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Facilitating End-of-Life Decision-Making Strategies for Communicating and Assessing

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Abstract

End-of-life decision-making is often a difficult process and one that many elderly patients and their families will undergo. The grounded theory study of nurses, physicians, and family members ($n = 20$) reported in this article examined provider behaviors that facilitated the process of decision-making near the end of patients' lives. According to participants, providers who are experienced and comfortable are more likely to engage in communication and assessment strategies that facilitate end-of-life decision-making. Communication strategies included: being clear, avoiding euphemisms, spelling out the goals and expectations of treatment, using words such as "death" and "dying," and being specific when using such words as "hope" and "better." Assessment strategies included: assessing patients' physical conditions and end-of-life wishes, patients' and family members' understandings of the disease and prognosis, and their expectations and goals. An important first step for improved care is making explicit the provider's communicating and assessing strategies that facilitate end-of-life decision-making.

It is important for providers who care for older adults to recognize that their patients are approaching life's final developmental stage. This developmental stage ultimately ends in death. As a result, decision-making regarding end-of-life treatment is a common process for most patients and their families. Although proactive planning for end-of-life care is ideal, this process often does not begin until late in the patient's dying trajectory. Advance directives represent one method to provide patients with the means to proactively determine their future care. However, advance directives do not and should not take the place of ongoing discussions with patients and their families regarding wishes for end-of-life care. Delayed or inadequate planning may have profound negative consequences for patients, families, and providers.

Individuals, families, and health care providers are challenged when decisions need to be made regarding the utility of treatment goals that affect the quality of life and death. This article presents specific strategies that families and providers have identified for nurses and physicians to use to facilitate decision-making near the end of life.

Background

There is increasing evidence that the narrow scope of typical advance directives is often insufficient to adequately aid families in end-of-life decision-making (Bradley, Peiris, &

Wetle, 1998; Happ et al., 1999; Mezey, Kluger, Maislin, & Mittelman, 1996). While the Patient Self-Determination Act has resulted in more discussions of end-of-life wishes, as many as 80% of nursing home residents continue to lack documented treatment wishes in their medical records (Bradley et al., 1998; Suri, Egleston, Brody, & Rudberg, 1999). The presence of poorer physical and cognitive function, increasing age, and White ethnicity have been associated with the presence of an advance directive (Suri et al., 1999). A study by Happ et al. (1999) found that end-of-life discussions with frail older adults and their families were delayed until late in the dying trajectory, if they occurred at all. These delayed end-of-life discussions significantly contributed to inadequate attention to and treatment of pain and symptom distress in most residents (Happ et al., 1999). Other studies provide evidence that families may not be as actively involved in the process of end-of-life decision-making in long-term care settings as they would prefer (Kayser-Jones, 1995; Wilson & Daley, 1999).

Two qualitative studies identified a clear role for nurses in facilitating patient and family participation in end-of-life decision-making. Wilson and Daley (1999) identified that nurses play a significant role in helping older adults and their families through the dying process. In the other study, nurses were often the first to identify a need to reevaluate treatment goals, which was facilitated by the intervention of an advance practice nurse (Happ et al., 1999).

Wilson and Daley (1999) provided specific recommendations to long-term care nurses on how they can actively improve the dying process for nursing home residents, which included aiding families in identification that death was imminent. In a descriptive study of bereaved family members ($n = 32$), provider behaviors described by family members as helpful included timely communication, encouraging advance care planning, facilitating family consensus, and accommodating family grief (Tilden, Tolle, Garland, & Nelson, 1995).

The available literature identifies end-of-life decision-making as a problematic area for many older adults and their families. There is a need to identify strategies providers can use to facilitate, or at least not impede, decision-making near the end of life. The strategies described were part of a study on negotiating decisions near the end of life (Norton, 1999; Norton & Bowers, 2000). In the context of the study, provider and family participants identified behaviors that facilitated and impeded end-of-life decision-making. The facilitative behaviors are the focus of this article.

Methods

Sample

The sample consisted of 20 participants from a mid-sized Midwestern city. Ten participants were RNs in specialties of home health care ($n = 3$), intensive care ($n = 4$) and oncology ($n = 3$). Five participants were physicians with specialties in oncology ($n = 3$) and family practice ($n = 2$). Five participants were immediate family members of patients with a life threatening illness or recent decedents (deceased between 6 months to 2 years), and of these, three were designated proxy decision-makers. All providers routinely worked with elderly individuals in their practices and four of the five family member participants were family members of patients older than age 65. Eighteen of the participants in this study were of Euro-American descent and two were of Latino-American descent. Though not exclusively, the providers in this study worked primarily with Euro-Americans.

