



# Exploring Patients' Experience with Clinicians Who Recognize Their Unmet Palliative Needs: An Inpatient Study

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## Abstract

**Background:** Given the national shortage of palliative care specialists relative to the need for their services, engaging nonspecialists is important to ensure patients with serious illness have an opportunity to share their goals and values with their providers. Hospital medicine clinicians are well positioned to conduct these conversations given they care for many medically complex patients. Yet, little is known about the patient experience of inpatient goals and values conversations led by hospitalist teams.

**Objective:** To assess patients' experience and perception of the quality of goals and values conversations.

**Design/Setting/Participation:** Single center, tertiary care, nonrandomized, two group cohort trial of patients hospitalized on general medical inpatient units staffed by hospital medicine clinicians previously trained to conduct serious illness conversations.

**Intervention:** An automated screening tool was used to identify patients at increased risk for unmet palliative needs. The multidisciplinary team was informed of the screen's results on the intervention units but not on the control units. Intervention unit clinicians were asked to consider talking with patients about their goals and values.

**Results:** One hundred thirty patients participated in the study. The intervention patients reported improved quality of communication and fewer anxiety and depression symptoms compared with the control patients. Hospice utilization in addition to emergency department visits and hospital readmissions did not differ between the two groups.

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A core focus of palliative care communication is understanding the goals and values of patients and their caregivers and working to harmonize the care offered, where possible, with those expressed priorities. Effective communication about goals and values impacts several outcomes. Patients report that having conversations about their illness with clinicians, friends, or family—being heard and understood—improves the illness experience by reducing isolation, providing wider access to information, and strengthening social and emotional support.<sup>1,2</sup> Effective communication is also associated with improved patient and family understanding, enhanced therapeutic relationships, increased access to services and compliance with treatment, and improved quality of life and mood.<sup>1,3,4</sup> Studies also suggest that while communication training can improve clinical skills, there is a need for more integration of the patient's perspective.<sup>5</sup>

Hospital Medicine clinicians are routinely involved in the care of complex, seriously ill patients and need to understand their patients' priorities to provide tailored patient-centered care. Hospital Medicine's national organization, the Society of Hospital Medicine, even defines this ability as one of its core competencies.<sup>6</sup> However, it is unclear whether goals and values conversations facilitated by hospitalists have similar positive effects on patients compared with those facilitated by specialist palliative care clinicians. Given the relative paucity of specialist palliative care providers compared with the number of patients who need these services<sup>7</sup> and the enormous growth of hospitalists over the past two decades, it is important to understand how hospitalist clinicians can best communicate with patients and families facing serious illness and the impact those communications have on the patient experience.

The Serious Illness Care Program (SICP) works to enhance the skills of nonpalliative care providers, including hospitalists, to facilitate goals and values conversations.<sup>8</sup> In this study, we examine if notifying SICP-trained hospitalists and the interprofessional care team of which of their patients have possible unmet palliative needs affects these patients' overall experience and their attitudes toward their care. We hypothesized that providing the clinical team with this information would improve patients' understanding of the prognosis and their experience of being understood by providers, without adversely impacting their mood. We also hypothesized that goals and values conversations would be more commonly documented in the electronic health record (EHR).

## Methods

### Setting

The study was performed at Massachusetts General Hospital (MGH), a founding member of Partners HealthCare. MGH is a tertiary academic medical center in Boston with 999 beds and a teaching hospital of Harvard Medical School. The study was conducted on regionalized hospital medicine units with specific units designated as intervention units and others as control units for the study. Patients were assigned to the units by the hospital's admitting office, not by study staff. Attempts were made to keep clinicians working on those floors, when possible, so that they either worked on intervention or control floors, minimizing crossover. Before the study, all the Hospital Medicine clinicians completed 2.5 hours of dedicated training in serious illness conversations using an approach modified from Ariadne Lab's SICP.<sup>8</sup>

### Study sample

The study hospital developed an automated, EHR-embedded screening tool to identify patients at increased risk for unmet palliative needs (Appendix A1). The tool identified patients with high-risk diagnoses (e.g., terms associated with advanced illnesses such as metastatic cancer, or advanced liver or chronic obstructive pulmonary disease); limited prognosis; and language regarding the need for advance care planning, palliative care, or family meetings.

