

Determining Consistency of Surrogate Decisions and End-of-Life Care Received with Patient Goals-of-Care Preferences

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Abstract

Background: Care consistent with preferences is the goal of advance care planning (ACP). However, comparing written preferences to actual end-of-life care may not capture consistency of care with preferences.

Objective: We evaluated four additional types of consistency, using prospective data on written preferences and active clinical decision making by patients and their surrogates.

Methods: Secondary analysis of data was done from a trial of an ACP intervention for patient-surrogate dyads. Forty-five patients died during the trial and comprised the sample for the analysis. Sources of data included patients' preferences in a written goals-of-care tool, medical record reviews, and two-week postbereavement interviews with surrogates to complement medical record reviews.

Results: Twenty-four patients (53.3%) received care consistent with written preferences and 11 (24.4%) inconsistent with written preferences. The remaining 10 patients (22.2%) died suddenly with no opportunity for treatment decision making. Eleven (24.4%) were able to participate in decision making with their surrogates; of those, 9 (81.8%) received care consistent with their expressed preferences. Twenty-two patients were incapacitated and thus the surrogate made treatment decisions alone; of those, 18 (81.8%) made decisions consistent with the patient's written preference.

Conclusions: Simply comparing documented preferences for end-of-life care and medical records of care delivered does not adequately reflect the process of ACP and treatment decision making at the end of life. To understand consistency between preferences and end-of-life care, investigators need data on written and real-time expressed preferences.

Introduction

ADVANCE CARE PLANNING (ACP) in which patients and surrogates discuss and document preferences for treatment in future health states^{1,2} has been recognized as a way to promote end-of-life care that is consistent with patients' preferences.^{3,4} Several studies have examined whether an ACP intervention promotes consistency between a patient's preferences and the treatments the patient actually receives near the end of life.⁵⁻⁸ How such consistency was conceptualized and determined varied across the studies; in general a patient's early documented preferences were compared to medical record documentation of the end-of-life care the patient received (e.g., ICU admissions, CPR, mechanical ventilation, and location of death).

Unfortunately, this way of determining consistency between preferences and end-of-life care reflects a limited aspect of treatment decisions at the end of life and may fail to capture ACP as a process unfolding over several time points. Consider situations wherein the patient is able to make his or her own decisions up until the point of death. In such situations, the patient's decisions may differ from his or her previously documented preferences. Also consider cases wherein the surrogate makes decisions that honor the patient's previously stated wishes, but the care team discounts the surrogate's decision. In the former case, delivered care would be determined as having been inconsistent with the patient's documented preferences, when in fact it was consistent with the patient's most recently expressed preference. In the latter case, care would also be determined as being

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inconsistent, but an important distinction would have been lost: whether the surrogate or the care team was dishonoring the patient's preferences.

To add further complexity, while a patient's election of a do-not-resuscitate (DNR) order allows for a relatively clear-cut consistency determination (with the medical record revealing that CPR was performed or not),⁸ most end-of-life preferences are not so simple. End-of-life preferences are commonly stated in terms of goals of care or as an overarching value in favor of either comfort care or aggressive treatments. Such preferences often leave a great deal of room for debate as to whether care was consistent with a patient's wishes. Despite these complexities, there have been few discussions about how to define and measure consistency between patient preferences and treatment decisions at the end of life.

The purpose of this analysis was to examine several types of consistency by comparing surrogate treatment decisions and treatment actually received with patients' previously expressed written preferences. We used data from 45 patients who died during a longitudinal trial of an ACP intervention and their surrogates.

Methods

Study design

The present study is a secondary analysis of data from a larger trial that tested the efficacy of an ACP intervention on patient and surrogate preparation for end-of-life decision making and postbereavement outcomes for surrogates. During the original study, patients and surrogates completed measures of preparedness outcomes at baseline and 2, 6, and 12 months later, and surrogates completed measures of bereavement outcomes at baseline, 2 weeks, and 3 and 6 months after the patient's death. Details of the study design have been described elsewhere.⁹ For the purpose of this descriptive analysis, the data from the intervention and control groups were combined.

Setting and participants

The original study included 210 dyads of patients from 20 free-standing outpatient dialysis centers in eight counties in North Carolina and their surrogates, who met the following inclusion criteria: age 18 years or older; self-identified African American or white; on dialysis for at least six months prior to enrollment; Charlson Comorbidity Index (CCI)¹⁰ score ≥ 6 or CCI score = 5 and hospitalization in the last six months; English speaking; no hearing impairment; < 3 errors on the Short Portable Mental Status Questionnaire¹¹; and an English-speaking surrogate over age 18 who could participate. Of the 210 patients, 45 died during the study and comprised the subgroup for this analysis.