After Institutional Review Board approval, study provider participants were recruited via letters of invitation and family members were recruited via church newsletters and convenience sampling. All interviews were conducted at a time and place of participant choosing, tape-recorded, and transcribed verbatim. Early interview questions were open-

ended becoming increasingly focused as the study progressed. (See Table 1 for examples of interview questions.).

Data Analysis

The data were analyzed using open coding, constant comparative and dimensional analysis, axial coding, and theoretical sampling consistent with a grounded theory research design (Bowers, 1989; Glaser & Strauss, 1967; Schatzman, 1991; Strauss, 1987). Memos and matrices were used to track the evolving theory and the methodological choices made by the researcher during the study. As analysis progressed, interview questions and theoretical sampling evolved and focused on collecting data to saturate the links between and among categories. All interviews were entered into a computer software program designed to assist qualitative data management (QRS NUD * IST — Non- numerical Unstructured Data Indexing Searching and Theory-building, 1997). Methodological procedures are described in greater depth elsewhere (Norton & Bowers, 2000). Several procedures were integrated into the methodological design of this study to maximize the credibility of the results (Chenitz & Swanson, 1986; Guba & Lincoln, 1989; Strauss, 1987). These included the six processes described by Guba and Lincoln (1989): prolonged engagement, persistent observation, peer debriefing, negative case analysis, progressive subjectivity, and member checks.

Results

In the study reported in this article, participants identified provider (i.e., nurse and physician) behaviors that facilitated and impeded end-of-life decision-making—in particular, providers' willingness and ability to communicate and assess. Grounded in early interviews, the decision-making context of this study referred to decisions patients and families made in conjunction with providers regarding treatment choices near a patient's end of life. Specifically, how patients, families, and providers made decisions to forego curative treatments in favor of palliative ones. Most participants described making treatment decisions near the end of life as difficult. However, the decision-making process was seen as especially problematic when accompanied by disagreement and conflict among providers, patients, or family members.

Family members and providers consistently associated provider comfort and experience as central to facilitating the process of decision-making near the end of life. Both terms were used by providers and family members to describe and explain provider adequacy or inadequacy regarding decision-making. Experience, in general, referred to the length of time a provider has worked with patients who have been or are soon to be diagnosed with a terminal illness. Comfort was a much more difficult concept for participants to define, though they could easily describe examples of comfortable and uncomfortable providers. Most often comfort was manifested by the provider's willingness to engage the patient in conversation about dying and end-of-life choices, using the words death and dying in conversation, providing support for patient and family decision-makers, and being clear about terminal prognoses in conversations with patients.

Communicating

Communication with patients and families about treatment choices and the possibility of death was identified as central to facilitating decision-making near the end of life. Both provider and family members identified provider comfort and experience, for better and for worse, as often affecting providers' willingness to engage and be clear in such conversations.

Being willing—Participants identified providers' willingness to initiate and engage in discussions regarding end-of-life treatment choices as a central condition necessary for end-

of-life decision-making to occur. One provider noted that she often engaged patients or family members in conversations regarding end-of-life issues:

I'm very comfortable with talking to families, very comfortable with talking to patients about these kinds of issues [end-of-life decisions]. These kinds of hard issues, they're not something that makes me cringe and go, "Oh God, I don't think I'm up for this today."

Providers who were comfortable and more experienced were usually described as being willing to engage in end-of-life conversations and engaged much earlier in a patient's dying trajectory. On the other hand, one nurse noted:

Well, I think basically every nurse can probably ask the question, do you have advance directives, is this something that you've talked about? I don't know that every nurse will carry that further, and ask maybe some of the harder questions...to have someone who is really comfortable in discussing the psychosocial issues around advance directives, and really explore that. I don't think that that's the norm here.

All provider participants noted that providers who seemed uncomfortable discussing end-of-life issues tended to avoid or delay end-of-life conversations, often with profound negative consequences for patients and families. According to participants, delaying or avoiding conversations resulted in patients receiving burdensome and painful treatments and not having sufficient time to prepare for death.

Being clear—A second dimension in communicating with patients near the end of life involved provider clarity. Provider comfort and experience were linked by participants to their ability to be clear in conversations with patients and families, as one nurse described:

I think the more experience you have, the more times you've done it [end-of-life discussions], the more comfortable you are. I think there are some people that have a real hard time saying it to a patient, "I know that you're dying" and using that word dying. We all say things like, "you know your time is short" which is an okay thing to use, but I think the more comfortable people are with, basically talking about it directly, the better off they [providers] are.

