its underlying motivations. Five types of caregiving emerged: anticipatory (just in case), preventive (monitoring), supervisory (arranging, checking), instrumental (doing for, assisting), and protective (protecting the individual from threats to self-image). Conceptualizing caregiving by purpose rather than tasks revealed aspects of the role such as protective care, which had not emerged in previous studies. Daughters in Bowers's study considered protective care to be the most important and difficult form of care, because it created friction in their interactions with other family members or with health-care professionals, who did not understand this form of care.

Daughters' caregiving has also been examined from the perspective of competing demands. Matthews, Werkner, and Delaney (1989) examined the caregiving role of 50 pairs of sisters in which one sister was employed and the other was not. They found that when the parent's

physical or functional status was poor, the non-employed sister provided more tangible care, while the employed sister, in contrast, had to limit her involvement. They also found that the sisters' caregiving role depended on their past experience. For example, those who had acquired medical knowledge or training in the health professions were more involved with the medical aspect of their parent's care than their sisters.

While other studies have focused exclusively on the daughter's perspective, Bull and Jervis (1997) explored the ways in which mothers and daughters worked together, and found that they used information-seeking and problem-solving strategies to determine what was effective and to establish new routines. However, no studies to date have examined daughters' information seeking or whether their information needs change during the transition from the acute phase of cardiac illness to the early recovery period, which is a particularly stressful time for both patients and families (Rankin, 1992).

Previous studies of caregiving during cardiac illness have used a cross-sectional approach, have focused on caregiving in a community setting, and have looked primarily at the caregiving role of the spouse. The present study, in contrast, explored the experiences of daughters caring for a parent with a cardiac illness in hospital and at 6 to 8 weeks post-discharge. The inquiry was guided by the following questions: (1) *What role do adult daughters play when a parent has been hospitalized for a cardiac condition?* (2) *How does this role develop and how does it change during the recovery period?*

## **Methods**

### ***Design and Data Collection***

A prospective design was used. Data were collected through participant observation. Methods of grounded theory were used in the data analysis to examine the relationship among different aspects of the caregiving process.

In the context of her regular practice, the nurse researcher identified patients with cardiac illness whose daughters were actively involved in their care. Patients were asked if their daughters could be approached to discuss their caregiving experiences in depth. In families with more than one daughter, the daughter identified by the patient as most involved in his or her care was approached. The institution's ethical procedures regarding informed consent were followed. The patients and daughters were informed about the purpose of the study and were told that their participation was voluntary, that they could withdraw at any time, that all documentation would be stored in a secure place, and that their names would not be published or appear in any documentation.

Once a daughter agreed to participate, data were collected through participant observation and unstructured/semi-structured interviews carried out over the course of the hospital stay. Additional data were collected through interviews and conversations with the patient and other family members in order to validate the categories that were emerging through the data analysis. Where possible, follow-up interviews were conducted with the daughters post-discharge. All the women requested telephone rather than face-to-face interviews because these were easier to arrange and took less time out of their hectic day.

The number of contacts per family ranged from one to seven. The variation relates to length of hospital stay, as a longer stay afforded more opportunities to interview daughters and other family members. Data on participants' feelings, thoughts, and behaviours were obtained through such open-ended questions as "In every family, children help out in different ways; could you tell me about your experience?" or "Could you tell me how you came to be involved in helping your parent in this way?" The interviews could not be audiotaped for logistical reasons. Most of the face-to-face conversations with the daughters occurred while they were providing care to the patient. Highlights of these conversations, as well as the post-discharge telephone interviews, were recorded immediately following the interaction, and detailed field notes were completed the same day.

### **Sample**

A convenience sample was recruited from a cardiac unit in a large metropolitan teaching hospital. The inclusion criteria were: a daughter caring for a parent who was hospitalized for a cardiac event; expected discharge within 1 month; and ability to speak English or French.

The sample consisted of nine daughters. In all families both the parent and the daughter were interviewed. In four families spouses and other daughters also served as informants. Patients ranged in age from 49 to 86 years (*mean* = 74.3 years). Five of the patients were female and four were male. In three cases the patient's spouse was also involved in some aspect of care. All of the daughters were adults; however, their ages were not obtained. Four of the nine daughters were married but only one indicated that she had children. The majority of the daughters (80%) worked outside of the home. In three of the five families with more than one daughter, the eldest daughter was the caregiver.