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from ambulatory sites, intensive care unit transfers, or transfers from other services or hospitals), or were previously enrolled in the study. Our initial target was to enroll 50 patients for baseline pre-implementation data collection and an additional 100 patients on control units and 100 on intervention units, or 250 total patients. Due to lower than anticipated triggering rates and higher than anticipated refusal rates by patients, we revised this goal to a total of 130 patients. As we had no baseline data upon which to do power calculations, and no prior published studies addressed these issues, these enrollment goals were intended as a pragmatic estimation.

Clinicians who worked on control and intervention units who participated in this study were informed that they could involve specialty palliative care consultants as they deemed medically appropriate and that this study did not preclude these specialists' involvement in any way.

## Intervention and control groups

Every weekday, the research assistant (RA) would review all new admissions to the study units to determine who screened positive ("triggered") using the algorithm and thus were eligible for enrollment. Thereafter, on intervention units, the RA attended the morning multidisciplinary rounds and notified the clinicians present (typically the doctor, nurse practitioner, physician assistant, nurse, case manager, and social worker) about which patients "triggered" for being at risk for unmet palliative care needs and asked clinicians to consider whether a SIC would be appropriate. On control units, newly admitted patients triggering the screen were identified, but this information was not shared with the multidisciplinary team. Patients were then approached regarding enrollment and asked to complete the self-report questionnaires, although they were not informed that they had triggered the screening tool.

## Survey tools and data collection

Enrolled patients completed a demographic questionnaire and the Hospital Anxiety and Depression Scale (HADS)<sup>9</sup> at enrollment. They subsequently completed the HADS, the Consultation and Relational Empathy (CARE) Measure,<sup>10</sup> and Quality of Serious Illness Conversation (QSIC) Questionnaire 1–2 weeks post-hospitalization. The HADS is a validated, 14-item, self-report instrument that assesses anxiety and depression symptoms in the past week, with higher scores indicating worse symptoms. The CARE Measure is a validated, 10-item, self-report instrument that measures empathy in the context of therapeutic relationships, with higher scores indicating greater empathy and person-centered care. The QSIC is a recently developed 5-item instrument that assesses patients' perceptions of conversations with their hospital clinicians regarding their prognosis, life values, goals of care, and preparation for the future.

Additionally, study staff performed a review of the EHR to determine patients' Braden and Morse Fall Scores (measures of pressure ulcer risk and fall risk, respectively, as surrogate markers of frailty) and the nursing assessment of their activities of daily living (ADLs). There were 11 ADLs assessed upon admission, and the number of ADLs that required assistance at that time was recorded. Finally, study staff reviewed the EHR to determine data on the presence of a SIC in the Advance Care Planning module in the EHR (or in other locations of the EHR), length of hospital stay, 30-day readmission rate, 30-day ED utilization rate, discharge disposition, hospice utilization, completion of advance care planning documentation, changes in code status documentation during hospitalization, and rate of specialty palliative care consultations.

## Statistical analyses

We used the Statistical Package for Social Sciences (IBM SS, v.25) for all statistical analyses. To describe the sample, we first calculated frequencies, means, standard deviations, median, and interquartile ranges for the

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The Partners Institutional Review Board approved this study before initiation.

## Results

Of the 202 patients approached, 130 (64.4%) consented to participate. As shown in Table 1, the two study groups were not statistically different across demographic and clinical characteristics, although patients on the intervention units were older (mean = 69.8 years) compared with the control patients (mean = 65.6 years). The patient sample was predominantly Caucasian, and there was a higher percentage of married patients on the intervention versus control units (52.7% vs. 38.2%). Upon admission, the Braden scores, Morse scores, and ADLs assessments were similar between the study groups.

**Table 1. Baseline Demographic Characteristics**

<b>Variable</b>	<b>Control unit (N = 55)</b>	<b>Intervention unit (N = 75)</b>	<b>p</b>
Age, years, mean (SD)	65.6 (13.8)	69.8 (12.1)	0.066
Gender, <i>n</i> (%)			
Female	28 (50.9)	40 (53.3)	
Male	27 (49.1)	35 (46.7)	0.785
Race, <i>n</i> (%) <sup>a</sup>			
American Indian or Alaska Native	0 (0)	0 (0)	
Asian	1 (1.8)	1 (1.3)	
Black	1 (1.8)	1 (1.3)	
White	53 (96.4)	72 (96.0)	
Unknown/not reported	0 (0)	1 (1.3)	0.915
Ethnicity, <i>n</i> (%)			
Hispanic or Latino	1 (1.8)	0 (0)	

