

The Role of the Family in Treatment Decision Making by Patients With Cancer

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Purpose/Objectives: To examine family disagreements about treatment decisions for patients with advanced lung cancer.

Research Approach: Descriptive, qualitative study.

Setting: A large comprehensive cancer center in Cleveland, OH.

Participants: 37 patients with stage III or IV lung cancer and 40 caregivers (24 primary and 16 secondary) from 26 families were interviewed.

Methodologic Approach: Open-ended audiotaped interviews were transcribed verbatim. NUD*IST (non-numerical unstructured data indexing, searching, and theorizing) computer software (QSR International, Melbourne, Australia) was used to perform content analysis.

Main Research Variables: Vast differences in opinions between patients and family caregivers about treatment decisions and care.

Findings: Sixty-five percent of families reported various family disagreements that mainly concerned routine treatment decisions, discontinuation of therapeutic treatment, and use of hospice care.

Conclusions: Family disagreements about treatment decisions for patients with advanced lung cancer are common and include a wide range of issues. Family members play an important role in the selection of patients' doctors, hospitals, treatment options, and provisions of care.

Interpretation: The findings suggest that nurses need to be aware of differences of opinion between patients with advanced cancer and their caregivers. Knowledge of family disagreements about treatment decisions can help nurses' efforts to integrate families into decision-making processes in clinical settings to facilitate family communications and improve patients' and caregivers' satisfaction with treatment decisions.

Lung cancer is the leading cause of cancer deaths among women and men (American Cancer Society, 2003). Difficulties in the early detection of lung cancer often delay its diagnosis. At the time of diagnosis, most patients with lung cancer are older than age 65 (Edwards et al., 2002). The older age of most patients with lung cancer imposes physical limitations on their ability to endure suffering and accustoms them to being more passive than younger patients in making treatment decisions (Petrisek, Laliberte, Allen, & Mor, 1997; Siminoff, Ravdin, Colabianchi, & Sturm, 2000). Spouses of patients with lung cancer often are deceased or in frail health themselves. Although adult children usually do not live at or near home, they often are actively involved in making treatment decisions, despite their limited insight into the physical and social needs of the patients (Lederberg, 1989). Given the numerous treatment decisions that need to be made in a short time period, families' impact on patients' treatment decision making can be profound. As cancer progresses and treatment outcomes become more uncertain, disagreements between family members and patients become more frequent. Fam-

Key Points . . .

- ▶ Patients with advanced cancer and their caregivers are likely to move from fighting to accepting cancer at different paces. Caregivers' personal understanding, knowledge, and experiences of death influence their empathy with patients' wishes.
- ▶ Family relations affect the degree of family concordance in making treatment decisions. Prior family dynamics set a tone for current treatment decision making in the family.
- ▶ In most situations, caregivers act as patient advocates in ensuring quality care. Family opinions have a significant impact on patients' treatment decisions and psychological well-being.

ily members may take increasingly proactive roles as decision makers when patients become further debilitated. Thus, treatment decision making centers on patients' and family members' concordance.

The existing literature sheds light on several contextual factors that may affect family behaviors in treatment decision making. Patients with cancer and their family caregivers experience tremendous stress (Akechi, Okamura, Nishiwaki, & Uchitomi, 2002; Cameron, Franche, Cheung, & Stewart, 2002; Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). The experience can cause patients and caregivers to have different perceptions of patient stress and symptoms (Lobchuk & Degner, 2002; Porter et al., 2002; Redinbaugh, Baum, DeMoss, Fello, & Arnold, 2002) and contribute to family disagreements about treatment. Based on individual physical, functional, and psychological states, patients and caregivers develop their own needs (Longman, Atwood, Sherman, Benedict, & Shang, 1992; Silveira & Winstead-Fry, 1997; Steele & Fitch, 1996). Differing needs may contribute to disagreements during treatment decisions. In addition, existing family relationships can affect decision making. A family that

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lacks cohesion or is otherwise conflicted is more likely to disagree about treatment decisions (Lieberman & Fisher, 1999). Overall, these findings suggest that a variety of contextual factors can increase family disagreements about treatment decision making, and families' roles in this process need to be examined carefully.