Patient end-of-life preferences measured

Patients completed the goals-of-care tool¹² as an outcome measure at baseline and 2, 6, and 12 months or until death. This tool included two scenarios describing medical conditions that commonly occur in dialysis patients. In the first, the patient developed a severe complication and could not speak for him or herself; the medical team believed recovery unlikely and continuing life-sustaining

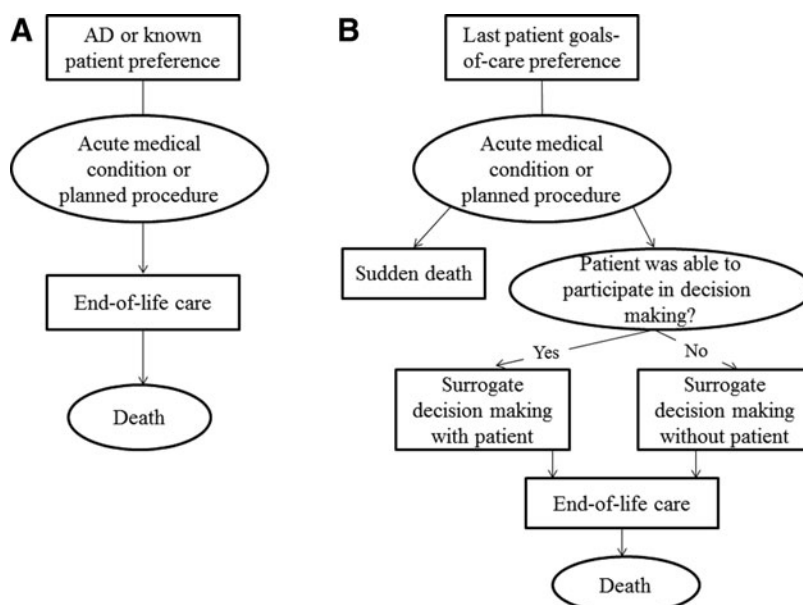
treatment, including dialysis, would no longer be beneficial. In the second scenario, the patient developed advanced dementia. Each scenario had three response options: "The goals of care should focus on delaying my death, and thus I want to continue life-sustaining treatment"; "The goals of care should focus on my comfort and peace, and thus I do not want life-sustaining treatment, including dialysis"; and "I am not sure." For the current analysis, the two responses in the last completed goals-of-care tool prior to death were combined to create an overarching goals-of-care preference: *comfort care only* if the patient chose comfort care only for both scenarios, or *not comfort care only* if the patient chose treatment focused on delaying death for both scenarios or the responses were mixed or included "unsure."

End-of-life care data

During the original study, patients' medical records at the dialysis center and hospital were reviewed every two weeks until the patient's death or study end. Data on primary acute medical conditions causing hospital admissions and treatments were collected. Upon the patient's death, the surrogate was interviewed at two-week postbereavement to ask about the patient's last month prior to death and the surrogate's end-of-life experiences. These interviews complemented medical record reviews in cases where the medical record provided incomplete data (e.g., whether the surrogate was involved in treatment decision making). An Excel spreadsheet was created to display mortality data and treatment decisions chronologically.

Types of consistency

Three authors (MS, SW, and LH) initially reviewed the Excel spreadsheet to identify possible types of consistency determination. The common approach to consistency determination is: (1) Comparing the patient's preference and end-of-life care received. As Figure 1 presents, we defined four additional types of consistency determination depending on whether an acute medical condition/planned procedure led to sudden death, or if instead there was an opportunity for the patient and/or surrogate to be involved in treatment decision making. In the case of sudden death, there would be no possible consistency determination. If the patient was able to participate in decision making and a surrogate made decisions jointly with the patient, then three types of consistency could exist; (2) consistency is determined between the patient's decisions while facing end of life and last goals-of-care preference (i.e., a comparison between the patient's verbal expression of preference at the end of life and his or her written preference expressed on the goals-of-care tool); (3) Consistency is determined between the patient's verbally expressed decisions while facing end of life and the surrogate's later decisions to honor the patient's decisions; and (4) Consistency is determined between the patient's verbally expressed decisions while facing end of life and the care the patient received. If the patient was incapacitated and the surrogate made decisions without the patient, then (5) consistency between the patient's last written goals-of-care preference and the surrogate's decisions could be determined. A surrogate's decisions inconsistent with the



Type of consistency determination

A. Common determination	1. Consistency between the patient's last written goals-of-care preference and end-of-life care the patient received
B. SPIRIT trial	
Surrogate decision making with patient (as they actually face end of life)	2. Consistency between the patient's decisions at the end of life and his/her last written goals-of-care preference
	3. Consistency between the patient's decisions at the end of life and the surrogate's decisions
	4. Consistency between the patient's decisions at the end of life and end-of-life care the patient received
Surrogate decision making without patient	5. Consistency between the patient's last written goals-of-care preference and the surrogate's decisions

SPIRIT, Sharing the Patient's Illness Representations to Increase Trust.

