

## ORIGINAL RESEARCH

## Opportunity Lost: End-of-Life Discussions in Cancer Patients Who Die in the Hospital

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**BACKGROUND:** End-of-life discussions are associated with decreased use of life-sustaining treatments in patients dying of cancer in the outpatient setting, but little is known about discussions that take place during terminal hospitalizations.

**OBJECTIVES:** To determine the proportion of patients assessed by the clinical team to have decisional capacity on admission, how many of these patients participated or had a surrogate participate in a discussion about end-of-life care, and whether patient participation was associated with treatments received.

**DESIGN:** Retrospective review.

**SETTING:** Inpatient.

**PATIENTS:** Adult patients with advanced cancer who died in the hospital between January 1, 2004 and December 31, 2007.

**RESULTS:** Of the 145 inpatients meeting inclusion criteria, 115 patients (79%) were documented to have decisional capacity on admission. Among these patients, 46 (40%)

were documented to lose decisional capacity prior to an end-of-life discussion and had the discussion held instead by a surrogate. Patients who had surrogate participation in the end-of-life discussions were more likely to receive mechanical ventilation (56.5% vs 23.2%,  $P < 0.01$ ), artificial nutrition (45.7% vs 25.0%,  $P = 0.03$ ), chemotherapy (39.1% vs 5.4%,  $P < 0.01$ ), and intensive care unit (ICU) treatment (56.5% vs 23.2%,  $P < 0.01$ ) compared to patients who participated in discussions. There was no difference between palliative treatments received.

**CONCLUSION:** The majority of patients with advanced cancer are considered to have decisional capacity at the time of their terminal hospitalization. Many lose decisional capacity before having an end-of-life discussion and have surrogate decision-makers participate in these discussions. These patients received more aggressive life-sustaining treatments prior to death and represent a missed opportunity to improve end-of-life care. *Journal of Hospital Medicine* 2013;8:334–340 © 2012 Society of Hospital Medicine

Most patients prefer to die at home, pain free and without the use of life-sustaining treatments<sup>1,2</sup> yet the majority of patients with serious illness die in the hospital.<sup>3–5</sup> When hospitalized patient die, the care is frequently focused on life-sustaining treatments<sup>6</sup>; pain, dyspnea, and agitation levels are higher when compared with patients who die in non-hospital settings.<sup>7–9</sup> End-of-life discussions and their products (ie, advanced directives) can clarify treatment options with patients and family,<sup>10</sup> and help ensure that patients receive care consistent with their beliefs.<sup>11–13</sup> End-of-life discussions are associated with a decrease use of life-sustaining treatments, improved quality of life, and reduced costs of care.<sup>14,15</sup> For the majority of

patients dying of cancer, the first end-of-life discussion takes place in the hospital setting.<sup>16</sup>

Conducting end-of-life conversations in the hospital setting can be challenging. Patients are acutely ill and nearly 40% are incapable of making their own medical decisions.<sup>17</sup> In order to participate in an end-of-life discussion, a physician must determine that a patient meets the 4 criteria of decisional capacity as outlined by Appelbaum and Grisso:<sup>18</sup> Does the patient (1) communicate a clear and consistent choice; (2) understand the relevant information surrounding that decision; (3) appreciate the consequences of that decision; and (4) communicate reasoning for that decision?<sup>19</sup> In practice, however, clinicians inaccurately assign capacity up to 25% of the time.<sup>17</sup> When a physician determines, accurately or inaccurately, that the patient does not meet this standard for decisional capacity, discussions must be held instead with a surrogate decision-maker. Surrogate decision-making can make communication with the physician more difficult,<sup>20</sup> delay important medical decisions,<sup>21</sup> and be stressful on the decision-maker.<sup>22</sup> To our knowledge, no studies have examined patient and surrogate participation in end-of-life discussions at

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the time of terminal hospitalization and its association with end-of-life treatments received.

Our goals were to examine physician assessment of decisional capacity and the prevalence of end-of-life discussions during the terminal hospitalization of patients with advanced cancer. Our research questions were: (1) What proportion of patients were assessed to have decisional capacity by the clinical team at the time of their terminal hospital admission? (2) What proportion of these patients had a documented discussion about end-of-life care with the clinical team, and for what proportion was the conversation held instead by the patient's surrogate decision-maker because the patient was considered to have lost decisional capacity? (3) Was patient participation in a discussion about end-of-life care associated with life-sustaining and palliative treatments received?