Despite the implication that family influence on treatment decision making is an important research area, studies examining this area are few. Therefore, the authors conducted a qualitative study using in-depth interviews to examine the role of family members in making treatment decisions for patients with advanced lung cancer. The study attempted to answer the following questions.

- In what areas do family disagreements occur regarding patients' treatment decisions?
- What are the major differences of opinions between patients and family members while making treatment decisions?
- Why do these differences of opinions about treatment decision making exist?

Methods

Sample

This study was conducted over one year at a large comprehensive cancer center in Cleveland, OH. Using tumor registry data and the hospital's computer system, the research team identified all patients with stage III or IV lung cancer who were admitted to the cancer center from May 1999 through April 2000. The names of 164 patients were forwarded to their physicians, who gave consent to contact 60 patients (37%). The remaining 104 patients were not included in the study because 32 patients were deceased, 2 patients had relocated, and 70 patients were considered too sick to participate. An institutional review board-approved written consent form was mailed with a letter or read over the telephone to the 60 patients to obtain their consent. Twenty-three patients (38%) chose not to participate because of illness.

Patient participants were asked to provide the names of their family caregivers. Researchers then mailed or read institutional review board-approved consent forms to these family caregivers. Because of limited time and resources, the team decided to recruit 40 family caregivers, which was a sample size near that of patient participants. The first 40 family caregivers to give consent were enrolled in the study, for a total of 24 primary and 16 secondary caregivers. These family caregivers came from 26 families, constituting a triad of patients and primary and secondary caregivers in 14 families and a patient-caregiver dyad in the remaining 12 families.

Data Collection

Originally, the study was designed in a focus group format. Researchers conducted a literature review to formulate a discussion guide to encourage focus group discussions. Questions were asked sequentially about participants' treatment goals and outcome expectations, decision-making process through interaction with physicians, willingness to forgo curative treatment for immediate quality of life, and opinions about palliative care or hospice. These questions were aimed at capturing participants' experiences at three critical decision junctures: initial treatment, trade-offs, and end of life.

Thirteen patient participants attended four focus group meetings with four women and nine men, including three African

Americans. Each meeting lasted 60–90 minutes. An investigator and a research assistant, who was an experienced group moderator, facilitated the meetings. Researchers experienced great difficulty in recruiting patients for the focus groups because of the 23 patients who declined to participate in the study because of illness. A closer look at possible causes revealed that most focus group participants either had been in remission or were newly diagnosed and had just started treatment. Meanwhile, patients who either chose not to participate or did not show up for scheduled group meetings were more seriously ill and suffering from the side effects of ongoing therapy. Patients attributed their inability to attend focus groups to their fragile and unpredictable physical conditions that could change daily. Thus, researchers decided to conduct telephone interviews to obtain these participants' views.

The discussion guide was adapted to suit a telephone interview. First, the questions were asked chronologically (from diagnosis to current condition) to facilitate information recall and meet participants' desire to share their experiences. Interviewers proceeded with the outlined issues but stayed flexible when participants chose not to respond, were uncomfortable with the topic, or were not near enough to the end of life to discuss hospice issues. Some of the patients and family caregivers were reinterviewed at a later time to obtain missing information or clarifications.

The research assistant was trained to conduct the telephone interviews. Because telephone interviews do not allow for observation of facial expressions, researchers paid a great deal of attention to the interviewers' sensitivity, question framing, and voice tones while soliciting the needed information and making telephone conversations comfortable for respondents. At the completion of each interview, one of the investigators listened to the audiotaped conversations, identified issues that needed further clarification, and discussed them with the interviewer the next day. They reviewed strategies to deal with situations when participants stammered or hesitated to talk. Through this monitoring process, the interviewer learned to maintain emotional support, remain nonjudgmental, and rephrase questions to ease responses if participants struggled to respond. If these efforts failed, the interviewer proceeded with the next question and noted the need for a separate or follow-up interview. Using this approach, researchers were able to explore these issues in detail and clarify all aspects of the respondents' situations until data saturation was reached.