### **Analysis**

The data were analyzed line by line for statements or observations regarding the nature of the daughter's caregiving and how she came to take on the caregiver role. Similar examples across clients were grouped

together to create a preliminary list of substantive categories. Using the constant comparative method, the preliminary categories and their supporting data were examined for overlap. This process was continued throughout data collection. Preliminary categories were collapsed as global themes were identified. The hierarchy of emergent sub-categories, categories, and themes was confirmed and refined in a back-and-forth process as data collection proceeded (Strauss & Corbin, 1990). Data collection was terminated once it became clear that no new categories were emerging and that the data were confirming the existing set.

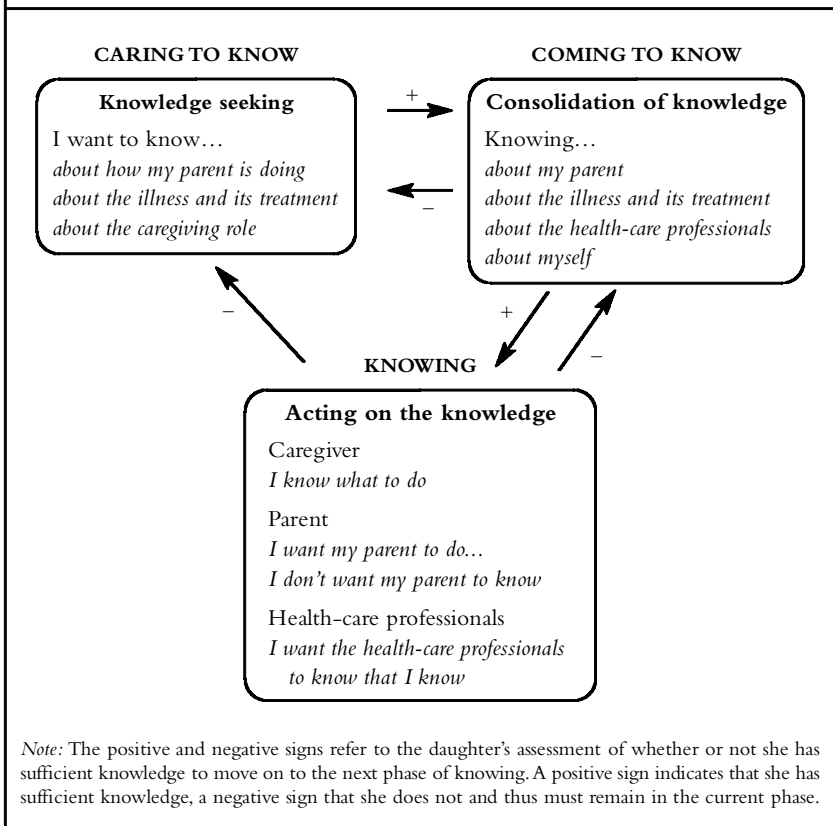
The observational and verbal data collected from conversations with multiple informants within a family and from the interviews with different families served to validate the results. For those families in which a second daughter participated in the caregiving, the information she provided was used to corroborate the emerging themes regarding the caregiving process and family styles of caring. As the categories were identified, they were shared with the informants to ensure that the interpretations were accurate (Guba & Lincoln, 1981). In addition, the nurse researcher's reactions to events were recorded to increase self-awareness so that credibility would be maintained. An audit trail was established to keep track of decisions taken during analysis (Appleton, 1995). A nursing colleague recoded a random sample of 30% of the data collected from the daughters using the coding guidelines and category definitions developed by the nurse researcher. An interrater reliability of 95% was achieved.

## **Findings**

### ***Caring: The Process of Knowing***

The daughters were engaged in a dynamic process of "knowing" in order to care for their ill parent. They were found to move between three different dimensions in a non-linear process: knowledge seeking (*I want to know*), consolidation of understanding (*knowing*), and acting on their knowledge (*I know what to do*). Whenever daughters were confronted by an event such as a new medication, an unfamiliar diagnostic test, or a change in the parent's condition they would engage in active knowledge seeking. This served to increase their confidence. As they grew more confident they began to act on their knowledge in providing care. Analysis revealed an ongoing secondary process of assessing the adequacy and completeness of their knowledge, which allowed them to move back and forth among the three dimensions (see Figure 1). This process occurred both in the hospital and later at home, as daughters spent considerable time and energy seeking and processing information and attending to the physical and emotional responses of their parent.

Figure 1 *Caregiving: The Process of Knowing*



**Knowledge seeking.** Daughters demonstrated commitment and perseverance in acquiring knowledge about their hospitalized parent's situation. Changes in the patient's condition, the treatment, and the hospital environment (in terms of both physical setting and personnel) necessitated their using a variety of strategies to keep informed. The data indicated that daughters wanted to "know" about the parent's subjective experience, the objective aspect of the illness and its management, and how they might take on a caregiving role during the hospital stay.