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Variable	Control unit (N = 55)	Intervention unit (N = 75)	p
Married/partner	21 (38.2)	39 (52.7)	0.136
Single	13 (23.6)	8 (10.8)	
Divorced/separated	13 (23.6)	13 (17.6)	
Widowed	8 (14.5)	14 (18.9)	
Education, n (%)			
High school or less	23 (43.4)	32 (43.2)	0.875
Some or completed college	22 (41.5)	33 (44.6)	
Graduate school	8 (15.0)	9 (12.2)	
Religion, n (%) <sup>a</sup>			
Catholic	29 (52.7)	42 (58.3)	0.092
Other Christian (e.g., Protestant)	12 (21.8)	22 (30.6)	
Jewish	4 (7.3)	1 (1.4)	
Atheist	0 (0)	1 (1.4)	
None	6 (10.9)	5 (6.9)	
Other	4 (7.3)	1 (1.4)	
Hospital length of stay, days, median (IQR)	5.0 (3.0–7.0)	6.0 (4.0–10.0)	0.117
Reason for hospitalization, n (%)			

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Variable	Control unit (N = 55)	Intervention unit (N = 75)	p
Chronic obstructive pulmonary disease	11 (20.0)	7 (9.3)	
Pneumonia	3 (5.5)	9 (12.0)	
Other respiratory	7 (12.7)	10 (13.3)	
Gastrointestinal	12 (21.8)	13 (17.3)	
Other medical conditions	16 (29.1)	23 (30.7)	
Nurse assessments upon admission, mean (SD)			
Braden Score	19.00 (3.2)	19.08 (3.4)	0.892
Morse Fall Risk Score	52.45 (22.8)	53.33 (20.7)	0.819
Activities of Daily Living Score	1.82 (2.2)	1.63 (2.2)	0.625
We used the independent samples <i>t</i> test, chi-square test, and independent samples median test to compare group differences in baseline demographic and clinical variables.			
<sup>a</sup> Results are from chi-square tests comparing the following groups for Race (White vs. All Other Categories) and Religion (Catholic vs. Other Christian vs. All Other Categories).			
IQR, interquartile range; SD, standard deviation.			

The results of the HADS and CARE questionnaires are detailed in Table 2, demonstrating that patients on the intervention units reported significantly fewer anxiety and depression symptoms compared with the control patients. Similarly, patients on the intervention units scored higher on the CARE Questionnaire, reflecting a perception of higher clinician empathy, compassion, and communication skills than control patients. When asked specifically about the conversations patients had with their clinicians during their hospital stay, a greater proportion of intervention patients agreed with statements that they appreciated their clinicians bringing up the patient's personal goals for the future and liked the way the conversations with clinicians about their illness were conducted. Moreover, a higher proportion of patients on the intervention units noted that the conversations that they had with clinicians about their illness increased their understanding of what might happen in the future and would influence how they prepare for the future compared with the control patients (Table 3).

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Outcome measure	Control unit adjusted mean (SE)	Intervention unit adjusted mean (SE)	Between-group adjusted mean difference (SE)	95% CI	p
HADS-Anxiety ( <i>n</i> = 105)	7.39 (0.35)	6.41 (0.30)	0.99 (0.48)	0.04 to 1.94	0.042
HADS-Depression ( <i>n</i> = 105)	6.17 (0.26)	5.18 (0.23)	0.99 (0.36)	0.29 to 1.70	0.006
CARE Questionnaire ( <i>n</i> = 103)	38.16 (1.18)	43.24 (0.99)	-5.08 (1.59)	-8.23 to -1.93	0.002

Results from analysis of covariance models adjusting for baseline values of HADS and patient age.

CARE, Consultation and Relational Empathy; CI, confidence interval; HADS-Anxiety, Hospital Anxiety and Depression Scale–Anxiety Subscale; HADS-Depression, Hospital Anxiety and Depression Scale–Depression Subscale; SE, standard error.