A total of 64 participants were interviewed individually via phone, including 24 patients and 40 family caregivers. Each interview took 20–40 minutes. Follow-up interviews also were conducted with 19 participants: 14 patients (which included two focus group participants) and 5 caregivers. All of the focus group discussions and telephone interviews were audiotaped and transcribed.

Data Analysis

NUD*IST (non-numerical unstructured data indexing, searching, and theorizing) computer software (QSR International, Melbourne, Australia) was used to facilitate the analysis of the transcribed interviews. NUD*IST is an application designed to help investigators classify transcribed text into categories according to common themes. The basic functions of NUD*IST include node creation and organization of nodes in a hierarchical manner. The nodes contain emerging ideas and related data (Richards, 1998). They are

formed by assembling and labeling text addressing the same themes. Each assembled node can be linked logically to other nodes horizontally or vertically, thus creating index systems. For example, family disagreement about clinical trials can be titled “disagreeing about clinical trials,” which parallels another node, “disagreeing about hospice.” Both nodes can be affiliated to a parent node, “family decision-making behavior.” Creation and organization of nodes can occur simultaneously.

The analysis of meaning in context required several steps. Initially, researchers read transcriptions and identified themes conveyed in each conversation’s paragraphs. Then, NUD*IST software was used to create nodes to represent the identified themes and sort paragraphs containing the same themes to their respective nodes. A paragraph would be affiliated to multiple nodes if it included more than one theme. Next, all nodes were organized in a logical order. After researchers analyzed the data for patients and family caregivers separately, two parent nodes of “patient decision-making behavior” and “family decision-making behavior” were created. They contained nodes of “selecting doctors,” “seeking aggressive treatment,” “trade-off issues,” and “considering hospice,” as well as nodes of disagreement concerning “diagnosis,” “treatment,” “hospice,” “clinical trials,” and “caretaking.” Table 1 lists the themes and contents that were categorized. Researchers analyzed the transcribed text carefully and compiled specific issues that emerged from each node category and summarized them. The summary was used to identify common themes, supporting evidence, and relations among the themes. Finally, researchers examined the findings by family unit to compare the similarities and differences between patients and caregivers within each family, specifically regarding trade-off issues and end-of-life care. This comparison allowed identification of family disagreements about these issues.

Because the number of focus group participants was small, researchers were able to identify individual participants on the audiotapes and analyze focus group discussion on the basis of individual views as was done with other participants interviewed by phone. This approach allowed researchers to analyze patient-caregiver differences in a family and count individual reports of certain events. The counts and percentages were calculated for the patients, caregivers, and families.

To ensure credibility, the data coding was rechecked for the identified themes using NUD*IST and checked again on paper. In addition, researchers interviewed four patients and their six caregivers who were identified and recruited from a community hospital. Results obtained from the cancer center were compared with results from a local hospital population. A recurrence of the identified thematic issues was observed without any differences in thematic issues in community hospital patient reports. This result confirmed the study’s findings.

Results

Sample

Thirty-seven patients were enrolled, including 17 females (46%) and 20 males (54%). Ten (27%) were African American, and the remaining 27 (73%) were Caucasian. The patient participants had a mean age of 62 years, with 28 participants (76%) aged 55 or older. Patients who had a diagnosis for less than six months, one year, or two years comprised 27%, 30%, and 24% of the sample, respectively. Eleven percent of patients had been diagnosed with lung cancer for more than two years.

The primary family caregivers included 20 spouses or partners, 4 daughters, and 1 other relative. The secondary family caregivers included 11 children and 4 other relatives, primarily siblings. Twenty-eight of the caregiver participants (70%) were female, and six (15%) were African American. Twenty-two family caregivers (55%) were under the age of 55.

The final study sample contained 77 participants, including 37 patients with lung cancer and 40 family caregivers. Forty-five participants (58%) were women, and 16 participants were African American (21%) (see Table 2).

