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Seriously ill patients' prioritized goals and their clinicians' perceptions of those goals

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Abstract

Context: Seriously ill patients whose prioritized healthcare goals are understood by their clinicians are likely better positioned to receive goal-concordant care.

Objectives: To examine the proportion of seriously ill patients whose prioritized healthcare goal is accurately perceived by their clinician and identify factors associated with accurate perception.

Methods: Secondary analysis of a multicenter cluster-randomized trial of outpatients with serious illness and their clinicians. Approximately two weeks after a clinic visit, patients reported their current prioritized healthcare goal - extending life over relief of pain and discomfort, or

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relief of pain and discomfort over extending life - and clinicians reported their perception of their patients' current prioritized healthcare goal; matching these items defined accurate perception.

Results: Of 252 patients with a prioritized healthcare goal, 60% had their goal accurately perceived by their clinician, 27% were cared for by clinicians who perceived prioritization of the alternative goal, and 13% had their clinician answer unsure. Patients who were older (OR 1.03 per year; 95%CI 1.01, 1.05), had stable goals (OR 2.52; 95%CI 1.26, 5.05), and had a recent goals-of-care discussion (OR 1.78, 95%CI 1.00, 3.16) were more likely to have their goals accurately perceived.

Conclusion: A majority of seriously ill outpatients are cared for by clinicians who accurately perceive their patients' prioritized healthcare goals. However, a substantial portion are not and may be at higher risk for goal-discordant care. Interventions that facilitate goals-of-care discussions may help align care with goals, as recent discussions were associated with accurate perceptions of patients' prioritized goals.

Terms for Indexing

goal-concordant care; goals-of-care; goals; values; preferences; palliative care; serious illness; end-of-life; advance care planning (ACP); clinician understanding; clinician identification; clinician perception

INTRODUCTION

Patients' receipt of goal-concordant care - medical care consistent with their personal values and goals - is of paramount importance to patients, families, and clinicians.[1–5] In its absence, patients may experience unwanted burdensome treatments, and families may experience psychological distress. Clinicians can help ensure patients receive goal-concordant care through a process that begins by focusing on the values and overarching healthcare goals of patients.[6–8] With an understanding of what is important to patients, clinicians can help patients identify medical treatments that align with their goals, given their health circumstances.[6–11] This shared decision making process is especially important for patients with serious illness whose goals may be varied, difficult to predict, and often diverge from default medical care focused primarily on extending life.[12–17] To effectively carry out this process, patients' goals must be understood by their clinicians.

While there are studies of clinicians' perceptions of patients' goals generally,[18,19] there are no studies examining clinicians' understanding of the *values and goals* of their individual seriously ill patients. Prior researchers have examined clinicians' perception of *treatment preferences* of their individual seriously ill patients,[20–26] like cardiopulmonary resuscitation (CPR), but that approach does not fully reflect the shared decision making process that is key to ensuring treatments authentically align with patients' goals.[9] Without explicit efforts by clinicians to inform and support patients' decision making around goals of care, patients may struggle to understand the implications of complex medical decisions and to identify treatments aligned with their goals.[15,27–29] Hence, knowing whether clinicians understand patients' goals is an important step in ensuring that patients receive goal-concordant care. In this study, we examined alignment between the prioritized healthcare goals of

seriously ill outpatients and their clinicians' perception of those goals. We also examined factors associated with patients whose goals were accurately perceived, to identify potential mechanisms that underlie accurate perception and also to explore face validity of using this novel comparison as a process measure in future studies focused on the underdeveloped research area of identifying implementation gaps in the process of delivering of goal-concordant care.

METHODS

Design

We conducted a secondary analysis of a multicenter cluster-randomized trial of a patient-specific communication-priming intervention designed to increase goals-of-care discussions (GOCDs) compared to usual care for seriously ill outpatients.[30] Clinicians were randomized to usual care or intervention, and patients followed their clinician's assignment. The intervention was patient-specific communication tips delivered to clinicians and patients prior to an index clinic visit, defined as the first scheduled visit after enrollment. Details of the randomized trial and this sample have been published.[14,30–34] Institutional review boards approved the study, and participants provided written informed consent.