## METHODS

### Design

This is a retrospective cohort study of consecutive adult patients with advanced cancer who died at the University of Michigan Hospital, Ann Arbor, MI, from January 1, 2004 through December 31, 2007. This study was exempted from review by the University of Michigan (UM) Institutional Review Board because decedent data were used.

### Sample

The UM Cancer Registry is a database of all cancer patients treated at the UM Comprehensive Cancer Center. We used the Registry to identify patients who met the following criteria: (1) age  $\geq 18$  years at time of cancer diagnosis; (2) estimated probability of 5-year survival  $\leq 20\%$  at time of diagnosis, as predicted by the SEER Cancer Statistics Review<sup>23</sup>; (3) the entirety of cancer treatment was received at University of Michigan Health System (UMHS); and (4) the patient died while admitted to the University Hospital between January 1, 2004 and December 31, 2007.

UMHS is a healthcare system and academic medical center consisting of hospitals, health centers, and clinics, including the University of Michigan Hospital and Comprehensive Cancer Center. Over 4000 cancer patients are admitted to University Hospital and 80,000 outpatient visits occur to the Cancer Center every year. It serves as a major cancer referral center for the patients of Michigan and the greater Midwest. The University of Michigan implemented a palliative care consult service that was started in 2005, during the time period of our study.

### Data Collection

Data were abstracted by review of the medical record by an internist (M.Z.) using a comprehensive chart abstraction instrument based on a previously validated tool.<sup>24</sup> Demographic data abstracted from the medical record included age, religious affiliation, race, ethnicity, and marital status. The original abstraction

tool, which included 83 items, was reduced to include 47 items focusing on information related to advanced care planning, hospital course, and end-of-life discussions. Specific items included: reasons for admission, primary hospital service, occurrence and timing of end-of-life decision-making, whether patient or family preferences were elicited through an end-of-life discussion, clinician's assessment of patient's decisional capacity at time of admission and end-of-life conversations, whether a comfort care plan was made, and whether palliative morphine was used.

The chart abstraction tool was pilot tested on the medical records of 10 patients, who were not included in the study, and refined to improve completeness of data collection. A copy of the abstraction tool is available upon request.

## Definition of Key Variables

### *Decisional Capacity Assessment*

Decisional capacity assessment is a reflection of the clinical team's assessment of the patient's decisional capacity on admission, and was determined through examination of the medical record in the first 24 hours of admission. Positive decision-making capacity assessment was assumed if the clinician assessment of decisional capacity was documented in the mental status exam, or if the clinician documented conversations between clinician and patient in the history that suggested intact decision-making capacity (ie, clinician documented terms such as "patient stated..." or "patient described..." and then described a coherent or sensible statement which implied patient capacity and intact mental status), or if the clinician's documentation of the assessment and plan stated or suggested decisions were being made by the patient. Other supportive information from the record was used to corroborate the evidence used to determine the clinician's assessment of the patient's decisional capacity, including whether the patient signed consent forms.

### *End-of-Life Discussions*

The presence of an end-of-life discussion was presumed when the clinician documented a "discussion with the patient," "discussion with family," or "family meeting" concerning treatment preferences, or when the clinician quoted the patient's preferences in a fashion that documents a face-to-face discussion or directly described the elicitation of preferences from the patient or family.

### *Living Will*

A living will was identified as present if the document was scanned into the patient's medical record, or if the chart indicated that the patient or family stated that the patient had completed a living will.

### *Health Care Proxy*

Health Care Proxy or Durable Power of Attorney for Healthcare was identified as present if the document

was scanned into the patient's medical record, or if the chart indicated that the patient or family stated that the patient had completed such a document.

### **Do Not Resuscitate (DNR) on Admission**

DNR status was identified as present if the patient had documents with established DNR orders, or if a physician explicitly documented code status as DNR in the admission note or other documents placed in the record within the first 24 hours of admission.