Analysis of the interviews indicated that family disagreement about treatment decisions was widespread. Seventeen (65%) of the 26 families reported various disputes. An additional four families (15%) reported avoidance of discussing end-of-life care. Family disagreements occurred in three major areas: routine treatment decisions, trade-off decisions on discontinuation of curative treatment, and consideration of hospice care. Among the five families that did not report family disagreement, three supported patient decisions to stop therapeutic treatment and accept hospice care, and the other two families agreed to patients’ decisions about pursuing extensive therapeutic treatment.

Table 1. Themes and Contents

Main Themes	Subcategories	Contents
Family influence on routine treatment decisions (decisions concerning logistic issues of receiving treatment)	Selecting doctors	Family persuaded patient to switch doctors.
	Family interaction and disagreement with doctors	Family questioned doctors about their opinions, practice, or attitudes.
	Family disagreement with patients about treatment-related issues	Family disagreed about treatment options (where or how to get them).
	Family disagreement with patients about caretaking	Family was overattentive and insisted that patient take vitamins and quit smoking.
Family influence on trade-off decisions (decisions to trade the length of survival for immediate quality of life)	Family opinions or concerns about trade-off decisions	Family was generally less enthusiastic about making trade-off decisions.
Family influence on hospice use (decisions regarding whether and where to receive hospice)	Family disagreement about hospice use	Family was reluctant to discuss hospice.
	Family disagreement about where to receive hospice care	Family preferred to keep patient at home for hospice care.

Table 2. Sample Demographics

Variable	Patients (N = 37)		Caregivers (N = 40)	
	n	%	n	%
Age (years)				
≥ 55	28	76	18	45
< 55	9	24	22	55
Gender				
Male	20	54	12	30
Female	17	46	28	70
Race				
Caucasian	27	73	34	85
African American	10	27	6	15
Time since diagnosis				
≤ 6 months	10	27	–	–
≤ 1 year	11	30	–	–
≤ 2 years	9	24	–	–
> 2 years	4	11	–	–
Missing	3	8	–	–
Family role				
Spouse or partner	–	–	20	48
Children	–	–	15	38
Sibling	–	–	3	10
Parent	–	–	1	3
Others	–	–	1	3
Interview format				
Individual phone interview	24	65	40	100
Focus group	13	35	–	–

Note. Because of rounding, not all percentages total 100.

Family Involvement in Routine Treatment Decisions

Routine treatment decisions refer to conventional treatment issues that patients and families often encounter during the treatment process. In this study, these issues concerned four main areas: selection of patients' doctors, interaction with patients' doctors, influences on patients' treatment decisions, and provisions of care.

Selecting doctors: Family decision making about treatments for patients with advanced lung cancer begins with the selection of a doctor. According to patients' and caregivers' reports, 14 patients (38%) had switched doctors, including three focus group participants. More than two-thirds of these patients (n = 10) were persuaded by their family members to do so. Five families wanted patients to switch because their initial doctors had not offered treatment, fearing that the risks of treatment might exceed potential benefits. Another five families urged patients to find another physician because they perceived the doctor to be callous in how he or she announced the diagnosis, ignored family questions and needs, or made patients and caregivers feel that "no hope" existed. Patients in these families accepted family decisions and echoed the family members' opinions about their doctors.

Family interaction and disagreement with doctors: Family caregivers disagreed with the doctors on various issues, with or without patient concurrence. Five caregivers (13%) reported that they openly expressed critical views of doctors that were not shared by the patients. These caregivers confronted the doctors without patients' consent because they considered the doctors too "rude," "untrustworthy," or "incompetent." The other three family caregivers (8%) expressed a lack of trust in some of the doctors that they encountered, although their con-

cerns did not result in an immediate dismissal of the doctors because of various circumstances (e.g., the doctor referred the patient to another doctor by his or her own initiative).

Ten family caregivers (25%), primarily daughters or sons, refused to accept doctors' opinions without question. They actively searched for information, sought second opinions, and challenged doctors with well-prepared questions. An additional four caregivers (10%) questioned the doctors' practices, and they reported arguing with doctors about diagnostic procedures, use of pain medication, and type or amount of treatment. In one case, a family caregiver demanded that the patient's doctor start chemotherapy early and then asked the doctor to reduce the dose of radiation when the patient began to suffer from treatment side effects.