Population

The randomized trial included clinicians in outpatient settings and their patients with serious illness recruited from two large health systems in the Pacific Northwest. Eligible clinicians were physicians or nurse practitioners providing primary or specialty care to 5 eligible patients. Using clinic schedules and electronic health records (EHRs), consecutive eligible patients cared for by the participating clinician were identified and recruited between March 2014 and May 2016. Eligible patients were 18 years old, had 2 clinic visits with the participating clinician within the prior 18 months, and had 1 qualifying diagnosis or condition (Supplement S1).[35–39]

Data Collection

Data were obtained from patient and clinician questionnaires completed at enrollment and approximately two weeks following the index clinic visit, and from the EHR. For clinicians and patients in the intervention arm, the index visit included the intervention.[30]

Outcome

The primary outcome was accurate perception of a patient's prioritized healthcare goal by their clinician, among patients with a prioritized healthcare goal. This was determined by matching clinician response to patient response on survey items (Supplement S1) completed approximately two weeks after the index visit. The survey items asked the patient's current top priority (extending life versus relief of pain and discomfort), and were developed for the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT).[40–43] The primary outcome was a dichotomous variable: accurate when a clinician selected the same goal as their patient, or inaccurate when a clinician selected a different response including if a clinician selected unsure.

Exposures

We selected ten exposure variables *a priori* to minimize multiple comparisons. Patient demographics from enrollment questionnaires included: age, gender, race and ethnicity (white and non-Hispanic vs. minority), and education level. These were selected because their demonstrated associations with treatment preferences suggest potential associations with clinician perception of healthcare goals.[44] Clinician demographics from enrollment questionnaires included age, gender, and practice type (primary vs. specialty care). Additional variables based on prespecified hypotheses (Supplement S1) included: a dichotomous variable of the patients' goal following the index visit (relief of pain and discomfort versus extending life); stable goals, defined as no change in patient goal between enrollment and after-visit questionnaires; and occurrence of a GOCD, defined as clinician report of a discussion during the index visit on after-visit questionairres.[45–48]

Statistical Analysis

For analysis, we used the sample of all patients who both reported a goal and had their clinician report the patient's goal. We pooled patients from both arms of the trial to increase sample size and ability to detect differences. We modeled accurate perception from patients clustered within clinician using a logit link and generalized estimating equation with independence correlation structure and robust standard errors.[45,46] We used intercept-only models to obtain point and 95% confidence interval estimates of the proportion of patients with accurately perceived goals. We fit models with each exposure variable (unadjusted) and a model with all exposure variables (multivariate). Our primary multivariate model included clinician-reported occurrence of a GOCD, as this was of primary interest for this study. We did not adjust for the intervention because the primary and only goal of the intervention was to cause a GOCD, and adjusting for variables on a causal pathway potentially weakens associations and reduces interpretability of coefficients and p-values.[49,50] Though not our primary interest, we fit supplemental multivariate models: one with receipt of intervention as an exposure variable instead of GOCD; and one with receipt of intervention and GOCD as exposure variables, recognizing this model presents interpretation challenges described above. For analyses, $p < 0.05$ was evidence of statistical significance. We used R Version 3.5.1.

RESULTS

We identified 917 eligible patients for the randomized trial and 537 enrolled (Figure 1). After the index visit, 399 patients completed surveys, with 382 answering the goal question. Ninety-four (25%) patients were unsure of their goal and excluded. Of the remaining, 36 were excluded because their clinician did not complete an after-visit survey (n=32) or did not respond to the goal question (n=4). This resulted in a complete case sample of 252 patients and 105 clinicians. Patients' median age was 77 years and half were women. Most patients were white and non-Hispanic (82%; Table 1). Participation rates were similar across demographics and clinical characteristics (Supplement S2). Patients completed surveys a median of 12 days (IQR 21.5) after the visit. Clinicians' median age was 45 years and half were women. Most clinicians were white and non-Hispanic (78%). Half practiced primary as opposed to specialty care (Table 2). Participation rates were similar across demographics and

clinical characteristics (Supplement S2). Clinicians completed surveys a median of 9 days (IQR 26.75) after the visit.