According to many provider participants, providers unwilling to use words such as "death" and "dying" send mixed messages to patients and their families regarding terminal prognoses. One family member described the consequences of vague language on her family:

I just think if we would have had some honesty...I think that there were just some things that we would have been able to deal with it [her father's dying] better as a family, and not fought as much [sic].

Though this participant knew that her father's prognosis was terminal, family conflict ensued when one provider focused only on symptoms that had improved. For some members, this generated the impression that the patient's condition was no longer terminal.

A common source of unclear communication stemmed from the ambiguous use of words such as "hope" and "better." For example, a provider may say "your Mom's respiratory status is better," when "better" means her condition has been stabilized by intubation and mechanical ventilation and her overall prognosis is unchanged or worse. The phrase "there is always hope," for example, may be interpreted in a number of ways as hope for: survival, a miracle, a good death, or a cure. Thus, the use of words such as "hope" and "better" without being specific as to what there was hope for, often led to multiple or conflicting interpretations. Multiple interpretations were likely to lead to confusion and disputed

decision-making. One family member described how other family members stopped listening to bad news after a provider said he was hopeful about her mother's prognosis:

Because they [other family members] were trying to pull, like, every tiny shred of hope that the doctor might say, instead of just, like, taking the message and taking it for reality. And I don't know if the doctors really realize that just by saying one word that was hopeful about her, that that is the word that they keyed in on. And they just shut off their listening after that.

At the same time, experienced providers were often frustrated by the negation of all hope by providers. One nurse, in describing her discomfort in talking with patients about end-of-life choices, used several common phrases:

After the doctor gives them some sort of prognosis, and many times, "there is nothing more that we can do," that kind of thing. I think I myself tend to approach those things [end-of-life discussions] later rather than sooner, even though sooner would be better. Maybe it is just making people feel that there isn't any hope.

Note the phrases "there is nothing more we can do" and "there isn't any hope." Many experienced providers described both phrases as frustrating because many things could be done. Experienced providers described pain and symptom management, hospice referral, as well as helping the patient and family prepare for death as things that could be done for the patient and family. Others noted that there is always something to hope for, and made a deliberate effort to redirect what people hope for (e.g., a "good" death, attending a major family event). One nurse provider described comments such as "there is no hope" as one way of abandoning the patient.

Clarifying prognosis and goals of treatment—A common source of problems in decision-making was patient or family confusion regarding the goals and expectations of treatment. One provider noted that the goals of treatment are often unclear to patients and their families, especially the differences among curing, prolonging survival, and palliating symptoms. To clarify goals of treatment, providers often need to clarify the prognosis. Some providers are uncomfortable doing this, as one physician described:

And I think it is important to set out that they are your different goals. We euphemistically use the term "response rate." Your tumor will "respond." But a 50% response rate in a tumor doesn't mean much because you've still got tumor there. But patients seem to hang on this, "Oh, it's got a 50% response rate."

According to this provider, when patients hear a 50% response rate they often infer a 50% cure rate unless the provider is very clear about the meanings of the terms they are using. One consequence of the lack of clarity was that patients or family members are often left with a false impression about the patient's condition, which often resulted in problematic decision-making.

Communication strategies that facilitated end-of-life decision-making were:

- Being clear.
- Avoiding euphemisms.
- Being specific about the goals and expectations of treatment.
- Using words such as "death" and "dying."
- Helping patients and families maintain hope with specific referents.

Assessing

Assessing refers to an ongoing process of information gathering by providers. Assessing was a critical first step in a provider identifying a need for end-of-life discussions. Experienced providers often focused on the importance of assessing for deterioration in the patient's physical condition, understanding about illness and prognosis, end-of-life wishes, and goals and expectations.

Recognizing deteriorating conditions—Experienced providers described the importance of recognizing deterioration in the patient's condition that may signal a shift from a chronic to a terminal phase of illness. These providers regularly assessed for signs that the patient's condition was deteriorating and initiated end-of-life discussions with those for whom death appeared imminent. Many providers identified changes that may herald a terminal phase of illness, these included:

- Worsening symptoms, especially shortness of breath, fatigue, confusion and pain.
- Loss of appetite.
- Weight loss.
- Increasing frequency or severity of exacerbations.
- Decreased activity tolerance.
- Increased use of assistive devices.
- Talk of death.
- Finishing business.
- Talking to dead relatives.
- Withdrawal.

One nurse noted:

There are just changes that just kind of—that are different for everybody—that just kind of click together and you just know that things are not going to be much longer.