Disagreement with patients about treatment: Family caregivers disagreed with patients about a number of treatment decisions. Such family discordance was observed with six patients (16%). One patient, whose family caregivers were not interviewed, reported disagreement with his family about taking a new medication. Family caregivers of another five patients reported that they disagreed with patients about using a diagnostic procedure, undergoing radiation therapy, participating in a clinical trial, or having brain surgery. In one family, a daughter tried to persuade a patient to have brain surgery to stop tumor metastasis, and the patient refused out of fear of adverse surgical consequences. In another family, a daughter pushed a patient to enter a clinical trial a few thousand miles away, and the patient rejected the idea to stay with the family.

Disagreement between patients and family caregivers also centered on the issue of seeking health care. This disagreement was observed in an additional five patients (14%), including three focus group participants. According to patients' and caregivers' reports, family caregivers of two patients urged patients to seek medical attention for physical symptoms when the patients deliberately avoided seeing a doctor for diagnosis. Family caregivers in two other families reported disagreements with patients about which hospital to attend for treatment. In the end, two patients and their family members disagreed on accepting a do-not-resuscitate order. A patient expressed his apprehension about his children possibly deciding to have him sustained through life-support machines. He decided to die at home to avoid medical resuscitation in a hospital.

Disagreement with patients about caretaking: Family care of patients typically involves monitoring patients' medications and conditions and assisting in daily living. In this study, 10 patients (27%), including 4 focus group participants, complained of being burdened by caregivers' overattentiveness. They reported that their caregivers constantly reminded them of their physical limitations, activity levels, behaviors, and diet. They felt frustrated about being "treated like a baby."

In addition, three patients (8%) complained that family caregivers pushed them to take supplemental vitamin pills, hoping to strengthen their immune systems against cancer. A daughter mentioned that she grabbed her mother at one time to force her to take the pills. She said, "It was like, 'You have got to take these pills. You do not have an option here.'"

Smoking was another contentious issue. Six caregivers (13%) from five families reported frustration or anger about patients' persistent smoking. Two caregivers had given up their persuasive efforts, but the rest still felt hurt. A patient's spouse said, "Every time he lights up that cigarette, he has taken a day away from me. I just get very angry." Another

caregiver said, "If he [the doctor] finds out . . . he won't give up on her [the patient], but it is going to discourage him."

Family Role in Trade-Off Decision Making

Advanced lung cancer often is not operable and is refractory to therapeutic treatment. Only about 25% of patients with stage IV lung cancer respond to chemotherapy with prolonged life from six weeks to five months (Grilli, Oxman, & Julian, 1993; Marino, Pampallona, Preatoni, Cantoni, & Invernizzi, 1994). Experience of treatment side effects was common. In fact, five patients (14%) reported being hospitalized for life-threatening conditions induced by treatment side effects.

One of the most important treatment decisions confronting these patients was whether to switch from therapeutic to palliative treatments that were aimed at managing symptoms. In this study, 15 patients (41%) reported willingness to continue pursuing therapeutic treatment and 14 patients (38%) decided to end therapeutic treatment. Meanwhile, 17 caregivers (43%) wanted more therapeutic treatment and only 8 (20%) caregivers agreed to end it. Clearly, fewer caregivers were willing to give up active searches for a cure.

Family concerns about trade-offs: Family caregivers presented a number of reasons for pursuing therapeutic treatment when and if the cancer would recur. Their main concern was to keep patients alive. With this goal in mind, they considered treatment rewarding if it could shrink a tumor, even if it caused severe side effects. One caregiver said, "He had other little cancer on his neck on the lymph node. He had the radiation, and it seemed like it went away completely. So I think with something like that happening, then something else will help." The caregivers also felt that all medication options had to be tried to find the one that would work. A caregiver said, "Everybody's body is different and it reacts differently. . . . You have just got to find the right medicine that will either cure it or keep it to a minimum." Furthermore, caregivers believed that trying various treatment options would buy time until new treatment opportunities became available.

