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## Decisional role in seriously ill hospitalized patients near the end of life: The patient's and provider's perspective

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### Abstract

*Decisions about whether or not to implement life-sustaining therapies are complex and are becoming more so as the ability to prolong life with advanced technologies and care increases. The objectives of this study were: (1) to determine seriously ill hospitalized patients' preferences for decisional role with respect to decisions about life-sustaining treatments, and (2) to determine if providers were aware of patients' preferences.*

*This prospective, descriptive pilot study was conducted at an Ontario teaching hospital. One hundred and seventeen seriously ill adult patients admitted with cancer and non-cancerous conditions participated in a structured interview. Fifty-three nurses and 63 physicians responsible for the care of the participating patients also participated. Patients and providers were asked similar questions about end-of-life discussions and preference for decisional responsibility for life-sustaining treatments.*

*Most patients (n=89, 77%) had thought about end-of-life issues and were willing to discuss these with their physicians and nurses, but few (n=37, 37%) reported such discussions. Preferences for decisional role varied; most indicated a preference for a shared role (n=80, 80%) and there were no differences in patients with or without cancer. Generally, both physicians and nurses were not aware of or did not determine accurately patient preferences for decisional role.*

*The findings from this study show that seriously ill hospitalized patients have thought about and are willing to share in discussions about end-of-life care with their providers, yet many have not.*



Helene Hudson, 1945-1993

### Statement of issue

In Canada, over 70% of deaths occur in the hospital. Patients with a primary diagnosis of cancer account for approximately 30% of these deaths. With the ability to prolong life with advanced technology and care, patients with primary and secondary diagnoses of cancer (and their family members) are, increasingly, confronted with decisions about whether or not to implement life-sustaining therapies. These are difficult, value-laden treatment decisions. Preferences for treatment are often unknown or not sought. Many studies examining end-of-life issues describe responsibility for these decisions (i.e., the decision to treat or to withhold or withdraw treatment) from the physician's perspective. Although several position papers have been written, very little research has been conducted investigating the role of nurses in end-of-life care and end-of-life decision-making.

Recent studies of end-of-life care suggest that improvements in communication and the decision-making process may lead to improvements in quality end-of-life care. A large five-centre study conducted in the United States, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) enrolled over 9,000 patients. The objective of this two-phase study was to improve end-of-life decision-making and reduce the frequency of mechanically supported painful and prolonged processes of dying. In phase one, the process of decision-making and patient outcomes were described and observed in 4,301 patients. There were shortcomings in communication and evidence of aggressive life-sustaining treatments: only 47% of physicians knew patients' preferences, 46% of do not resuscitate (DNR) orders were written within two days of death, 38% of patients had a 10-day ICU stay, and many experienced moderate to severe pain in their last days of life. The findings from phase one suggested that management was most impacted by poor physician-patient communication. In phase two, a nurse-based intervention was designed. A "skilled" nurse made many contacts with the family, patient, and physician to elicit preferences, improve patient and family's understanding of outcomes, encourage attention to pain control, and, overall facilitate advance care planning and communication. This study relied solely on the nurse as a communicator, facilitator, and advocate to improve the decision-making process. There were no significant differences in the measured clinical or economic outcomes. The apparent failure of this intervention strongly suggests that there are other more powerful determinants of the decision-making process that are not completely understood.

Therefore, the purpose of this research was twofold: (1) to determine seriously ill hospitalized cancer and non-cancer patients' preference for decisional role with respect to end-of-life decisions, and (2) to determine if their providers (nurses and physicians) were aware of their preferred role. We hypothesized that seriously ill hospitalized patients would prefer to defer or share the responsibility about end-of-life treatments to their health care providers and that cancer and non-cancer patients may have different experiences as the illness trajectory for cancer is more predictable and, historically, cancer patients have received more formal palliative and advance care planning. Secondly, we hypothesized that most providers would be unaware of patients' preferences. The long-term goal of the End-of-Life Research

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Working Group (EOLRWG) is to develop and evaluate processes that enhance decision-making around end-of-life issues. Health care providers (nurse and physician) are essential for the process. Ultimately, with better decision-making processes, the effectiveness and quality of end-of-life care will be enhanced.