### **Intensive Care Unit (ICU) Treatment**

Patients were defined as having received ICU treatment if they were admitted directly or subsequently transferred to the ICU during the hospital course.

### **Comfort Care**

Comfort care was defined as present only if the phrases "comfort care," "palliative care," or "supportive care," were documented.

### **Palliative Opioid Therapy**

Treatments with morphine or other opioids were recorded as palliative only if it was explicitly stated that these medications were used in the context of palliative or end-of-life care.

### **Data Analysis**

We report the proportion of patients who were documented to lack decisional capacity at the time of hospital admission. We compared patient characteristics for those with and without documentation of decisional capacity on admission, and patients with decisional capacity on admission who did and did not participate in discussions about end-of-life care using chi-square tests for categorical data, *t* tests for normally distributed continuous variables, and Mann-Whitney *U* tests for non-normally distributed continuous variables. We examined whether documentation of a discussion about end-of-life care was associated with life-sustaining and palliative treatments received using chi-square for categorical treatments, and Mann-Whitney *U* tests for days from admission to initiation of comfort care. We used  $P < 0.05$  to signify statistical significance.

## **RESULTS**

### **Characteristics of Population and Decisional Capacity on Admission**

The characteristics of the 145 patients who met entry criteria are summarized in Table 1. The most common types of cancers were lung cancer and leukemia/lymphoma. Of the 145 patients, the medical team's assessment of the patient's decisional capacity on admission could be established for 142 patients. As documented within the first 24 hours of admission, 27 patients (19%) were considered not to have decisional

**TABLE 1.** Characteristics of Patients With and Without Documented Decision-Making Capacity

	Decision-Making Capacity on Admission*		P Value
	No (N = 27) N (%)	Yes (N = 115) N (%)	
Age >65	15 (55.6)	60 (52.2)	0.75
Gender (male)	14 (51.9)	68 (59.1)	0.46
Cancer type			0.67
Lung	12 (44.4)	42 (36.5)	
Bone marrow	5 (18.5)	35 (30.4)	
Liver	3 (11.1)	6 (5.2)	
Pancreas	3 (11.1)	7 (6.10)	
Esophagus	1 (3.7)	8 (7.0)	
Colon	1 (3.7)	6 (5.2)	
Other†	2 (7.4)	11 (9.6)	
Prior to admission			
Cancer diagnosis known	23 (85.2)	91 (79.1)	0.48
Living will completed	6 (22.2)	26 (22.6)	0.97
Health care proxy established	3 (11.1)	26 (22.6)	0.18
DNR established	8 (29.6)	27 (23.5)	0.79

Abbreviations: DNR, do not resuscitate.

\*Decisional capacity as assessed and documented by the clinician; clinicians assessment of decisional capacity could not be determined in 3 patients.

†Other cancer types: rectal, stomach, bone sarcoma, renal cell, laryngeal, renal pelvic.

capacity, and 115 patients (79%) were considered to have decisional capacity. Both of these groups had similar age and gender distributions. There were no significant differences in the distribution of cancer type between those with and without decisional capacity. In both groups, the majority of the cancer diagnoses were made prior to admission. There was no difference in DNR orders established prior to or on admission between the groups (Table 1).

### **End-of-Life Discussion in Patients With Decisional Capacity on Admission**

Of the 115 patients assessed to have intact decisional capacity on admission, 56 (48.7%) participated in an end-of-life discussion with the medical team during their terminal hospitalization. For the remaining 59 patients who did not participate in an end-of-life discussion during the terminal hospital course, 46 (40.0%) had documentation suggesting they lost decisional capacity prior to a conversation and that the end-of-life discussions were held instead with the patient's surrogate decision-maker, and 13 (11.3%) had no evidence of any end-of-life discussion (with the patient or surrogate).