FIG. 1. Common way of consistency determination (A) and four additional types of consistency determination in the SPIRIT trial (B). (AD, advance directive.)

patient preference might result in end-of-life care inconsistent with the patient preference.

The three authors independently reviewed five randomly selected cases to determine the types of end-of-life decision making and consistency (consistent or inconsistent or uncertain due to lack of data). Any discrepancies among the authors were discussed for resolution and decision rules were developed. Three additional cases were reviewed by MS, SW, and LH to apply the decision rules. The decision rules were refined before being used by three authors (MS, MM, and SK) who independently determined the pathways and consistency for all 45 cases. Any discrepancies were resolved by group consensus. Descriptive statistics were used to summarize the study variables. Types of consistency were summarized using frequencies and percentages with 95% confidence intervals.

Results

Sample characteristics

African Americans comprised slightly over 50% of the subsample ($n=24$ dyads, 53.3%). Roughly half of the pa-

tients ($n=21$, 46.7%) and a majority of the surrogates ($n=34$, 75.6%) were women (see Table 1). All but one patient were on chronic hemodialysis prior to death.

End-of-life care

All 45 deaths occurred after an acute medical condition or a planned procedure (see Table 2). The most frequent acute condition was cardiovascular, such as heart attack or stroke. A median of six days elapsed from the acute condition or procedure to death. Thirty-four patients (75.6%) were admitted to the hospital for the acute condition. Half of all decedents received ICU care ($n=22$, 48.9%). Only a small percentage of the patients received palliative care or hospice care before death ($n=8$, 17.8%), and a majority ($n=31$, 68.9%) died in the hospital or in a skilled nursing facility.

Consistency between written preferences and end-of-life care

A majority of the patients' overarching goals-of-care preference was comfort care only ($n=30$, 66.7%) (see

TABLE 1. BASELINE CHARACTERISTICS OF PATIENTS AND SURROGATES

Characteristic	Participants, n (%) ^a	
	Patient (N=45)	Surrogate (N=45)
<i>Sociodemographics</i>		
Age, mean (SD), years	64.4 (12.6)	57.1 (13.7)
Women	21 (46.7)	34 (75.6)
Black, race ^b	24 (53.5)	24 (53.5)
Formal education completed, mean (SD), years	12.9 (3.4)	13.6 (2.6)
Protestant, religion	36 (80.0)	36 (80.0)
Annual income		
<\$20,000	20 (44.4)	11 (24.4)
\$20,000 – \$50,000	18 (40.0)	18 (40.0)
> \$50,000	6 (13.3)	13 (28.9)
Declined to answer	1 (2.2)	3 (6.7)
Surrogate's relationship to patient		
Spouse/partner	-	18 (40.0)
Parent	-	13 (28.9)
Sibling	-	6 (13.3)
Child	-	3 (6.7)
Friend	-	3 (6.7)
Other	-	2 (4.4)
<i>Patient medical</i>		
Hemodialysis	44 (97.8)	-
Years on dialysis, mean (SD)	4.9 (4.4)	-
CCI, mean (SD)	8.8 (1.8)	-
Has an AD	16 (35.6)	-
DNR order at the clinic	8 (17.8)	-

^aDue to rounding, percentages may not sum to 100.

^bSelf-identified.

AD, advance directive; CCI, Charlson Comorbidity Index. DNR, do-not-resuscitate.

Table 3). The last completion of the goals-of-care tool occurred a median of three months prior to death. Using the first definition of consistency, end-of-life care was consistent with written preferences for 24 (53.3%) patients and inconsistent for 11 (24.4%). Ten patients (22.2%) died suddenly at home or in a nursing or dialysis facility, leaving no opportunity for treatment decision making, and thus consistency could not be determined.

Consistency using additional information on decision making

Of the 45 cases, 11 acutely ill patients (24.4%) were able to participate in their own medical decisions with their surrogates, and 22 surrogates (48.9%) made treatment decisions without the patient due to the patient's incapacitation. There were two cases (4.4%) for which a decision-making process could not be determined due to lack of data as to who made the decision.