**Table 3. Between-Group Differences in Patient Perceptions of Serious Illness Conversations per Self-Report on the Quality of Serious Illness Conversation Questionnaire**

To what extent ...	Control unit, <i>n</i> (%)	Intervention unit, <i>n</i> (%)	Odds ratio (95% CI)	p
Did you appreciate your clinician bringing up your personal goals for the future?				
Not at all/slightly/somewhat	9 (37.5)	5 (14.3)	4.65 (1.16–18.59)	0.030
Very much/extremely	15 (62.5)	30 (85.7)		
Did you appreciate your clinician asking about your fears and worries about the future?				
Not at all/slightly/somewhat	7 (41.2)	6 (23.1)	3.15 (0.78–12.81)	0.110
Very much/extremely	10 (58.8)	20 (76.9)		

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To what extent ...	Control unit, <i>n</i> (%)	Intervention unit, <i>n</i> (%)	Odds ratio (95% CI)	<i>p</i>
Did you like the way the conversations with your clinician about your illness were set up?				
Not at all/slightly/somewhat	20 (50.0)	16 (30.2)	2.61 (1.07–6.32)	0.034
Very much/extremely	20 (50.0)	37 (69.8)		
Will the conversations you had with your clinician about your illness influence how you prepare for the future?				
Not at all/slightly/somewhat	22 (57.9)	12 (24.5)	5.82 (2.11–16.05)	0.001
Very much/extremely	16 (42.1)	37 (75.5)		
Did discussing your illness with your clinician increase your understanding of what might happen in the future?				
Not at all/slightly/somewhat	30 (75.0)	14 (28.0)	7.79 (2.95–20.53)	<0.001
Very much/extremely	10 (25.0)	36 (72.0)		
Odds ratios derived from logistic regression models comparing “Not at all/Slight/Somewhat” vs. “Very Much/Extremely” between groups, adjusting for patient age. For each item, the missing responses ( <i>N</i> = 23) and the “Not Applicable” responses ( <i>N</i> = 48, 64, 14, 20, and 17, respectively) did not differ significantly between the groups.				

EHR review demonstrated no differences in rates of documented SICs, advance care planning, or palliative consultations during the hospital stay. Hospice utilization immediately following discharge, in addition to ED visits and hospital readmissions within 30 days after discharge, did not differ between the groups (Table 4). There was a higher percentage of family participation in goals of care conversations among patients on the intervention units compared with control patients (13% vs. 5%), although this difference was not statistically significant.

**Table 4. Between-Group Differences in Serious Illness Conversations, Advance Care Planning Documentation, and Service Utilization**

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Variable	Control unit (N = 55)	Intervention unit (N = 75)	p
SIC documented in ACP module during admission, <i>n</i> (%)			
Yes	2 (3.6)	1 (1.3)	0.573
No	53 (96.4)	74 (98.7)	
Any ACP notes documented during admission, <i>n</i> (%)			
Yes	0 (0)	3 (4.0)	0.262
No	55 (100.0)	72 (96.0)	
Any goals of care/values discussion by any clinician documented during admission, <i>n</i> (%)			
Yes	6 (10.9)	14 (18.7)	0.325
No	49 (89.1)	61 (81.3)	
Family participation in any SIC or goals of care discussion, <i>n</i> (%)			
Yes	3 (5.5)	10 (13.3)	0.188
No	52 (94.5)	65 (86.7)	
Code status change during admission, <i>n</i> (%)			
Yes	10 (18.2)	7 (9.3)	0.188
No	45 (81.8)	68 (90.7)	

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Variable	Control unit (N = 55)	Intervention unit (N = 75)	p
No	50 (90.9)	66 (88.0)	
Discharge disposition, <i>n</i> (%)			
Home	20 (36.4)	20 (26.7)	
Visiting nurses/home care services	24 (43.6)	38 (50.7)	
Skilled nursing/rehabilitation facility	10 (18.2)	14 (18.7)	
Hospice services	1 (1.8)	1 (1.3)	
Other (passed away during hospitalization)	0	2 (2.7)	0.337
ED visit within 30 days after hospitalization, <i>n</i> (%)			
Yes	5 (9.1)	8 (10.7)	
No	50 (90.9)	67 (89.3)	1.00
Hospital readmission within 30 days, <i>n</i> (%)			
Yes	20 (36.4)	19 (25.3)	
No	35 (63.6)	56 (74.7)	

*p*-Values derived from two-sided Fisher's exact tests. For discharge disposition, we compared "Home" vs other categories combined. "Other" data cases were excluded from the analysis.

ACP, advance care planning; ED, emergency department; SIC, serious illness conversation.

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## Discussion

Effectively caring for patients with serious illness requires clinicians to recognize when these patients have unmet needs. Reliably detecting these needs, therefore, is the starting point for efforts to improve the care of seriously ill

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having unmet palliative needs as determined by an automated EHR algorithm. We then compared the experience of those patients with patients on a control unit whose providers were not informed of unmet needs.