The main reason for family caregivers to seriously consider ending treatment was severe treatment side effects. At a certain point, family caregivers became more sympathetic to patients as they watched them suffering. As one caregiver said, "You then come to the realization that they are better off dying, because you don't want them going through anymore." However, patients' and caregivers' acceptance of death was not synchronous. In this study, family responses to patients' decisions to discontinue therapeutic treatment varied. Three families (12%) reported unequivocal support for patient trade-off decisions. Nine families (35%) reported discordance between patients and caregivers. Seven of these nine families wanted more treatment than patients desired. Tension and conflict occurred in three of these families, including verbal fights with patients or among family members. In addition, six families (23%) supported patients' decisions to pursue extensive treatment, and patients in another six families (23%) reported following their doctors' recommendation strictly without consulting their families.

Family Influence on Hospice Use

Once patients have decided to stop therapeutic treatment, they may continue to receive palliative care, including chemotherapy, radiation, or other medicines, for symptom relief. For those who have few symptoms or are not appropriate candidates for further treatment, hospice provides pain management

and professional end-of-life care. However, patients and family members associated hospice care with death. They often referred to hospice as a place where "you are waiting to die" because "you cannot have hospice until you have chosen to do no more treatment."

Family discordance on discussing or considering hospice: The study findings indicate that patients and family caregivers in 10 families (39%) had considered hospice and 3 families had accepted it. Twelve families (46%) never discussed hospice care. In 10 of these families, family caregivers were unwilling or refused to discuss the issue. Patients in two families (8%) said that they did not talk about end-of-life care because of their concerns about family response.

Some patients expressed positive views of hospice care. They believed that hospice could reduce their family's physical, emotional, and financial caregiving burden significantly. A woman with stage IV cancer who experienced a great deal of difficulty in taking care of her parents said,

It was just a horrible, horrible experience. So, I don't want to do that to my kids. I don't care what they do with me, but I won't go to them, and I don't want them to have to take care of me.

Patients also believed that hospice workers were well-trained professionals and could manage their pain better than their family caregivers could. One patient said,

I would be better off somewhere else than at home, because in that other place they probably could do a little more for me than I would be getting at home, at least to make me more comfortable and [give] medication to try to ease the pain.

Nevertheless, when asked about hospice, family caregivers typically responded, "She is not at that point in time, so hospice is not appropriate as yet," or "I am too busy thinking about living to think about dying." They were concerned deeply about potential adverse consequences of talking about death with patients. Six caregivers (15%) openly admitted that they would avoid discussing hospice with patients for fear that it would accelerate the patient's death. One caregiver said,

I think if we discuss it, it would depress her and I don't want her to get into that depression, because this happened to my neighbor. My sister and she get cancer at the same time, but she got depressed when she got it, and she just didn't have that fight in her. She died.

Family caregivers avoided talking to patients about hospice even as they watched their conditions deteriorate. Two caregivers (5%) expressed their wishes that the doctors would initiate a discussion about hospice with the patient. Eight caregivers (20%) admitted that they would take care of the patients at home when they near death without acknowledging it to the patients. A 73-year-old woman with cancer indicated no plans to use hospice. A few days later, her family stated that she was receiving hospice care simply because she needed to be washed. Talking about end-of-life care appeared so difficult in some families that decision making was impeded by the families' silence.

Family disagreement about where to receive hospice care: Hospice care can be delivered in patients' homes or provided at hospice facilities. The issue of where patients should receive hospice care also can be contentious. Although most

families wished to take care of patients at home, six patients (16%) said that they would like to move into a hospice facility at an appropriate time. Caregivers that researchers spoke to in three of the six families indicated that the patients' desire to enter hospice care was received negatively in all these families. The families insisted that making patients feel comfortable was far more important than any considerations of caregiving burdens.

Discussion

The findings of this study have several important implications. First, 65% of families reported family discordance regarding treatment issues. This suggests that family disagreements about treatment decisions for patients with advanced cancer are common. Second, family disagreements about treatment decisions occur in a large range of issues, including selection of doctors, treatment options, therapeutic versus palliative care, and choice of caregiving styles. Third, the degree of family disagreements may change over time. Family disagreements were magnified when treatments became too toxic or futile and patients began to consider trading off survival for immediate quality of life. These desires were muffled by family silence or escalated as patients approached the end of life.