When comparing those patients who participated in an end-of-life discussion with those patients whose surrogate participated in the discussion, there were no significant differences in gender and age distributions (Table 2). There was a significant difference in the type of cancers between the 2 groups. Among patients who participated in their end-of-life discussions, bone marrow cancer was proportionately more prevalent (17.9% vs 2.2%;  $P < 0.01$ ) and

**TABLE 2.** Among Patients With Documented Decision-Making Capacity on Admission, the Characteristics of Patients by Status of Their Participation in End-of-Life Discussions

	Patients With Documented Decision-Making Capacity on Admission (N = 115)			P Value
	N = 13		N = 102	
	End-of-Life discussion not documented	End-of-Life discussion with surrogate with patient (N = 46)	End-of-Life discussion with patient (N = 56)	
	N (%)	N (%)	N (%)	
Age ≥65	9 (69.2)	18 (39.1)	27 (48.2)	0.36
Gender (male)	10 (76.9)	27 (60.0)	31 (55.4)	0.64
Cancer type				
Lung	3 (23.1)	19 (41.3)	9 (16.1)	
Bone marrow	7 (53.9)	1 (2.2)	10 (17.9)	
Liver	1 (7.7)	3 (6.5)	2 (3.6)	
Pancreas	1 (7.7)	2 (4.4)	4 (7.1)	<0.01
Esophagus	0	6 (13.0)	2 (3.6)	
Colon	1 (7.7)	1 (2.2)	3 (5.4)	
Other*	0	1 (2.2)	10 (17.9)	
	Prior to Admission			
Cancer diagnosis known	10 (76.9)	37 (80.4)	43 (76.8)	0.66
Living will completed	4 (30.8)	10 (21.7)	12 (21.4)	0.97
Health care proxy established				
	3 (23.1)	13 (28.3)	10 (17.9)	0.21
DNR established	2 (15.4)	8 (17.4)	17 (30.4)	0.04

Abbreviations: DNR, do not resuscitate.

\*Other cancer types: rectal, stomach, bone sarcoma, renal cell, laryngeal, renal pelvic.

lung cancer was less prevalent (16.1% vs 41.3%;  $P < 0.01$ ), when compared to those who required surrogate participation. Timing of cancer diagnosis and prevalence of advance directives were similar between the 2 groups. The proportion of patients who had an established DNR order prior to admission was higher among those who did participate in end-of-life discussions when compared to those who had surrogate participation in these discussions (30.4% vs 17.4%;  $P < 0.04$ ).

### Life-Prolonging and Palliative Care Treatments Received and Participation in End-of-Life Discussions

Life-prolonging treatments were more likely to be used for patients whose end-of-life discussions were held by patient's surrogate decision-maker, in comparison to those patients who participated in the discussions themselves. Patients who had conversations held by surrogates were more likely to receive ventilator support (56.5% vs 23.2%,  $P < 0.01$ ), chemotherapy (39.1% vs 5.4%,  $P < 0.01$ ), artificial nutrition or hydration (45.7% vs 25.0%,  $P = 0.03$ ), and antibiotics (97.8% vs 78.6%,  $P < 0.01$ ), when compared to patients who participated in their own end-of-life discussion. Intensive care treatment rates also differed significantly between the 2 groups; 56.5% of those who did not participate in end-of-life discussions, and only 23.2% of those patients who did participate,

**TABLE 3.** Patient or Surrogate Participation in End-of-Life Discussions, Treatments Received, and Timing of Advanced Care Planning Among Patients With Documented Decision-Making Capacity on Admission

	Patients With Documented Decision-Making Capacity on Admission (N = 115)		
	End-of-Life Discussion		P Value
	With Surrogate (N = 46)	With Patient (N = 56)	
	N (%)	N (%)	
Life-Prolonging Treatment			
Ventilatory support	26 (56.5)	13 (23.2)	<0.01
Chemotherapy	18 (39.1)	3 (5.4)	<0.01
Artificial nutrition or hydration	21 (45.7)	14 (25.0)	0.03
Antibiotics	45 (97.8)	44 (78.6)	<0.01
Cardiopulmonary resuscitation	7 (15.2)	4 (7.1)	0.19
ICU treatment (admit or transfer)	26 (56.5)	13 (23.2)	<0.01
Palliative Treatments			
Comfort care	39 (84.8)	45 (80.4)	0.56
Palliative morphine drip	24 (52.2)	33 (57.1)	0.62
	Mean (95% CI) [Range]	Mean (95% CI) [Range]	
Timing of Advanced Care Planning			
Length of hospitalization	15.8 d (11.4–20.2) [1–57]	10.3 d (1–46) [1–46]	0.03
Time to end-of-life discussion	14.0 d (9.9–18.1) [0–55]	6.1 d (3.8–8.4) [0–46]	<0.01
Time to comfort care	23.5 d (4.3–42.8) [1–374]	9.2 d (6.3–12.1) [0–46]	0.12