Although specific documentation in the EHR of goals and values conversations or other advance care planning efforts was limited in both cohorts, there were several differences noted between the two patient groups that suggested that informing the care team about patients' potential for unmet palliative care needs may have had a positive impact. Specifically, patients on the intervention units had higher CARE scores compared with patients on the control units. CARE scores are a composite measure of perceived clinician listening and compassion and patients' perception of how much they understand and have control over their care. Patients also reported that they appreciated the chance to discuss their priorities and to think with their clinicians about how to prepare for the future. In addition, the intervention group demonstrated favorable HADS scores, reflecting fewer anxiety and depression symptoms compared with the control group. No differences were noted between the groups with respect to hospice utilization, ED visits, or readmission rates.

A lack of adequate training regarding how to talk effectively with patients about their illness and their priorities as well as a fear of impacting the emotional state of patients have been found to be barriers for hospitalists conducting these types of conversations.<sup>15</sup> This study examined hospitalists who had been trained in how to conduct these conversations and demonstrated that when interacting with these trained clinicians, patients can have positive experiences with effective serious illness communication, reassuringly without adversely impacting the patients' mood.

Previous investigators have examined what qualifies as communication excellence, a complex concept because of the variation in patients' needs and their perceptions of what defines optimal and valuable communication. Feeling listened to is considered one of the key characteristics that patients sought in their providers when having goals and values conversations. Patients also valued autonomy, having choices, and feeling in control, as well as maintaining a sense of hopefulness.<sup>1</sup> This study adds to this important patient-centered literature.

Conducting these conversations during an acute hospitalization raises questions about issues of their timing. When looking at advanced cancer populations, patients preferred conversations at the time of diagnosis, which helped set shared expectations, avoided later surprises, helped the patients understand what is happening, and gave patients a sense of control.<sup>16</sup> While it may be relatively easier for cancer populations to define an appropriate time to have these conversations due to the somewhat more predictable nature of their illness and knowledge of when the diagnosis was made, it may be harder for chronically ill, general medical inpatients to identify a time frame when these conversations should happen. Irrespective, our intervention was associated with a positive impact on the patients' experiences during their hospitalization. How conversations held in other settings or at other times would have compared is unknown. Our clinical experience suggests that these conversations are ideally done iteratively, throughout the illness course, and that initial discussions can happen in many settings successfully, forming the foundation for future discussions.

We propose a few hypotheses to explain the positive findings seen in this study despite the low level of SICs documented in the EHR. First, it is likely that SICs were occurring but were not documented in the EHRs Advance Care Planning module as was requested. Supporting this hypothesis is the almost doubling of conversations about goals and values recorded outside the appropriate module of the EHR, as shown in Table 4. Second, as the RA identified patients who screened positive as having possible unmet palliative care needs during interprofessional rounds, the rest of the care team present was thus made aware, and this knowledge may have affected how other team members communicated with the patient, altering the communication milieu overall.

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sample. The remaining sample size was moderate, which hindered our ability to detect effects of small magnitude. Finally, as the study design was not a randomized controlled trial, we are unable to conclude definitively the degree to which the screening tool intervention led to improved patient-reported outcomes.

## Conclusions

This study reveals that training hospitalists in serious illness communication and subsequently informing the entire care team that their patients have been identified as having possible unmet palliative care needs was associated with improved experiences of care for these patients without detrimental impacts on their mood. It reinforces the need for further training on goals and values conversations to more effectively prepare clinicians to meet the needs and demands of patients and illustrates the importance of implementing systems to assist in identifying such hospitalized patients and ensuring their care team is aware of this finding.

## Funding Information

No funding was received to conduct this study.

## Author Disclosure Statement

No competing financial interests exist.

## Appendix A1. Reference

### Epic algorithm that was used for suspected unmet palliative care needs

- (1) Patient is in the hospital's chronic obstructive pulmonary disease (COPD) registry
- (2) Patient has end-stage liver disease on the problem list
- (3) Patient has one of the following in the problem list:
  - (a) End-stage management
  - (b) Goals of care, counseling/discussion
  - (c) Counseling regarding advance directives and goals of care
  - (d) Advanced care planning/counseling discussion

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**(4) The problem list contains one of the terms:**

- Metastatic
- Has metastasized
- Is oxygen dependent
- Prognosis is poor
- Has terminal condition
- Organ failure
- End-staged disease

**(5) A progress note in the last 90 days contain one of the expressions:**

- Metastatic
- Has metastasized
- Is oxygen dependent
- Organ failure
- Has terminal condition
- Have family meeting
- Is in grave or critical conditions

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