## **Background literature**

### **End-of-life decision-making**

Our current understanding of end-of-life decision-making stems from published conceptualizations and empirical results of studies of health care decision-making, predominantly studied in other patient populations. Several factors affect the process and/or outcomes of clinical decisions near the end of life. Intrapersonal factors include each patient's unique personal, physical, psychological, and sociocultural characteristics such as health status, patient preferences, their health care decision problems, beliefs, and values. The interpersonal factors are those factors that will influence the real world decisional interactions and the process of information exchange, deliberation, and, finally, the decision. Provider characteristics such as knowledge and skill, beliefs, and values will influence the nature and extent of the interactions. These interactions are influenced by the contextual nature of the environment in which they take place. Discussions about end-of-life care may be very different in a home setting versus an acute care setting.

Health care decision-making is interactional, which is both a strength and a weakness. Interactions are time- and energy-consuming and assume that both the provider and patients have an investment in the process and that there are treatment options available. With each interaction, there is a decision-making process. Charles and colleagues (1997) define three role models and three distinct analytic stages to the decision-making process: information exchange, deliberation about treatment options, and deciding on which treatment option. These processes will vary across patient-provider interactions depending on the nature of the patient-provider relationship. Information exchange refers to the types and amount of information exchanged. Depending on the model, the amount and direction of flow of information will vary. For example, when a patient assumes a passive role and the provider an active role, the flow of information is largely one way, from the provider to the patient. The provider communicates the minimum amount of information to the patient to satisfy the requirements of "informed consent." In the informed model, the flow is again from the provider to the patient, but this time the provider communicates all information desired by the patient to help him or her make the decision. In a shared decision-making model, the information exchange is two-way. The provider shares information relevant to making the decision, the patient provides information on values, lifestyles, fears, and preferences. The process of information exchange may be critical to decision-making near the end of life.

Research documenting the preferred role of seriously ill hospitalized patients is limited. Patients' perceived and desired role in the decision-making process has been studied more in other patient populations, most notably in ambulatory cancer patients. Compared to the general population, cancer patients prefer a more passive role in the decision-making process. While these studies of patients' preferred role are informative, they may not be generalizable to cancer (or non-cancer) patients making end-of-life treatment decisions (contrasted with cancer-related treatment decisions).

### **An organizing framework for end-of-life decision-making.**

We have attempted to integrate many of the concepts into an organizing framework to guide this study (and others) conducted by the End-of-Life Research Working Group (Heyland, Tranmer, & Feldman-Stewart, 2000). The framework consists of four "units of study": a) provider, b) patient, c) decision-making process, and d) outcome. It should be emphasized that this is an organizing framework and it cannot be overstated that conceptually, decision-making, especially near the end of life, is complex. The interactions are continuous, involve multiple providers and family members,

occur within a complex social environment of often conflicting priorities and values, and the decisions are value-laden and final. While we conceptualize the patient-provider interactions as one of three models (passive, collaborative, active) the models should not be construed to represent rigid processes or events. Patients and providers may move from one model to another from one interaction to the next or even within one interaction. For example, as a physician operating in an active role senses that his patient requires more information and participation in the decision-making, he may move to a more shared decision-making model. The optimal outcome(s) of the process will be unique for each individual and, consequently, are difficult to define and measure.

### **The nursing role in end-of-life decision-making**

If health care and end-of-life decision-making are thought of as a continuum, anchored by the patient at one end desiring full responsibility and control and the physician (provider) at the other end dictating clinical decisions about patient care, we hypothesize that the nurse functions in several roles as a facilitator, interpreter, and clarifier, and is often a filter through which communication occurs between the physician and patient. The nurse as the mediator interprets for the physician and advocates for the patient and family. Thus, if the nurse is participating by mediating patient preferences, then his/her perception of the degree of responsibility for patient decision-making should be congruent with that of the patient.