Of the 11 patients who were able to participate in their own medical decisions with their surrogates, 7 patients (63.6%) made decisions consistent with their last written goals-of-care preference (consistency type 2), whereas 4 (36.4%) made decisions that differed from their written preferences.

TABLE 2. CARE NEAR THE END OF LIFE (N=45)

Variable	Participants, n (%) ^a
Primary acute medical condition or procedure preceding death	
Heart attack or stroke	18 (40.0)
Infection	7 (15.6)
Failure to thrive	4 (8.9)
GI problems (e.g., bleeding, ischemic bowel)	4 (8.9)
Surgery or procedure (e.g., amputation)	4 (8.9)
Fall	3 (6.7)
Fistula/graft complication	3 (6.7)
Exacerbation of other chronic condition (e.g., heart failure)	2 (4.4)
Survival time since randomization, months	
Median (IQR)	8.0 (5.5–18.0)
Mean (SD)	12.0 (9.8)
Survival time since acute medical condition or procedure, days	
Median (IQR)	6.0 (2.0–10.0)
Mean (SD)	9.0 (12.8)
<i>Care following acute medical condition</i>	
Hospital admission	34 (75.6)
Length of hospital stay, days	
Median (IQR)	5.0 (0.5–9.5)
Mean (SD)	8.0 (13.1)
ICU admission	22 (48.9)
Length of ICU stay, days	
Median (IQR)	0.5 (0–4.8)
Mean (SD)	4.6 (12.6)
CPR	16 (35.6)
Palliative care or hospice use	8 (17.8)
Location of death	
ICU	17 (37.8)
Other unit in the hospital	11 (24.4)
Skilled nursing facility	3 (6.7)
Hospice unit	4 (8.9)
Home	10 (22.2)

^aDue to rounding, percentages may not sum to 100.

IQR, interquartile range; GI, gastrointestinal; ICU, intensive care unit; CPR, cardiopulmonary resuscitation.

Of these 11 patients, choices made by 9 surrogates (81.8%) were consistent with the patient's expressed treatment choices (consistency type 3), and 9 patients (81.8%) received actual end-of-life care consistent with choices expressed during acute illness (consistency type 4). Finally, of the 22 cases in which the surrogate made treatment decisions alone, surrogates' decisions were consistent with the patient's preference indicated in the last written goals-of-care tool (consistency type 5) in 18 cases (81.8%).

Discussion

We examined several ways to define consistency between patient preferences and treatment decisions at the end of life. The patient's preference expressed in the goals-of-care tool and end-of-life care received were consistent for roughly half of the sample. Several additional consistency

TABLE 3. CONSISTENCY BETWEEN PATIENT'S PREFERENCES AND TREATMENT DECISIONS (N=45)

Variable	Participants, n (% , 95% CI) ^a
Time between the last completed goals-of-care preference and death, month	
Median (IQR)	3.0 (1.0–6.0)
Mean (SD)	5.2 (6.7)
Preference expressed in the last goals-of-care tool ^b	
Comfort care only	30 (66.7, 52.9–80.5)
Not comfort care only	15 (33.3, 19.5–47.1)
Consistency type	
1. Consistency between last written goals-of-care preference and end-of-life care received	
Consistent	24 (53.3, 38.8–67.9)
Inconsistent	11 (24.4, 11.9–37.0)
Uncertain due to sudden death	10 (22.2, 10.1–34.3)
<i>Surrogate decision making with patient (n = 11)</i>	
2. Consistency between the patient's decisions at the end of life and last written goals-of-care preference	
Consistent	7 (63.6, 35.2–92.0)
Inconsistent	4 (36.4, 8.0–64.8)
3. Consistency between the patient's decisions at the end of life and surrogate's decisions	
Consistent	9 (81.8, 59.0–100.0)
Inconsistent	2 (18.2, 0–41.0)
4. Consistency between the patient's decisions at the end of life and end-of-life care received	
Consistent	9 (81.8, 59.0–100.0)
Inconsistent	2 (18.2, 0–41.0)
<i>Surrogate decision making without patient (n = 22)</i>	
5. Consistency between the patient's last written goals-of-care preference and the surrogate's decisions	
Consistent	18 (81.8, 65.7–97.9)
Inconsistent	4 (18.2, 2.1–34.3)

^aDue to rounding, percentages may not sum to 100.

^bBased on the last completed goals-of-care tool prior to death: comfort care only if the patient chose comfort care only for both scenarios; not comfort care only if the patient chose delaying death for both scenarios or the responses were mixed or included unsure. IQR, interquartile range.

determinations revealed that, in the cases wherein the patient was able to participate in treatment decision making up until death, end-of-life care received was consistent with the patient's decisions for a majority of the patients (81.8%). When surrogates made treatment decisions at the end of life without the patient because of the patient's incapacitation, a majority (81.8%) were determined to be consistent. Thus, real-time decision making sometimes superseded written preferences, and insight into this process resulted in higher rates of consistency.