Abbreviations: CI, confidence interval; ICU, intensive care unit. \*P value is for comparison of end-of-life discussion with surrogate vs end-of-life discussion with patient.

were admitted or transferred to the intensive care unit ( $P < 0.01$ ). There was no significant difference in the proportion of patients who received cardiopulmonary resuscitation (CPR) (15.2% vs 7.1%,  $P = 0.56$ ) (Table 3). Patients who lost decisional capacity and required a surrogate decision-maker to participate in their end-of-life discussions had longer length of stay (15.8 vs 10.3 days,  $P = 0.03$ ) and length of time to end-of-life discussions (14.0 vs 6.1 days,  $P < 0.01$ ) (Table 3).

A comparison of the proportion of patients receiving palliative treatments, such as palliative comfort care orders and morphine infusions, revealed no significant differences between those with and without a discussion about end-of-life care (Table 3). Furthermore, while the time interval from hospital admission to initiation of comfort care was shorter for those who did participate in end-of-life discussions compared with those had surrogate participation (9.3 vs 23.5 days,  $P = 0.13$  for equality), this difference was not statistically significant (Table 3).

Since a higher proportion of those who participated in end-of-life discussions during the hospitalization were admitted with a DNR order established prior to or on admission, we also examined the use of life-prolonging treatments in the subgroup of

patients who did not have a DNR order prior to admission. The difference in life-prolonging treatments between those who did and did not participate in end-of-life discussions was preserved among those patients who did not have DNR status on admission (data not shown).

## DISCUSSION

In this retrospective study of 145 terminal cancer patients who died in the hospital, we found that half of the patients had documentation suggesting that they lost decisional capacity during hospitalization and did not participate in end-of-life discussion with their healthcare providers. Among cancer patients in our study, 19% were determined not to have decisional capacity on admission, and another 32% were determined to lose decisional capacity during the hospital course. When patients did participate in documented discussions about end-of-life care, they were less likely to receive intensive life-sustaining treatments, less likely to be admitted or transferred to the ICU, and more likely to avoid prolonged hospitalization. The finding that the majority of cancer patients are assessed to have intact decisional capacity upon admission to their terminal hospitalization, but less than half of them participate in their own end-of-life conversation, suggests that there is an important lost opportunity to provide quality advanced care planning to hospitalized patients.

Advanced care planning is the act of defining a competent patient's wishes regarding their future healthcare in the event of loss of decisional capacity. For many of the patients who were determined to lose decisional capacity during their hospitalization in our study, a surrogate decision-maker was involved in a subsequent end-of-life discussion. This represents a missed opportunity in 2 ways. First, because surrogates may incorrectly predict patients' end-of-life treatment preferences in approximately one-third of the cases,<sup>25</sup> patients may receive care that is inconsistent with their beliefs. Second, reliance on surrogate decision-making may result in a greater burden on family members. Surrogate decision-making places a large burden on surrogates, and can lead to emotional and psychological stress that can last well beyond the death of the loved one.<sup>16,26</sup>

Our results reinforce the growing body of evidence suggesting that communication with the dying patient, both before and during the terminal hospitalization, promotes end-of-life care that involves less invasive life-prolonging treatments,<sup>10–15</sup> which is a consistently stated goal of most patients at the end of life.<sup>1,2</sup> Our findings are consistent with a recent randomized trial of hospitalized patients over the age of 80 which showed that advance care planning discussions were associated with decreased use of intensive life-sustaining treatments, increased patient and family satisfaction with care, as well as decreased psychological

symptoms among family members.<sup>27</sup> In addition, studies examining patients with advanced cancer have shown that discussions about end-of-life care in the outpatient setting resulted in less intensive life-sustaining treatments.<sup>14,15</sup> Nearly 20% of our cohort was determined by the clinical team to lack decisional capacity at the time of their terminal hospitalization, highlighting the importance of end-of-life discussion prior to hospitalization. Our results also extend these recent findings to the inpatient setting. Seventy-nine percent of patients in our study were determined to have decisional capacity at the time of their terminal hospitalization, and end-of-life discussion conducted with these patients was associated with decreased use of life-sustaining treatments.