Very few research studies have addressed the role of the nurse in end-of-life decisions, although some studies have addressed nursing attitudes towards end-of-life issues. Gaps in the decision-making process are evident and those that may involve nurses have not been adequately addressed. A recent study by Wilson and colleagues (1997) comparing interns' and attending physicians' abilities to predict end-of-life treatment choices of seriously ill hospitalized patients found that physicians often learned of the patients' CPR preferences from sources other than the patients. No specific data were given that quantified 'often.' No indications were given as to whom these sources were, although it is possible that one of the main sources was the patient's nurse. A study by Baggs (1993) found that the amount of collaboration between nurses and ICU house staff in the decision to transfer a patient out of the ICU, as reported by nurses, was a statistically significant predictor of risk of a negative patient outcome. As the collaboration increased, as reported by nurses, the incidence of negative patient outcomes decreased. Collaboration, as reported by house staff, was not statistically associated with patient outcomes. Although this study did not look especially at end-of-life decisions, the results indicate that the role nurses play in clinical decision-making can impact patient outcomes.

The aim of phase two of the SUPPORT study was to improve end-of-life decision-making and reduce the frequency of a mechanically supported, painful, and prolonged process of death. In this randomized controlled study, physician groupings were randomized to receive the intervention or not. The intervention consisted of nurses: (1) providing prognostic information to physicians; (2) eliciting patient preferences; (3) encouraging physician attention to pain control; (4) facilitating advanced care planning; and (5) facilitating physician-patient communication. Although the SUPPORT trial failed to achieve statistical significance on any of the five primary outcomes: physician understanding of patient preferences; incidence and time of documentation of do-not-resuscitate orders; the amount of pain experienced by patients; time spent in intensive care unit, comatose or receiving mechanical ventilation before death; and hospital resource use - one cannot conclude that there is no role for nurses in end-of-life decisions.

Oddi and Cassidy (1998) in a critical commentary of the SUPPORT trial suggested that the poor outcomes might have been related to the investigators' inadequate understanding of, and consequently the incorporation of the nursing skill and knowledge into the project design and intervention. Nurses were to independently develop their role, similar to "nurse specialists." The nurse selection criteria, background education, preparation, and

responsibilities varied between sites. Nurses may have failed as communicators because their information was not valued or perceived as credible. Nurses may have failed in their role as patient advocates because of a lack of assertiveness and support by the health care team. Nurses were caught in the middle between families and patients and the physicians - there was little evidence of collaboration. However, Oliverio and Fraulo (1998) favourably commented on their role as nurse clinicians. They stated that they came to understand the complexities and fears of patients and families in this process and perhaps it was these complexities that explain why the communication efforts seemingly demonstrated no benefit. They felt strongly that it was the nursing role to advocate for appropriate care in accordance with patients' and families' preferences in conjunction with the clinical judgment of the health care team. The nursing role was to make sense of the complex factors, such as high technology, hope, futility, and the burden of the decisions. They also suggested that outcomes related to process and comfort and caring may be more appropriate to measure.

## Summary

End-of-life decision-making for seriously ill hospitalized cancer and non-cancer patients is complex. Recent research suggests that our efforts to improve the care near the end of life have not been successful. Specifically, the nursing role remains underdeveloped and underutilized. Therefore, the purpose of this study was to explore important aspects of end-of-life decision-making in seriously ill hospitalized cancer and non-cancer patients from both a patient and a provider perspective.

## Research questions

In this study we posed three research questions:

1. What role do seriously ill hospitalized patients wish to assume in decisions about life-sustaining treatments?
2. Is there a difference in preferences for decisional role in patients diagnosed with cancer or non-cancerous conditions?
3. Are health care providers (nurses and physicians) aware of patients' preferences for decisional role and if so what is the congruency?

## Research method

The study design was a case-specific, cross-sectional survey administered in face-to-face interviews. The study was conducted in an acute care, university-affiliated hospital in southeastern Ontario. The study population consisted of those patients admitted to the Kingston General Hospital who met the patient inclusion/exclusion criteria, the patients' assigned nurse, and the patients' attending and resident physicians.