Daughters' caregiving was heavily focused on knowledge seeking, especially during the hospital stay. Strategies included waiting to see what happened, visiting and phoning the parent, and asking the nurse what the doctors had said. A more assertive strategy involved confronting or cornering the doctors for information; one woman entered the cardiac

catheterization room, uninvited, minutes before her mother's angiogram in order to ask the doctor technical questions about the procedure.

Knowledge seeking, whether in the hospital setting or in the community, about the parent's status or treatment took considerable time and energy. As one daughter pointed out, "Information didn't exactly come flowing our way." The daughters' motivation for wanting to know also varied. Some felt it was their responsibility to know in order to ensure their parent's safety, while others indicated that they were simply curious about a medical procedure.

Many daughters progressed from wanting to know and seeking information to knowing about and understanding their parent's situation. Four daughters, however, had a wealth of past experience and knowledge, not only concerning their parent's response to the illness, but also concerning the health-care system. Thus, these daughters channelled their energies into consolidating their understanding.

**Consolidation of understanding.** Daughters had a sense of knowing the parent, the illness, the health-care system, the health-care professionals, and themselves: "You know some nurses are very nice and others are terrible"; "I have learned to cope... I can't run around like I used to." The patients also recognized that their daughters had knowledge and were able to use it: "I need my daughter — she knows a lot more about this than I do."

This phase in the process was marked by increasing confidence. Through their presence at the bedside, the daughters came to know the illness, its treatment, and their parent's responses. However, although they came to see themselves as experts, the women struggled to be acknowledged as credible authorities in the care of their parent:

*I know her. For her to get that upset is rare. He [the doctor] was very abrupt with her. They have to know that they shouldn't talk to elderly people like that. She is already sick — she doesn't need this. She is very sensitive. I already told one of his residents and I will also complain...*

Consolidation of understanding often led daughters to act on their knowledge or to seek additional knowledge. One woman, for example, moved from knowing herself to acting on the knowledge by setting limits on her caregiving involvement:

*Now, I find I have to do less. Now, I am the only one to visit at the hospital and make the arrangements. It is draining on me too. Yes, I have to set limits for myself and my job.*

When daughters determined that their knowledge was incomplete, they sought further information:



*He has a new medication. I called a few pharmacies but no one had heard of it before. One place told me they could order it in for the next day. I figured out that this would mean he would miss two doses. I wasn't sure this was a good idea [so] I called a nurse at the hospital.*

**Acting on the knowledge.** Daughters' knowledge guided their actions with respect to their caregiving role and influenced their interactions with health-care professionals and with their parent.

**I know what to do.** The women took action based on their knowledge of both their parent and the situation. One mother validated her daughter's stated caregiving competence: "My daughter knew that I would be out of food so she went shopping for me before picking me up."

**I want the health-care professionals to know that I know.** As daughters' competence increased, they sought to share their knowledge with the health-care professionals:

*I told the first resident we saw in the emergency [room] that she [my mother] has bad arthritis and that it runs in the family.*

They seemed to have two motives for sharing information with health-care professionals: to demonstrate that they were knowledgeable and should be consulted, and to improve the quality of care by containing the professionals' lack of sensitivity.

**I want my parent to do...** Frequently, daughters wanted their parent to comply with a lifestyle change, a treatment decision, or a medical restriction. In some cases they merely suggested to the parent that he or she make a lifestyle change. In other cases they were adamant about what the parent should do. One daughter told her parent, "No, you're going to quit completely! You haven't smoked while you've been in the hospital."

**I don't want my parent to know.** The daughters were selective about the information they shared with their parent. They also attempted to control the information that others shared with their parent. Some daughters wanted the parent as well as other family members to know what was happening: "We share it with the rest of the family so that everyone knows what is going on." Others, in order to protect the parent, concealed their own reactions or withheld information about the severity of the illness or changes in medical treatment. In some cases these attempts failed because health-care professionals shared information, unaware of the daughter's desire to protect her parent. One daughter said, "It really was not your job to tell this news to my father; it could have been very harmful."

In summary, daughters had to actively seek knowledge about the parent's condition so that they could draw on it as caregivers. They

became engaged in this process for different reasons, and they used a variety of strategies to seek and act on knowledge gained about the parent, the situation, and themselves.