Of the 252 patients with a healthcare goal, 196 (78%) prioritized relief of pain and discomfort, while 56 (22%) prioritized extending life (Figure 2). Clinicians believed 128 patients (51%) would prioritize relief of pain and discomfort, while 90 (36%) would prioritize extending life; clinicians answered unsure for 34 patients (13%). The patient's goal was accurately perceived by clinicians for 151 patients (60%; 95%CI 53–66%). Instances of inaccurate perception included 67 patients whose clinician perceived the alternative goal, and 34 patients whose clinicians answered unsure.

Table 3 shows ten bivariate (unadjusted) models and a single adjusted multivariate model. In the adjusted model, patients more likely to have their goal accurately perceived by their clinician were older (OR 1.029 per year; 95%CI 1.005, 1.051), had stable goals since enrollment (OR 2.519; 95%CI 1.262, 5.053), and had their clinician report a GOCD at the index visit (OR 1.783, 95%CI 1.002, 3.158). These associations were similar in supplementary models (Supplements S3 and S4).

DISCUSSION

Clinicians should play an explicit role in helping seriously ill patients identify medical treatments that best align with their values and goals, given their health circumstances.[6–8] To do this effectively, clinicians must first understand their patients' values and goals. To our knowledge, this is the first study to compare individual patient-reported goals to clinician perception of their patients' goals. In this sample of seriously ill outpatients and their clinicians, we found 60% of patients with a prioritized healthcare goal were cared for by clinicians who accurately perceived their goal. While this represents a majority, there are reasons to have hoped for a higher proportion. First, patients had chronic, life-limiting illness such that serious illness communication should be a priority for their clinicians.[8] Second, understanding their patients' current overarching goals, such as an overall desire to focus on extending life or minimizing discomfort, should be an *initial* step in that process.[7] Third, clinicians had reasonable time to learn their patients' goals given patient-clinician pairs had 3 recent clinic visits, including one within a couple weeks. Despite these factors, 40% of patients were cared for by clinicians who did not accurately perceive their patients' goal. These findings suggest substantial room for clinicians to improve their understanding of the goals of their seriously ill patients.

One approach to improve understanding of patients' goals is for clinicians to discuss them with patients. A key finding from our study is that patients whose clinicians reported a recent GOCD were more likely to have their goals accurately perceived by their clinicians. Despite the importance of GOCDs, prior data suggests that clinicians commonly fail to conduct them or wait until late in the course of serious illness.[8,51] Clinician-reported barriers to GOCDs include lack of time, the perception that patients have difficulty accepting the prognosis or understanding its implications, and insufficient training.[52,53] Yet without discussions, seriously ill patients' goals are hard to predict,[14] which makes delivering goal-concordant care more challenging. Future research should evaluate challenges to

implementation of interventions that promote timely and high-quality GOCDs in real-world pragmatic settings and further assess impact on clinician understanding of patients' goals.

While prior studies have evaluated clinicians' perceptions of specific treatment preferences of seriously ill patients,[20–26] like CPR, this study provides a unique assessment of clinicians' perceptions of their individual patients' goals. Clinicians' understandings of patients' goals may be a more useful process measure for goal-concordant care than their identification of treatment preferences that may, or may not, reflect patients' goals.[9,14,15] Thus, this measure may have potential value for future quality improvement or implementation science studies. Identifying deficient steps in the process of delivering goal-concordant care allows for more tailored intervention development. Moreover, accurate perception of goals can be measured in real-time using this measure and thus could provide opportunities to target timely GOCDs.[3] As examples, this process measure might be used to prompt GOCDs and/or identify potentially lower quality discussions and prompt repeated discussions with added support if needed. For patients not ready to prioritize their goals, however, alternative and culturally-sensitive approaches may be needed.