Patient inclusion criteria required that patients were age 18 years or more; were admitted to hospital for medical reasons; had one or more of the following co-morbidities: (a) chronic obstructive lung disease (COPD) determined by the presence of two or more of a baseline pCO<sub>2</sub> of ≥ 45 torr, cor pulmonale, respiratory failure within the last year, or forced expiratory volume of ≤ 25%; (b) congestive heart failure (CHF) determined by New York Heart Association Class IV symptoms of ventricular function ≤ 25%; (c) cirrhosis determined by diagnostic imaging or esophageal varices and hepatic coma or class B or C liver disease, or (d) metastatic cancer (admitted with a complication); were expected to stay in hospital 72 hours or more; and could speak English. Patients with psychiatric illness, those who were expected to have difficulty in communication (language, cultural, or cognitive barriers), and those who were facing imminent death were excluded from the study. The patient inclusion criteria for the study sample were chosen to reflect the inclusion criteria used in the SUPPORT study. Patients whose condition may deteriorate to the point where they may be at risk of facing end-of-life decisions and whose probability of survival at six months was 50% were included in the sample.

Each study subject's assigned nurse, responsible resident, and attending physician were approached to participate in the study. The assigned nurse was the nurse assigned to the patient on the day of the interview. The attending physician was the staff physician who was responsible for the patient's in-hospital medical care at the time

the survey was administered to the patient. The most responsible resident was the senior resident assigned to the care of the patient.

## Measures

We obtained information from patients using a structured questionnaire administered by a research assistant. The questionnaire consisted of a preamble explaining the study objectives; questions to determine the patient's role in making decisions; questions determining with whom the patient feels comfortable discussing end-of-life issues; and a section to collect demographic data. We did not use the card sort approach as originally designed by Degner and Sloan (1992), as we were concerned about the time required to sort responses and we also wanted to use the same methodology with the physicians and nurses. The measurement tool for physicians and nurses consisted of a subset of questions of the questionnaire given to the patient. The health care provider questionnaire assessed the physicians' and nurses' perception of the role they thought the patient would desire with respect to end-of-life decisions. We also provided an opportunity for both patients and providers to comment on their responses.

## Data collection

All attending physicians were informed about the study and endorsement was sought for involvement of patients assigned to their care. Most attending physicians agreed to participate. A small number of physicians raised concern about the focus of the study on end-of-life issues, especially with "their patients" with whom they may not have discussed these issues. We attempted to reassure physicians that we were exploring the process of decision-making in an attempt to describe strengths and gaps and that we were only focusing on preferences for decisional role and not actual preferences for care.

Patients were approached for participation if they met the inclusion criteria and had been in hospital for at least three days. After patient consent was obtained, the research assistant conducted the interview. The nurse assigned to the patient on the day of the interview, the most responsible senior resident physician, and the attending physician were given a questionnaire to complete for each patient enrolled in the study. The research protocol was reviewed and approved by the Kingston Health Sciences Research Ethic Board.

**Table One: Patient characteristics of sample**

Characteristic	n	Cancer	n	Non-cancer
Gender	56		61	
Female		30 (54%)		27 (44%)
Male		26 (46%)		34 (56%)
Mean age	56	66 (SD 12)	61	72 (SD 18)
Expired within six months of interview*	43	74% (32)	37	54% (20)
ICU admission	56	4 (7%)	61	18 (30%)
Documented EOL discussions	56	17 (30%)	61	20 (33%)
Documented EOL order	56	20 (36%)	61	20 (33%)
Palliative care consult	56	24 (43%)	61	3 (5%)
Education	52		54	
Less than high school		17 (33%)		22 (41%)
Completed high school		14 (27%)		16 (30%)
More than high school		21 (41%)		16 (30%)
Living arrangements	52		54	
On own		10 (19%)		17 (31%)
With family		38 (73%)		33 (60%)
Supervised residence		4 (9%)		4 (9%)

\* Data only available on patients enrolled in first six months or those who expired before July 2000.

## Results

### Sample

Patient recruitment for this study began in July 1999 and provider recruitment in February 2000 and will continue for another six months. As of July 2000, the time of this report, the patient participation rate was 57% (122/215). The most common reason for non-participation was the patient's desire not to be in a study. The response/participation rate for nurses, residents, and attending physicians was 86% (46/53), 64% (19/29), and 77% (26/34) respectively. For the purpose of this report, the attending and resident responses are combined into physician responses.