### ***Factors Influencing Daughters' Caregiving Involvement***

When daughters and other family members were asked how the daughter had come to be involved in caregiving, the reasons most frequently given were *close family ties* and *helping each other*. One daughter stated:

*Our family has always been very close-knit. We go to parties together... We've always supported each other in everything, not just for health-related things, but in everything.*

The daughters' helpful and caring nature was also mentioned as a factor: "I have always been that way with everyone; even at work my boss tells me that I am so helpful." In addition, family members spoke of a family tradition of helping elderly relatives. One mother commented, "It's always the girls who take care of their parents... I also helped my mother when she was ill."

When daughters were asked how their family cared for the ill parent, four different styles of caregiving emerged: *we all support each other*; *my sister helps out in a different way*; *the chosen one*; and *I am the only one left*. These styles were corroborated in conversations with the parents and other family members. The four styles reflect the nature of daughters' caregiving and their level of involvement. The caregiving of the other family members was a contributing factor as well. Illness severity, the developmental stage of the family, and the daughters' level of involvement were of lesser importance than style of caregiving.

***We all support each other.*** In one family the daughter explained that everyone rallied to support the ill parent. This family was distinct because of the presence of a spouse caregiver and because all the children were involved in assisting the ill parent. The spouse commented, "It's like a circle. Our kids are in the circle... when something happens they all rush in to help... we feel supported by everyone."

***My sister helps out in a different way.*** In two families the caregiving was shared by two daughters. The sisters' roles were found to complement each other. The sister who was more involved during the parent's hospital stay either had a more flexible work schedule or was more comfortable in the hospital setting than the other sister:

*My sister doesn't come in to visit at the hospital as much as I do. She's not comfortable in hospitals... But when my dad is at home my sister comes over during the day and she makes him supper.*

*I came to the hospital at 10 in the morning that day. I wanted to be there to help him with the language. She [my sister] sees him more now that he is at home. She will come to visit for the whole day on the weekend with her husband.*

**The chosen one.** In four families only one daughter helped out even though other siblings were available. This seemed to be related to the parent's particularly close attachment to the one daughter, causing them to request help more often from her than from the other children. Similarly, these daughters were very attached to their parent. One parent stated:

*She is very helpful to me. If I need something done I will ask her. I take the path of least resistance. [laughing] She never kicks up a fuss or complains, and she never says no. It is easier [than asking my son].*

In other cases the parent relied heavily on one daughter because she lived closest or because she had fewer work or family demands. Daughters and parents also noted that the siblings' personalities shaped their caregiving role:

*I'm afraid my sister never came every week. She doesn't make much of an effort to visit. She never has.... No, my sister is selfish.*

**I am the only one left.** In two families the daughter was the only child remaining and the only person willing and able to assist the ill, widowed parent. One daughter stated, "I am involved because I am the only one in the family left." Both women had become experienced caregivers and described instances of rescuing their parents from disastrous situations:

*It's up to me to check everything. Because the emergency room doctor gave her Septra when she was on Coumadin, she nearly died. She would have died if I hadn't been there.*

## Summary

Daughters demonstrated considerable caregiving skill and involvement as they soothed and nurtured their parents and shielded them from the harsh realities of being a patient in hospital. Daughters rose to the occasion and inserted themselves into the chaotic and often unfriendly critical-care environment in order to advocate for their parents and ensure their peace of mind. Through tireless vigilance they seized every opportunity to access information, question personnel, and monitor treatments and procedures. When necessary, they challenged the decisions of professionals and offered alternative solutions. Over time, daughters became mindful of the culture and developed political savvy in order to engage

professionals in partnerships. Thus, in order to care expertly for their parents these women were committed to a process of knowing: knowing their parent under new circumstances, knowing the illness and its treatment, knowing the personnel, and knowing the unspoken rules of the hospital culture.

### **Discussion and Implications for Practice**

Most investigations of caregiving have focused on care that is provided in the home. The paucity of research on family caregiving during hospitalization seems to suggest that caregiving takes place only in the community. In the case of cardiac patients in particular, integrating family involvement into care is complicated by the perception that these patients are vulnerable and unstable and need to be protected from all possible sources of strain and anxiety. In fact, early studies concluded that the presence of family members at the bedside was detrimental to patients' well-being because it raised their anxiety levels (Frederickson, 1989). More recently, there has been a recognition that the presence of family members contributes to hospitalized patients' physical and emotional well-being (Simpson, 1991). The findings of the present study indicate that daughters are engaged in a non-linear process of caregiving that involves seeking knowledge, consolidating understanding, and acting to provide care that begins during hospitalization and continues in the early recovery period at home.