While this measure may be valuable and should be further developed, we acknowledge some unknowns. Particularly, how closely clinician understanding relates to goal-concordant care requires further study. For patients who prioritize extending life, clinician understanding may not be necessary for goal-concordant care since care focused on life-extension is often the default approach. For patients with alternative priorities, like independence or relief of discomfort, understanding these goals may not alone be sufficient to result in goal-concordant care without additional skills, like identifying aligned treatments, and implementing those treatments.[52] Furthermore, this measure has limitations. The questions broadly categorize goals, while patients' goals may be more nuanced.[12,13] Patients and clinicians that discussed those nuances, or alternative goals like independence, may have struggled to broadly categorize them when surveyed. Moreover, some patients may have potentially conflicting goals,[15,16] leaving clinicians unsure of their patients' top priority or whether one exists. Clinicians should strive to clarify goals in order to provide reliable guidance for treatment decisions and ensure goal-concordant care. Despite these limitations, our finding that GOCDs were associated with patients whose goals were accurately perceived suggests the measure has value; further development, including qualitative work, is worthwhile.

Our findings also suggest the importance of repeating discussions over time. While the majority of patients reported stable goals, about a third reported a different prioritized goal on enrollment and after-visit questionnaires; this group was less likely to have their current goal accurately perceived. Identifying and ranking values is a context-dependent process.[54,55] Contextual changes over the illness course can lead to changes in patients' priorities. One way for clinicians to ensure they stay attuned to potentially shifting priorities is to repeat discussions over time.

This study has limitations. First, as acknowledged, discussing goals of care with patients is different than responding to survey questions that may oversimplify complex perspectives. In this study, we did not explore how participants interpreted healthcare goal questions,

although the question was developed and cognitively tested for SUPPORT.[40,41] Second, some discordance could result from patients whose goals changed between the visit and questionnaire completion, although questionnaires were completed within about two weeks. Additionally, clinicians' recall of goals could have been influenced by this interval, though clinicians could review patient EHRs when completing questionnaires. Third, nearly half our sample of patient-clinician pairs received an intervention designed to promote GOCDs prior to answering the goal question, and this could have influenced our results. However, supplemental analyses, including adjustment for intervention group (previously shown to be effective at increasing patient-reported GOCDs[30]) provided similar conclusions (Supplements S3 and S4). Of note, control arm clinicians reported GOCDs with 44% of their patients, while intervention arm clinicians reported GOCDs with 90% of their patients. Fourth, some nonresponse bias may be present, as 27% of eligible patients and 22% of eligible clinicians participated; however, measured differences between responders and non-responders were minimal (Supplement S2). Fifth, current communication practices may be different than those between March 2014 and May 2016, when this study was conducted. Finally, although multicentered, our study occurred in one region of the U.S. with mostly white and non-Hispanic patients.

In this study, we examined prioritized healthcare goals of seriously ill outpatients and their clinicians' perceptions of their patients' goals. We found that 60% of patients with a prioritized goal were cared for by clinicians who accurately perceived their goal. We found that patients whose goals were accurately identified were more likely to be cared for by a clinician who reported a recent GOCD with the patient. To improve understanding of patients' goals, clinicians should conduct GOCDs early, focus attention on clarifying patients' priorities amongst potentially conflicting goals, and repeat discussions over time. Pragmatic clinical trials are needed to see how these practices can be supported in real-world settings. The novel process measure explored in this study may serve to support this research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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CONFLICTS OF INTEREST

Drs. Engelberg and Curtis report grant funding from PCORI during the conduct of the study. The remaining authors report no conflicts of interest.