### Patient characteristics

Results are reported on the first 117 patients enrolled in the study (see Table One). Patients enrolled in the study were elderly. Of those patients who were enrolled in the beginning six months of the study, 74% of patients with cancer and 54% of patients with non-cancerous conditions have expired. More of the patients with COPD and congestive heart failure had ICU admissions in comparison to the cancer patients. More cancer patients had received palliative care consults. However, only one-third of patients in both groups had recorded discussions about end-of-life (EOL) care or an EOL order on their patient record. Most patients either lived on their own or with another family member. In this sample, 58% (62/107) were married, 26% (28/107) divorced, and the remaining 15% (17/107) were either single or widowed. Most were retired (81%, 87/107).

### Nurse characteristics

Nurses (n=42) were employed on the medical surgical units. Twenty-nine per cent were in part-time positions, 60% in full-time positions, and the remaining 11% in temporary part-time or full-time. Nurses in this sample had worked for an average of 11 years with a range of work experience from one month to 33 years. In this hospital,

patient assignment is done on a shift-to-shift basis - there is no primary nurse assignment. A single clinical nurse specialist, palliative care, provides important support to patients and families.

### End-of-life discussions

In the first part of the interview, patients were asked the questions listed in Table Two. Most patients (77%, 89/116) have thought about treatments they would wish to receive if they developed a life-threatening complication. However, similar to what is recorded in the patient record, 37% of patients (43/116) reported having these discussions. Most are willing to discuss these issues with their physician. Those patients who wished not to discuss end-of-life care stated that they would discuss these issues with others (i.e., family physician) or they did not feel there was a need to discuss now. Very few discussions about end-of-life care with the nurse or other health care providers were reported (n=18, 16%). However, many patients expressed a willingness to talk with nurses. Over one-half of the sample reported that they had some form of advance directive - usually located outside the hospital (n=66, 57%).

### Preference for decisional role

In this sample, there was no difference with respect to desire for decisional role in patients with cancer and those without (see Table Three). The preferences for role varied. The majority of patients expressed a desire for a shared or a more active role in making decisions about life-sustaining treatments. Patients provided some very clear comments about their views. A patient who expressed the desire for a shared role reported:

"It makes more sense - I need to have the discussion between the doctor and myself as he would know the best treatments for me. He is a professional and could tell me what option was best and I would respect his/her opinion."

A patient who expressed the desire for a more active role reported, "This is my body and my decision. I want control - living and dying is up to the individual." Fewer patients, but still a substantial number, wished the physician to take more of a role. They stated, "I am not a

**Table Two: End-of-life discussions**

Questions	n	Cancer	n	Non-cancer
Have you thought about the kinds of treatments you want to receive if you develop a life-threatening complication?	56	43 (77%)	60	46 (77%)
Have you had any discussions with your physician, during this hospital stay, about your wishes?	56	21 (38%)	60	22 (37%)
• If no, would you be willing to discuss your wishes with your physician?	35	25 (71%)	32	26 (82%)
Have you had any discussions with your nurse or other health care providers, during this hospital stay, about your wishes?	56	7 (13%)	60	11 (18%)
• If no, would you be willing to discuss your wishes with other health care providers?	49	31 (63%)	49	30 (61%)
Are your wishes written down or recorded somewhere?	56	31 (55%)	60	35 (58%)

**Table Three: Preferences for decisional role**

Patients prefer:	Cancer (n=50)	Non-cancer (n=57)
To leave decisions to their doctor	5 (10%)	7 (12%)
Have the doctor make the final decisions but seriously consider their opinion	4 (8%)	6 (11%)
Have the doctor share responsibility for decisions	16 (32%)	21 (37%)
To make the final decisions after seriously considering their doctor's opinion	17 (34%)	13 (23%)
To make the decisions	8 (16%)	10 (18%)
<b>Patient preferences for family member's role:</b>		
Leave decisions to their doctor	5 (10%)	9 (16%)
Have the doctor make the final decisions but seriously consider their opinion	1 (2%)	7 (12%)
Have the doctor share responsibility for decisions	19 (38%)	17 (29%)
Make the final decisions after seriously considering their doctor's opinion	19 (38%)	15 (26%)
To make the decisions	6 (12%)	9 (16%)

doctor - I am unable to make that decision - he must know what he is doing." We also asked what role patients would wish their family member to assume if they were not able to participate. The same trend of responses was noted.