Many experienced providers noted it is especially difficult to definitively determine when death is approaching in patients who have illnesses characterized by multiple acute exacerbations such as chronic obstructive pulmonary disease or congestive heart failure.

Assessing understanding—Many experienced providers did not wait until death appeared imminent to begin assessing the patient's and family's understanding of the patient's condition. These providers routinely and proactively incorporated behaviors into their practices that helped them discover misunderstandings and the providers intervened early to mitigate them. One nurse described the importance of assessing the patient's and family's understanding of the patient's condition to identify and correct their misconceptions:

People would have notions about what was going on that, for lack of a better word, were not accurate. For example, if only he would eat more maybe he would not be dying.

An initial assessment that the patient or family did not understand the situation triggered an in-depth assessment including identifying and then correcting misunderstandings and misconceptions.

At the same time, family members described difficulties in obtaining the necessary information to make informed decisions. While providers described how problematic it was when patients and family members did not understand what was going on with the patient, it is the providers who are, in large part, responsible for deciding when, what, and how information is given to patients and families. One family member described how he initiated getting information from providers, which was not always easy. He said:

But there isn't, like, one person you know that you can just go and contact and say, "Gee, give me an update on my mom." You just kind of go to the front desk and say, "Who is in charge of my mom today?" and try and track them down.

Providers also tended to assume, sometimes incorrectly, that they knew what information the patient or family needed and wanted. Family members described a feeling that providers often had a more complete or a different understanding of what was going on with the patients than the family had. Family members often knew their understanding was inconsistent with providers but not how. Some family members were further frustrated by providers' perceived unwillingness to share information unless they were able to ask the correct question of the correct provider at the correct time. As one family member described:

But no matter what I asked, and how much I asked, it just, it [the information from the provider] wasn't giving us the full picture. But it was very frustrating because we didn't know what questions we should be asking.

Experienced nurses described priming patients and families with specific questions to ask other providers, usually physicians, as one way to assist families in getting the information they wanted.

Assessing End-of-Life Wishes—Another aspect of assessing involved routinely examining patients' end-of-life wishes. Though it is routine to ask patients whether or not they have an advance directive, many experienced providers used this question as a springboard into a more in-depth assessment of end-of-life preferences, especially when the patient was older, in a long-term care setting, or had a potentially terminal diagnosis. One nurse described the way an oncologist approached cancer patients:

He is very gentle about DNR (do not resuscitate orders) things. He says, "You know the State wants all doctors to talk to people about what happens—and God forbid." I use that term now, God forbid that you should die, your heart should stop beating, or something like that should happen.

Introducing a discussion about resuscitation as a mandated practice was described as easier than introducing a resuscitation discussion by noting that the patient's condition has deteriorated. However, other providers noted that this approach may preclude a discussion in which patients become aware that their death may actually be quite near. In general, providers reported that advance directives were not particularly helpful often because the preferences indicated were not specific or not relevant to the particular situation.

Assessing patient and family goals and expectations—A further aspect of assessing routinely engaged in by some experienced providers was examining patient and family goals and expectations. Simple questions such as, "What are your health goals?" or "What are your expectations of this treatment?" were integrated into initial assessments, regular visits, and at times when the patient's condition deteriorated. Providers then evaluated whether the goals of the patient seemed achievable and the expectations consistent with the providers' expectations. If not, a more in-depth assessment was performed. In-depth assessments were also triggered by seemingly unrealistic comments made by patients or

family members. The nurse who said the following noticed a comment that reflected inconsistencies between her and her patient's expectations of chemotherapy:

We see sometimes [sic] people who, we think, really are not doing well, but are waiting for their next chemotherapy, and they're waiting, you know, with bated breath because they're going to get better. And I'm looking at them going [sic], "Whoa! You know, I'm nervous!" And so, I gently try to talk with them.

The nurse identified a problem area (i.e., the patient's expectations for a cure), followed up with a more in-depth assessment, and created a teaching intervention focused on the palliative rather than the curative goals of chemotherapy. Following the teaching, she began a discussion regarding other options available to the patient (e.g., hospice). In contrast, providers often described how other providers, usually those with less experience, either failed to recognize or were unwilling to follow-up on inconsistencies in patient expectations. More experienced providers reported the need for ongoing assessments of patient goals and expectations throughout the course of a patient's illness trajectory, particularly when a life threatening event seemed imminent.

Assessing the patient's physical condition, as well as the patient's understanding of the disease process, understanding of the prognosis, end-of-life wishes, goals, and expectations were all varying types of assessments that experienced providers described as important to facilitating decision-making. Many providers noted that providers who were not comfortable were not likely to perform these assessments and thus failed to identify problems in decision-making earlier. Routinely performing these assessments along with the communication behaviors described earlier facilitated both the initiation and progression of the decision-making process.