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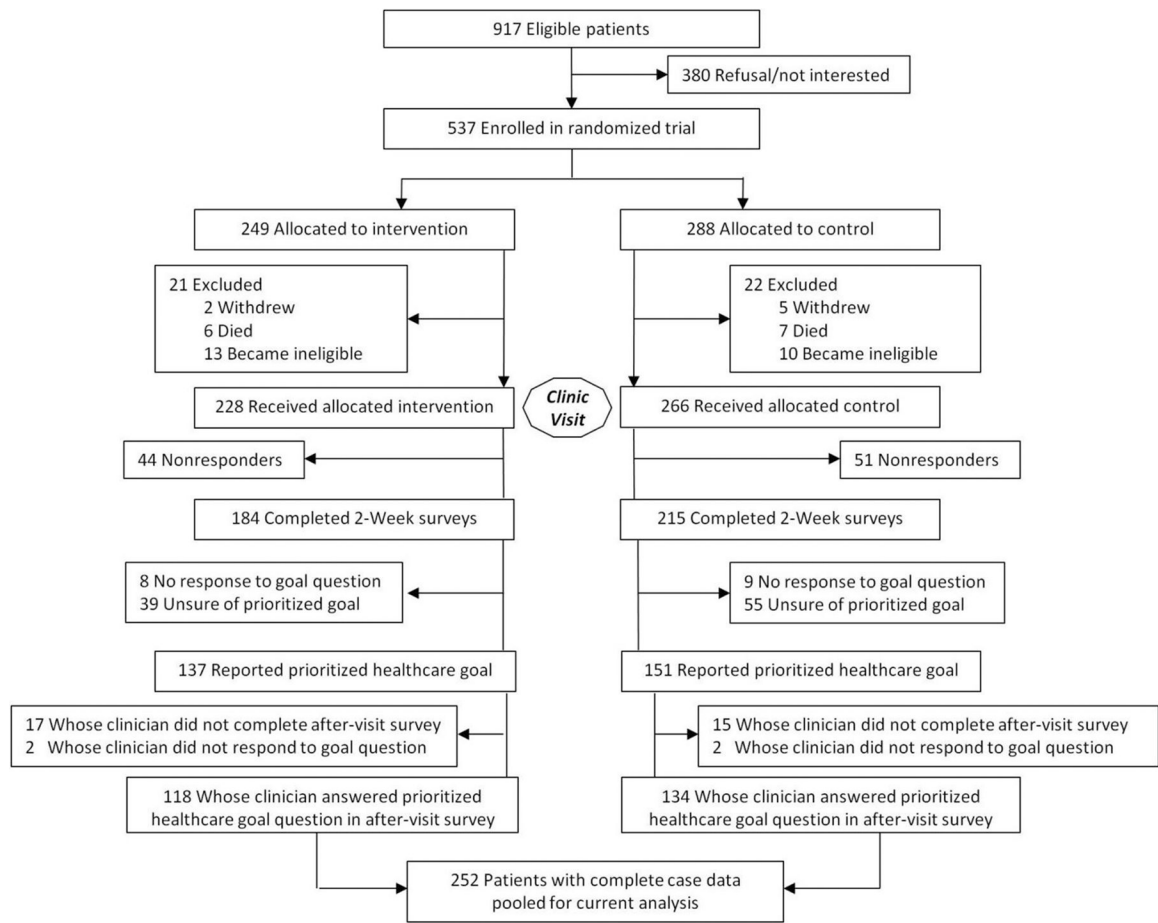
Figure 1. Patient Flow Diagram[a]
a. For clinician flow diagram, see original randomized trial report.[30]

Figure 2. Clinicians' perceptions of patients' prioritized goals among patients with a prioritized healthcare goal[a]

a. Sankey plot illustrating that among patients (n=252) with a prioritized healthcare goal, 196 (78%) prioritized relief of pain and discomfort, while 56 (22%) prioritized extending life. Overall, the patient's prioritized goal was accurately perceived by clinicians for 151 patients (60%; 95% CI: 53–66%).

Table 1.