In most situations, family caregivers acted as patient advocates by demanding quality care. Their discontent with doctors, arguments about treatment options, and, at times, coercive style of caregiving could put patients under additional stress. Although family rifts potentially can endanger treatment decision making for patients, the overall family presence amplified patient demands about the type and amount of medical care provided. These findings suggest that family opinions have a significant impact on doctors' treatment plans and patients' treatment decisions in addition to patients' psychological well-being.

Researchers observed limited family pressure on doctors from African American families. Although one African American family reported distrust in a doctor, none switched doctors. African American patients and caregivers reported following doctors' recommendations closely and relying heavily on their faith in God. This high level of compliance among African Americans may indicate more passivity in their approach to treatment decision making or a lack of access to the healthcare system. Few had nurses or physicians in the family or any family connections to the healthcare system.

This study's findings suggest that the patients and caregivers passed through the same stages, from fighting to accepting cancer, at different paces. Perhaps patients were ahead of family members in recognizing their approaching death because of personal physical experiences. Family members might not have accepted this fact until physical deterioration had been observed.

Caregivers' empathy with patients' wishes was fostered not by merely observing the patients' physical deterioration but also by the caregivers' personal understanding, knowledge, and experiences with death. One woman, whose husband was dying, explained that her own near-death experience with diabetes and loss of two legs had made her understand treatment miseries and appreciate the value of quality of life. Researchers also observed a few unusual cases where patients and families talked about death and dying. In these families, a caregiver worked in a health-related field or the family already

had experienced several losses from cancer or other diseases. Patients and caregivers with previous experiences appeared more realistic about the disease's course and felt more comfortable with handling the issue of death. Conversely, previous negative experiences had adverse effects on decision making. One daughter explained that she did not like any kind of nursing home for her mother because her grandmother was forced to enter one under a court order. Previous experience shapes caregivers' attitudes and greatly affects their decision-making behaviors.

The findings confirm the speculation that family relations affect the degree of family concordance in making treatment decisions. Family caregivers who were emotionally intimate with patients exhibited a great deal of empathy and respect for patient decisions, and noncohesive families appeared to face heightened discordance about treatment decisions.

The findings of this study have some limitations. First, the data collected in this study were self-reported. Because the questions were open-ended, participants' reports of various incidents or events were self-solicited. The percentages and rates of these occurrences are likely to change in a more rigorous study that is refractive to self-selection factors. However, family disagreement about treatment decisions may be more prevalent than what this article reports because a thorough probing is likely to generate more responses. Second, in this study, results of the focus group study were analyzed along with individual interviews. Although focus group participants were asked the same major questions as other participants, they were given a relatively shorter amount of time to respond and their responses could be affected by the presence of others. Nonetheless, the number of patients participating in the focus group meetings was small ($n = 13$, 35%), and only five focus group participants were selected for family interviews. Thus, if this bias existed, its effects were limited for patient and family samples.

Overall, this study provides new evidence to demonstrate that family disagreements about treatment decisions are significant and require serious research attention. These findings have important implications for clinical practice. They suggest that nurses should be aware of differences of opinions between patients and families and need to handle the differences with an understanding of the patients' and families' disparate needs and feelings. Because families have significant influence on patients' decisions and these decisions can affect patients' and family caregivers' quality of life, nurses need to integrate families into the decision-making process in clinical settings.

These findings also have important implications for future studies. They represent dilemmas and difficulties that may be experienced commonly by patients who are elderly or have other types of advanced cancers and, therefore, can be transferred to and tested in a study of a larger population. Studies with larger sample sizes or a diverse population of patients with advanced cancer should be conducted in the future to examine the prevalence and degree of family disagreement over time, identify the main correlates or factors that contribute to family disagreement, and evaluate the impact of family disagreement on patients' and caregivers' ability to cope with advanced disease and make treatment decisions that are informed and congruent with patients' values and goals.

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- ▶ Center to Advance Palliative Care
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