Seriously ill patients, particularly in hospital settings, have high symptom burden and subsequent poor quality of life.<sup>6</sup> These patients and families often report inadequate pain and symptom relief.<sup>8,28,29</sup> It is therefore reassuring that we found no difference in the proportion of patients who received comfort care and palliative morphine infusions according to whether they or a surrogate participated in the end-of-life discussions. In fact, the majority of patients were made DNR and received some form of comfort measure prior to death, although these comfort measures were frequently initiated only hours prior to death.

While our findings are consistent with research that has demonstrated that end-of-life discussions with patients are associated with a decrease in life-prolonging treatments, it is important to note that our observational study cannot establish a causal relationship between the end-of-life discussion and the subsequent use of life-sustaining treatments. It is possible that patients who have discussions about end-of-life care inherently prefer to have less intensive life-sustaining treatment at the end of life. Physicians may be more apt to engage in these types of discussions with patients who express interest in limited intervention. Interestingly, patients with a DNR order at the time of admission were more likely to participate in end-of-life care with their provider during their terminal hospitalization, which supports this alternate explanation. However, when we excluded all patients with a DNR on admission, our findings persisted. Regardless of the explanation for the association between end-of-life discussions and life-sustaining treatments, our study identifies a cohort of hospitalized patients who could benefit from improved end-of-life communication, and a clinical setting where opportunities remain to improve the quality of advanced care planning.

Discussions about end-of-life care with patients result in earlier transition to care focused on palliation.<sup>14</sup> Although we examined the timing to initiation of comfort care between those who participated and those who did not participate in end-of-life discussions, we were not able to demonstrate a statistically

significant difference. However, our cohort may not be suitable for an examination of this type of intervention, as early discussions about end-of-life care may have lead to early referral to hospice, and therefore death outside the hospital setting, making the patients ineligible for our study.

There are several additional limitations to our study. First, our study is subject to the potential biases inherent in retrospective chart review. For example, since we identified patients who died in the hospital, our study does not generalize to patients with advanced cancer who survive the hospitalization or who were discharged to die at home.<sup>30</sup> Furthermore, our use of the medical record to assess documentation of communication about end-of-life care and decisional capacity relies on the accuracy of clinician documentation. There may have been communication about end-of-life care that was not documented in the medical record, resulting in underestimation of the effects of end-of-life discussions. In clinical practice, the assessment of decisional capacity can be challenging.<sup>19,31,32</sup> Although clinicians are often accurate in identifying patients with capacity, in nearly one-quarter of all assessments, they mistakenly assign capacity to patients who lack decision-making capacity.<sup>17</sup> In our study, we examine clinician assessment of the patient's decisional capacity, but cannot assess either the accuracy of their clinical assessment or the accuracy of their documentation of this assessment. A second limitation is that the chart abstraction was conducted by a single reviewer without inter-rater assessment, although the abstraction tool was modified from a well-established tool.<sup>24</sup> A third limitation is that all of the patients were from a single academic center and the results may not generalize to other regions. Fourth, we did not assess for the potential effect of individual clinicians. Since most patients were cared for by multiple physicians, our study is not capable of assessing a clinician-level effect. Finally, our study was not able to address whether the care received by patients was in accord with their informed preferences.

We have shown that opportunities exist for advanced care planning at the time of the terminal hospitalization of patients with advanced cancer. The majority of these patients have documentation of decisional capacity at the time of admission, suggesting that opportunities exist to conduct end-of-life discussion while the patient retains decisional capacity. Furthermore, we found that patients who participate in these discussions about end-of-life care with their clinicians have an associated decrease in the use of life-sustaining treatments, which is consistent with prior studies.<sup>11,13–15,27</sup> Improving communication about end-of-life care for patients hospitalized with advanced cancer may represent an important opportunity to improve the concordance between patients' wishes for care at the end-of-life and the care that

these patients actually receive. Such communication may also decrease the burden on family members who are frequently asked to play the role of surrogate decision-maker without an opportunity to discuss these issues with the patient.

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