Emanuel and Scandrett¹³ have argued that the match (consistency) between a patient's goals and the care he or she received should be the gold standard for quality of palliative care. For this important benchmark of palliative care, our study raises an important issue: only comparing a documented patient preference with delivered care may be too limited to appropriately reflect the actual treatment decision-making process at the end of life. Previous efforts to assess consistency typically involved comparing the patient's medical records of delivered end-of-life care with the patient's preferences that had been documented immediately after an ACP discussion or an AD that was completed at some point in the past. This approach assumes that documented preferences are the patient's fixed decisions, when in fact there can be an important time interval between preference

statements and treatment. Real-time decisions likely incorporate new information that patients do not have when completing ADs.

Therefore, we examined end-of-life care consistency from a perspective that goes beyond those efforts by examining patients' preferences that were elicited most recently prior to death and later verbal preferences in comparison with surrogates' decisions and end-of-life care the patient received. Consistency between the patient's decisions and last written goals-of-care preference differs from the other types of consistency as it is a within-patient comparison. However, it was a meaningful determination because it revealed an important minority of patients was able to participate in decision making up until the point of death, and some of those decisions differed from their previously expressed preferences. For these patients, delivered end-of-life care was inconsistent with their preferences indicated in the goals-of-care tool, while clearly reflecting an autonomous patient's decisions at that time.

Differentiating types of consistency can be important for improving end-of-life care, because such differentiation may reveal specific problems that undermine quality of end-of-life care. For example, without a determination of the consistency between surrogate decisions and patient preference, it would be unclear whether an inconsistency of delivered end-of-life

care was due to the surrogate not fulfilling his or her role (possibly due to ineffective ACP) or rather to the care team's failure to honor the surrogate's decision. While delivered end-of-life care was consistent with the patient's preference for only 53% of the patients, 82% of the surrogates made treatment decisions that were consistent with the patient's preference or decisions.

Although sudden deaths are not uncommon among patients with serious chronic illness, such as dialysis patients, the role of sudden deaths in consistency determination has not been discussed previously. Slightly over 20% of the sample in our study and a similar percentage in a study by Detering et al.⁵ died suddenly. These sudden deaths included cases, for example, of unwitnessed death at home, and cardiac arrest at a nursing facility or dialysis center leading to death before any treatment could be given other than CPR. If our study had been focused on CPR preference only, we might have been able to determine consistency for these cases. However, we were looking beyond CPR preferences. Therefore, instead of making consistency determinations with little to no information about treatment decisions, we decided to distinguish cases of sudden death from cases where there was sufficient information to make a consistency determination.

Judgment calls are unavoidable in consistency determination, because what treatment should or should not be provided for a patient who has chosen comfort care only can be highly situational.⁸ For example, some patients who desire comfort care only may require hospital admission if comfort care cannot be provided in the patient's current location. Also, code status is not predictive of a patient's preferences for other kinds of treatments at the end of life; patients with a DNR order often want other aggressive treatments at the end of life.¹⁴ This matter adds to the complexity in consistency determination especially for dialysis patients, because code status at the dialysis center is made separately from and can be different from one made at the hospital.

In our study, care received following an acute medical condition was very similar to end-of-life care observed in a national sample.¹⁵ In the national sample, 76.0% experienced hospitalization and 48.9% received ICU care during the final month of life, and 44.8% died in a hospital.¹⁵ Even though 66.7% of our sample chose comfort care only in the event of an irreversible life-threatening complication, such preferences did not change the course after an acute medical condition for many patients. This might be associated with the fact that in the U.S. health care system, patients have little choice but to visit a hospital to manage an acute illness.³ Because numerous factors can affect end-of-life care consistency, it would be important that studies involving consistency determination make a concerted effort to minimize judgment calls and clearly describe the procedures employed for determination. Further, medical record reviews alone would be limited to reveal the complexity of treatment decision making at the end of life, and an additional source of information to complement medical record data would be necessary.

Our study findings are exploratory in nature because of the small sample and the small number of observations for individual consistency types. Also, the original study was conducted in a single region of the United States. The pathways after an acute illness and the four additional forms of

consistency determination in the study were based on what was observed in the sample, and thus may not be inclusive of all possible ways of defining consistency. Nonetheless, our analysis revealed several important aspects of end-of-life care consistency determination that may inform future research.

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