### Providers' awareness of preferences

The provider responses followed a similar pattern to that of the patients (see Table Four). However, we provided an opportunity for the providers to indicate that they could not determine patients' preferences. Forty-six per cent of the nurses in the sample indicated that they did not know the patient well enough to determine preferences for decisional role with respect to decisions about end-of-life care. Fewer physicians reported this "unawareness", however, fewer physicians responded which may indicate that unresponsiveness is similar to unawareness. Nurses commented that, "they were only just assigned the patient," "they did not think they knew the patient well enough to discuss these issues," "the patient was stable now and there was no need to talk about these issues." Physicians also stated that the patient was currently stable and there was no need to talk about end-of-life care. At times they did not know the patient well enough - i.e., they were the "covering" oncologists for inpatients.

The degree to which each patient and nurse agreed upon the preferred role was analyzed. An active role was coded if patients or providers indicated that the patient wished to decide with or without physician input, the collaborative role included the shared category, and the passive role included the categories in which the patient indicated that they wished the physician to decide either on his/her own or after consideration of their opinion. This categorical breakdown is similar to the one used by Degner and Sloan (1992) in their categorization after the unfolding of preferences using the card sort technique. Nurses agreed with patients 19% of the time, however when nurses assessed patient preferences the agreement was 38% (8/21). Patients reported more of a preference for an active role in comparison to a passive role. However, the actual discrepancy was small (i.e., a difference of one level).

Most nurses (95%, n=44) and 36% (n=16) of the physicians reported that they had no discussions with patients about life-sustaining treatments. Twenty-three per cent of the physicians (n=10) reported that they had discussed life-sustaining treatments with the patient and the patient agreed that they had done so. A substantial proportion of the physician population (30%, n=13) reported that either they had talked with the patient and the patient said they had not or, conversely, the physician had no discussions and the patient said they had. Overall, in this sample of patients there was a paucity of communication around end-of-life treatments.

### Summary of findings

Patients near the end of life differ with respect to role preference, however most (80%, n=80) prefer a shared process and active involvement in the decision-making. There were no differences in role preference between patients whose primary diagnosis was cancer in comparison to patients whose primary diagnosis was non-cancer related. Nurses (and physicians) in this acute care setting were not aware of or misinterpreted patients' preferences for decisional role. Common themes emerged: patient was not critical enough, only just assigned, role ambiguity, and lack of communication processes.

### Study strengths and limitations

The major strength of this study is that our sample accurately reflects patients who are near the end of life, as over 50% of patients enrolled in the first six months have expired. The second strength of this study is the use of comparison groups. In many hospitals, patients with cancer are often admitted with complications related either directly or indirectly to their cancer or other underlying conditions. Therefore, it was important to determine the similarities and differences in seriously ill hospitalized patients. Finally, this study reflects the real life world of the providers and the contextual influences of a tertiary teaching hospital, including multiple caregivers and patient assignments.

The major limitation of this study is the use of a cross-sectional survey to measure a complex process such as decision-making. We focused on certain aspects (i.e., decisional role) of decision-making at one point in time. While this produced some important findings, further longitudinal research could explore the influence of important determinants of effective decision-making during the end-of-life phase. Indeed, during the interviews the research assistants often commented on the "richness" of some of the interviews. Finally, the provider sample size is small. Data will continue to be collected until there is a large enough sample to generalize the findings.

### Discussion

The findings of this study show that in this sample of seriously ill hospitalized patients, most have thought about and are willing to discuss end-of-life treatments with both physicians and nurses, yet many have not. Nurses were not comfortable discussing these issues as they perceived this to be the physician role, and they were only just assigned the patients. The physicians often stated that "someone else" should do this or that the patient was not critical enough at this point. The research literature reports concerns about the late and inappropriate timing of end-of-life discussions, in particular referrals to palliative care or institution of EOL orders. The findings from this study support this concern. Unfortunately, most patients with the diagnostic conditions and criteria used in this study died within six months. Providers do not know if this is the sentinel admission that may be the patient's last - thus we should engage in end-of-life discussions before the critical end points of uncontrollable pain or symptoms or inevitable death. We have prognostic criteria and willing patients (and families) but, consistent with the acute care culture, we wait until there is a crisis. Thus, there is a need to focus end-of-life care beyond the "very end of life."