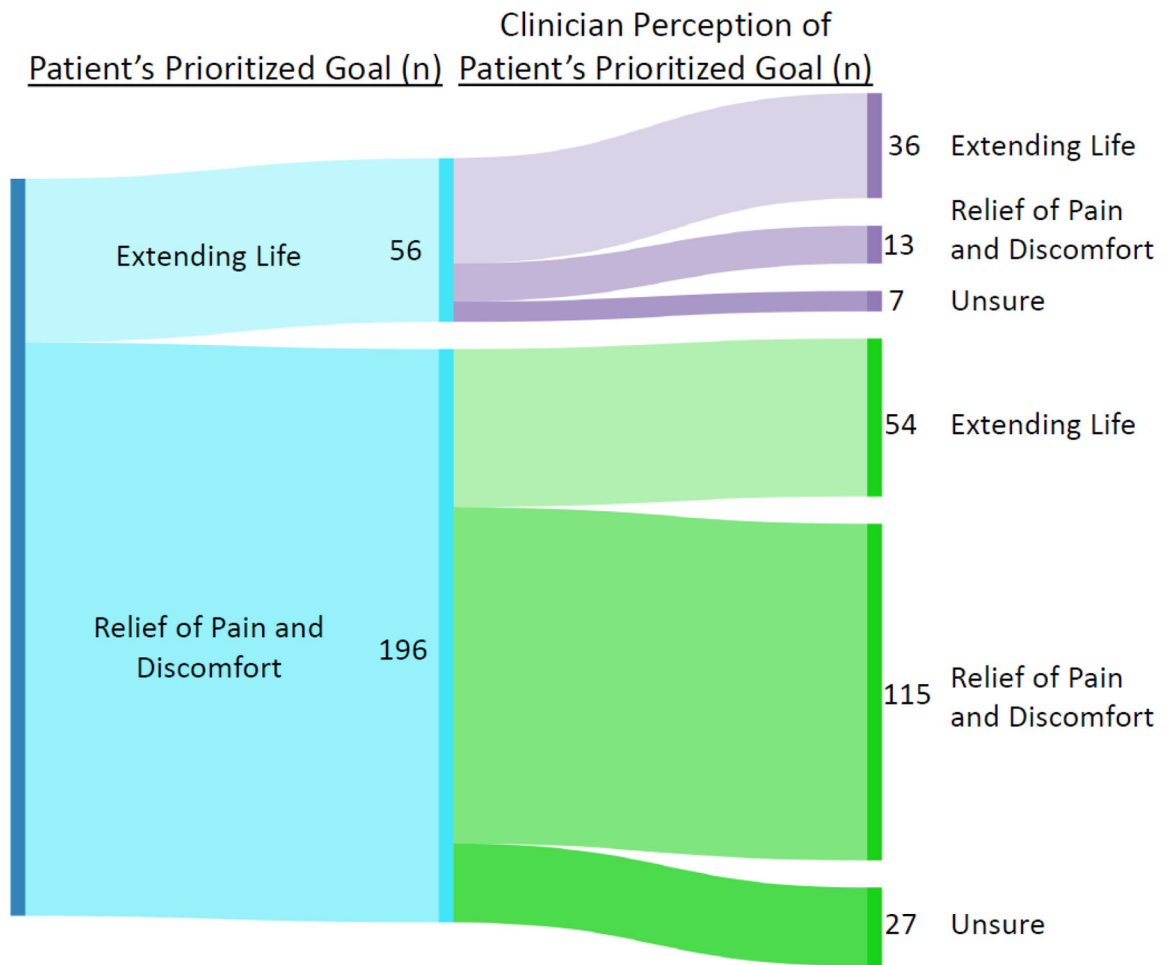Characteristics of patients with a prioritized healthcare goal, by accuracy of their clinician's perception of that goal

Characteristic	Total	Accurate	Inaccurate
Total, n (%)	252 (100.0)	151 (59.9)	101 (40.1)
Age (median, IQR)	76.5 (17.8)	76.7 (18.9)	76.3 (17.9)
Female	123 (48.8)	74 (49.0)	49 (48.5)
Racial or ethnic minority	46 (18.3)	29 (19.2)	17 (16.8)
Currently married or living with partner	109 (43.3)	64 (42.4)	45 (44.6)
Level of education			
8th grade or less	8 (3.2)	6 (4.0)	2 (2.0)
Some high school	13 (5.2)	8 (5.3)	5 (5.0)
High school diploma or equivalent	30 (11.9)	20 (13.3)	10 (9.9)
Trade school or some college	103 (40.9)	61 (40.4)	42 (41.6)
4-yr college degree	44 (17.5)	27 (17.9)	17 (16.8)
Some graduate school	12 (4.8)	6 (4.0)	6 (6.0)
Graduate degree	42 (16.7)	23 (15.2)	19 (18.8)
Self-perceived health status			
Poor	43 (17.1)	24 (15.9)	19 (18.8)
Fair	74 (29.4)	45 (29.8)	29 (28.7)
Good	88 (34.9)	58 (38.4)	30 (29.7)
Very good	37 (14.7)	18 (11.9)	19 (18.8)
Excellent	10 (4.0)	6 (4.0)	4 (4.0)
Charlson comorbidity score, median (IQR)	7 (3)	7 (3)	7 (3)
Qualifying diagnoses and conditions[a]			
Diagnoses			
Advanced cancer	42 (16.7)	20 (13.3)	22 (21.8)
Chronic lung disease	23 (9.1)	16 (10.6)	7 (6.9)
Heart failure	13 (5.2)	10 (6.6)	3 (3.0)
Liver failure	1 (0.4)	1 (0.7)	0 (0.0)
Renal failure	10 (4.0)	8 (5.3)	2 (2.0)
Conditions			
Age 75+ yrs with chronic life-limiting illness	93 (36.9)	57 (37.8)	36 (35.6)
Age 90+ yrs	22 (8.7)	17 (11.3)	5 (5.0)
Hospitalized with serious condition in 18 months before study enrollment	37 (14.7)	17 (11.3)	20 (19.8)
Charlson comorbidity score of 6+	209 (82.9)	125 (82.8)	84 (83.2)
Allocated to receive intervention	118 (46.8)	73 (48.3)	45 (44.6)
Prioritized goal of extending life	56 (22.2)	36 (23.8)	20 (19.8)
Stable prioritized goal since enrollment	172 (68.3)	112 (74.2)	60 (59.4)
Clinician reported occurrence of goals-of-care discussion at index clinic visit	165 (65.5)	107 (70.9)	58 (57.4)
Clinicians' perception of patients' prioritized goal			
Extending life	90 (35.7)	36 (23.8)	54 (53.5)