Discussion

In this article, behaviors were described that providers and families reported as influential in facilitating end-of-life decision-making for older adults and their families as dying moves from abstraction to impending reality. Proactive communication and on-going assessment become critical skills necessary to beginning this process in a sensitive, individualized manner. In the study reported in this article, the presence of a patient advance directive did not figure prominently. Rather, providers and family members described complex ongoing assessments and communication strategies that facilitated or impeded decision-making as patients moved through the illness trajectory. Any advance directives patients make (oral or written) freeze their preferences for end-of-life care at a single point in time. This may render the advance directive inadequate if the patient's context changes. Providers need all available strategies, including advance directives, to support ongoing discussions with patients to ensure their current wishes for end-of-life care are both known and followed.

Every nurse has the opportunity to make the process of end-of-life decision-making easier for both patients and their families. Benefits of facilitating end-of-life decision-making for patients and their families include providing time for anticipatory grieving, allowing for closure of psychosocial issues, the promotion of a "good death" consistent with the individual's values, and improved bereavement outcomes for families (Norton & Bowers, 2000; Wilson & Daley, 1999).

In the increasingly complex and fast-paced health care environment, end-of-life decision-making can become disjointed. Communication across settings can be problematic without skillful collaboration among professionals, patients, and families. Technology is available to prolong life; however, patients and families are often faced with the more fundamental question of should technology be used to prolong life when quality of life and recovery are

limited. Nurses are often in an ideal position to help patients and families address these very complex issues because of the frequency and intimacy of their encounters. Nurses share the responsibility for end-of-life decision-making with their colleagues, patients, and families.

The findings of this study have implications for nursing practice. Table 2 contains communicating and assessing strategies that can be used for patients or family members. In addition to identifying when a patient is moving from chronic illness to a dying trajectory, nurses have an obligation to prepare themselves to assist in end-of-life decision-making. Possibilities for increasing nurses' comfort and experience in end-of-life decision-making exist through increasing undergraduates' exposure to death and dying issues during clinical preparation (e.g., hospice settings), mentoring, and continuing education for professionals.

One important caveat to the implementation of the interventions suggested in this article is the consideration of patients' culture. The results of this study were from a context of providers who primarily work with Euro-Americans. Culture and ethnicity are known to be factors that affect an individual's willingness and interest in advance care planning (Berger, 1998). Cultural and ethnic diversity will continue to influence end-of-life decision-making as a growing percentage of the total United States population is increasingly represented by minority older adults (Kramarow, Lentzner, Rooks, Weeks, Saydah, 1999). Thus, the results are not transferable to patients from other cultures. Nurses must take into account cultural considerations when planning end-of-life care. Future studies are needed to understand whether the provider behaviors identified as facilitative, are in fact, appropriate for patients from diverse cultures.

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Keypoints: Facilitating End-of-Life Decision-Making

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1. Nurses are in an ideal position to help patients and families through the process of making health care decisions near the end of life.
2. Being willing to engage patients and families in end-of-life discussions, as well as being clear in such discussions, are critical components to facilitating the decision-making process.
3. Nurses should routinely incorporate assessments of patients' and families' goals, expectations, and information needs into their clinical practices.
4. It is important for nurses to take advantage of mentoring and education opportunities to improve their ability to work effectively with patients near the end of life and their families.

Table 1**Examples of Interview Questions**

Early interview question

How do patient care decisions get made here?

Evolving interview question

What sort of things are important to know when you are working with older adults near the end of life? If you had to precept new employees, what would you tell them about working with patients or family members near the end of a patient's life?

Later interview question

A provider's experience and comfort level in talking with patients near the end of life matters a great deal, especially with assessing and intervening with patients or their families. Can you give me examples from your practice about how a provider's comfort and experience matter?

Table 2**Strategies to Facilitate End-of-Life Decision-Making**

Communicating

- Be willing to both initiate and engage in discussions about end-of-life issues.
- Use words such as “death” and “dying” in discussions with patients and their families.
- Be specific when discussing what there is hope for (e.g., “a good death,” pain control).
- Clarify goals and burdens of treatment and prognosis.
- Collaborate with other providers to give consistent information.

Assessing

- Changes in the patient's condition that may signal a shift to a terminal phase.
 - Patients' and family members' understandings of the patients' conditions.
 - Patients' health goals and whether goals seem achievable.
 - Patients' and family members' expectations and whether they are consistent with providers'.
 - Patients' and family members' information needs.
-