Patient preferences for role varied, but many patients expressed a desire for sharing in some way the information exchange and deliberation and assuming of decisional responsibility. This was not what we expected as we hypothesized that patients, because of their serious illnesses, would defer responsibility to the care provider. There are two possible explanations for this finding. Firstly, the decision to end life is "high stake" and thus patients (and families)

**Table Four: Providers' awareness of preferences**

<b>This patient prefers to:</b>	<b>Nurse (n=46)</b>	<b>Physician (n=45)</b>
Leave decisions to the doctor	1 (2%)	3 (7%)
Leave decisions to the doctor but consider their opinion	3 (7%)	3 (7%)
Decide together	7 (15%)	14 (31%)
Make the decision but consider doctor's opinion	12 (26%)	19 (42%)
Make own decisions	2 (4%)	2 (4%)
Do not know	21 (46%)	4 (9%)
<b>Patient - provider agreement:</b>	<b>Nurse-patient dyads (n=42)</b>	<b>Physician-patient dyads (n=45)</b>
Patient and provider agree on preferred roles	8 (19%)	9 (21%)
Patient wished a more active role than provider determined	8 (19%)	17 (40%)
Patient wished a more passive role than provider determined	5 (12%)	13 (30%)
Provider not able to determine	21 (50%)	4 (12%)

more than likely feel strongly about how they wish this stage of life to unfold. They want to be involved and heard. Why do patients willingly choose a passive role? Is this their desire or a reaction to their feelings of vulnerability and loss of control or, conversely, could it be related to a sound trust in the decisions made by the physicians and others? It does not seem to be related to the severity of their illness or their inevitable death. Secondly, patients may perceive that there are no real options - either life or death. This is not the case with other medical or health care decisions. Furthermore, many of these patients had chronic conditions and were knowledgeable of their own condition and their experience. They could make an informed decision.

The majority of nurses in this sample either were unaware of or misinterpreted the patients' preferences. Based on position papers and policy statements, we assumed that a nurse would function as a clarifier, advocate, and mediator for patients with respect to decisions about end-of-life care; however, in this study, in this acute care setting, this was not the reality. In this hospital, nurses are assigned to patients on a shift-to-shift basis and communication about patient needs and care often focuses on the immediate needs - there is little emphasis and perhaps opportunity in a shift assignment to proactively discuss care issues that are not directly related to immediate care needs. However, many hospitals employ a number of strategies to address some of these gaps - discharge rounds, palliative care specialists, and advance care planning. Unfortunately, as evident in the results of this study, they are administered to a few (i.e., few palliative care consults to cancer patients and none to non-cancer patients) or very close to the end of life. It is concerning that some nurses are abdicating all of the responsibility of discussions about end-of-life care to the physician. Nurses do have a professional role and mandate in this regard, and hospital (and other) professional administrators need to provide the necessary supports for nurses to engage in this care. Oliverio and Fraulo (1998) offered some suggestions based on their experience in the SUPPORT trial. They recommended that (a) death needs to be understood as natural and inevitable; (b) discussions about end-of-life care issues need to occur early in all settings and be communicated thoroughly; (c) nurses need to be aware of the burden that family members experience when participating in end-of-life decisions and intervene to minimize the burden; (d) there is a need to consider the creation of cultures (and perhaps units) that support care near the end of life; and (e) patients need to be reassured that they will receive quality care regardless of decisional preferences. They also recommended that a role similar to the SUPPORT nurse be implemented in hospitals. We would recommend the development and evaluation of multi-faceted strategies to improve care near the end of life. This could include heightening awareness about end-of-life issues; increasing nursing knowledge and skill with respect to quality care issues near the end of life; supporting and mentoring nurses in patient advocacy roles; establishing methods of communication that are reliable and feasible; and establishing strategies that both providers and patients can engage, as they desire, in important decisions about care.

Historically, nurses have provided compassionate care to dying patients and their families. We need to extend this care to patients as they approach the end of life. Patients are willing to be involved. Nurses in the acute care setting need to incorporate end-of-life care processes into their repertoire of knowledge and skilled care that they normally provide to seriously ill hospitalized patients. The challenge for nurses (and physicians) is to provide this care in an acute care environment that is ever-changing, complex, and treatment-oriented. 🍀

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