Characteristic	Total	Accurate	Inaccurate
Relief of pain and discomfort	128 (50.8)	115 (76.2)	13 (12.9)
Unsure	34 (13.5)	N/A	34 (33.7)

[a.]Qualifying diagnoses and conditions do not add to 100%, as patients could have more than one qualifying diagnosis or condition.

Table 2.

Characteristics of clinicians

Characteristic	
Total, n	105 (100.0)
Age, median (IQR)	45 (16)
Female	52 (49.5)
Racial or ethnic minority	23 (21.9)
Primary vs. specialty care	
Primary care	53 (50.5)
Family medicine	24 (22.9)
Internal medicine	26 (24.8)
Geriatrics	3 (2.9)
Specialty care	52 (49.5)
Oncology	22 (21.0)
Pulmonology	6 (5.7)
Cardiology	16 (15.2)
Gastroenterology	2 (1.9)
Nephrology	6 (5.7)
Patients per clinician, median (IQR)	2 (2)
Randomized to receive intervention	51 (48.6)

Table 3.

Bivariate and multivariate marginal models examining associations with accurate perception of prioritized healthcare goal[a]

Characteristic	Bivariate Models		Multivariate Model	
	OR (95% CI)	p-value	OR (95% CI)	p-value
Patient characteristics				
Age (per year)	**1.023 (1.001, 1.041)**	**0.042**	**1.029 (1.005, 1.051)**	**0.020**
Female	1.020 (0.623, 1.665)	0.938	0.849 (0.504, 1.433)	0.541
Racial or ethnic minority	1.175 (0.615, 2.248)	0.626	2.230 (0.703, 2.858)	0.330
Education (per level)	0.901 (0.753, 1.073)	0.248	0.868 (0.725, 1.041)	0.120
Prioritized goal was extending life	1.268 (0.633, 2.535)	0.503	2.094 (0.958, 4.572)	0.064
Prioritized goal was stable since enrollment	**1.962 (1.088, 3.525)**	**0.025**	**2.519 (1.262, 5.053)**	**0.009**
Clinician characteristics				
Age (per year)	1.007 (0.980, 1.030)	0.620	1.008 (0.976, 1.041)	0.642
Female	1.047 (0.610, 1.804)	0.867	1.181 (0.642, 2.181)	0.593
Primary Care	1.048 (0.609, 1.804)	0.867	0.861 (0.491, 1.507)	0.603
Communication processes				
Clinician reported occurrence of goals-of-care discussion at index clinic visit	**1.803 (1.061, 3.065)**	**0.029**	**1.783 (1.002, 3.158)**	**0.049**

[a.] Marginal models with logit link, estimation with GEE, independence correlation structure, robust standard errors, and patients clustered under clinicians. Only the listed variables were included in the single multivariate model. Bold items represent exposure variables that met the pre-specified level of statistical significance (p-value <0.05).