The theme of *knowledge seeking* is described by Jamerson et al. (1996) in a study of family members' experiences in the intensive-care unit. These authors found caregiving to be characterized by information seeking, tracking, and garnering resources. A number of other studies have also documented patients' and families' need for information, especially during hospitalization (Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990). Artinian (1991) found that 40% of wives of coronary artery bypass graft patients rated not knowing specific facts about their husband's treatment and prognosis as extremely stressful. Moser, Dracup, and Marsden (1993) found that spouses of myocardial infarction patients did not reduce their need for information on the patient's status and care during the early recovery period. In the present study, similarly, a large part of daughters' caregiving was focused on managing information, a process driven by self-evaluation. In the hospital setting in particular, daughters spent much time and energy seeking information about the patient's status and treatment.

With respect to the theme of *consolidating understanding*, the literature also suggests that knowing the patient and his or her needs and preferences is central to the caregiving role (Hasselkus, 1988; King, 1993; Pratt,

Jones, Shin, & Walker, 1989). Brown and Stetz (1999) conclude that developing caregiving competency, knowledge, and skill is a central concern for caregivers. The present study highlights the importance of going beyond the acquisition of knowledge to developing competency in active caregiving. The daughters constantly evaluated their competency, as they strove to acquire more knowledge and to consolidate that knowledge.

In the process of *acting on the knowledge*, the daughters provided direct care, advised their parents on how best to care for themselves, protected their parents by withholding information, and actively negotiated the nature and quality of the professional care provided. Sometimes, *acting on the knowledge* caused them to risk confrontation in order to ensure proper care. Such incidents were characterized by power and control. Callery and Smith (1991) attribute this tension to the imbalance of power between formal and informal caregivers. Davis (1992) notes that tension may arise in triangular relationships involving caregivers, care recipients, and health-care professionals, because caregivers feel they have to compete for the role of caregiver and defend their credibility. Similar tensions are described by Hasselkus (1988), who found that caregivers rarely admit that the professional knows best.

The theoretical processes that emerged in this study are consistent with the findings of Shumacher, Stewart, Archbold, Dodd, and Dibble (2000). These authors describe processes by which female caregivers — primarily spouses of patients with cancer — monitor, interpret, make decisions, take action, make adjustments, provide hands-on care, access resources, work with the ill person, and navigate the health-care system. Similarly, in the present study daughters observed and then provided direct care to the parent with cardiac disease. They too monitored and posed questions, and then made their own assessment of what was occurring, what to expect, and what should be done. They asked questions about procedures and protocols and navigated the system. In other words, the daughters were active learners throughout the hospital stay and continued to be engaged in a learning and self-evaluation process while caring for the parent at home. Clearly, both studies indicate that caregiving is an evolving process common to a number of patient populations.

This emerging theory has implications for nurses working with family caregivers. It suggests that nurses should recognize that daughters and other family caregivers are engaged in a process of learning to care for the ill person and are likely to welcome the opportunity to acquire information as well as new skills. By describing the signs and symptoms being monitored, describing impending procedures, offering assistance with information gathering, and encouraging hands-on care, nurses can help build competence among family members and enhance their effec-

tiveness as caregivers. Finally, nurses need to appreciate the fact that the caregiving process is not linear but is characterized by a back-and-forth movement across a number of dimensions and that the timing of nursing interventions is therefore critical. Caregivers may not always be ready to learn new skills or to act on the knowledge they have acquired. Reticence should be interpreted not as a refusal to participate but rather as a function of timing. Awareness of the process of seeking, consolidating, and acting will help nurses to know how and when to intervene in order to best facilitate the caregiving process.

Nurses should also take into account the family context in which caregiving takes place. Different caregiving styles affect the way in which caregiving evolves — that is, the degree to which the caregiver is involved and the distribution of caregiving responsibilities within the family. For example, in *the chosen one* a family member is designated as caregiver. A nursing approach that is supportive of this family style will ensure that all information, teaching, and resource planning are conveyed to that person and will help other family members to find ways to support their chosen caregiver.

This study did not address the caregiving contribution of sons in the family unit. Future research could explore the mix of siblings in the family and the implications for caregiving. Further testing of the theory in the home is indicated. Does the caregiving process differ when the patient's status is relatively stable? Finally, examining the process in different patient populations would contribute to the development of a robust theory of caregiving that clinicians can use in tailoring and timing interventions to the particular characteristics of family caregivers.

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