

Original Article

A novel Scale to Assess Palliative Care Patients' Experience of Feeling Heard and Understood



Maria O. Edelen, PhD, Anthony Rodriguez, PhD, Wenjing Huang, PhD, Robert Gramling, MD, DSc, and Sangeeta C. Ahluwalia, PhD

Behavioral & Policy Sciences Department, RAND Corporation, Boston, Massachusetts, USA; University of Vermont, Department of Family Medicine, Burlington, Vermont; Behavioral & Policy Sciences Department, RAND Corporation, Santa Monica, California, USA

Abstract

Context. Patient experience of palliative care serves as an important indicator of quality and patient-centeredness.

Objectives. To develop a novel patient-reported scale measuring ambulatory palliative care patients' experience of feeling heard and understood by their providers.

Methods. We used self-reported patient experience data collected via mixed-mode survey administration. We conducted an exploratory factor analysis (EFA) and an expert panel ranking exercise to reduce the 10-item set based on underlying dimensionality. We then used item response theory (IRT) to calibrate remaining items based on psychometric properties and test information and precision. We considered item-level fit and examined the standardized local dependence chi-square statistics. We evaluated candidate items for differential item functioning by survey mode. We evaluated the test-retest reliability and validity of the final scale.

Results. The EFA yielded a single factor (9/10 items had loadings > 0.80 on the single factor). We removed two items with the lowest factor loadings and ranked by the expert panel as being least reflective of the overall construct. IRT calibration of the remaining eight items showed high slopes (range 2.66 – 5.18); location parameters were all negative (range -0.90 - -0.36). We removed two more items based on local dependence indices and item-level fit. Combining psychometric information with the expert ratings we established the final 4-item scale, which was reliable (Cronbach's alpha = 0.84; polychoric correlation coefficient = 0.72) and had good convergent validity.

Conclusions. This novel multi-item Feeling Heard and Understood scale can be used to measure and improve ambulatory palliative care patient experience. *J Pain Symptom Manage* 2022;63:689–697. © 2022 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

Key Words

Patient experience, outpatient palliative care, communication, survey methods, item response theory

Key Message

This article describes the development of a novel patient-reported measure palliative care patients' experience of feeling heard and understood by their providers. Combining psychometric methods with expert input we finalized a 4-item scale demonstrating strong reliability and validity that could be used in accountability programs to improve ambulatory palliative care.

Introduction

Palliative care has expanded rapidly in the past two decades to meet the needs of patients with serious

illness,^{1,2} with a concurrent emphasis on the systematic measurement of palliative care quality. Quality measure information can help patients distinguish between and choose providers, guide improvement efforts, and incentivize better care. For palliative care, measuring patient experience is central to understanding quality, given the highly interpersonal and interactional nature of palliative care and the emotionally difficult context within which palliative care is often provided. Patients may struggle to accept their prognosis, feel anxious, isolated, and distressed, and experience profound losses of capabilities, time, and connection.³⁻⁶ Palliative care offers necessary physical, emotional, and spiritual

Address correspondence to: Sangeeta C. Ahluwalia, PhD, Behavioral & Policy Sciences Department, RAND Corporation, 1776 Main Street, Santa Monica, CA 90401, USA. E-mail: sahluwal@rand.org

Accepted for publication: 4 January 2022.

support to help patients navigate these challenges^{2,7} and a patient's experience of this process is a crucial indicator of the quality of care. This is especially relevant in ambulatory settings, where palliative care can complement treatment-focused care from the time of diagnosis with specialized symptom management, advance care planning, and psychosocial support.

Evidence suggests there is opportunity to improve the quality of ambulatory palliative care. Patients with serious illness often report feeling "silenced, ignored, and misunderstood" in medical institutions.⁸⁻¹⁰ Many patients with serious illness experience inadequate communication from their health care providers about prognosis and treatment options¹¹⁻¹⁴ and receive care that is not consistent with their preferences.¹⁵⁻¹⁸ Palliative care providers play a critical role in assuring that patients with serious illness are treated with dignity and respect, and are seen, heard, and valued.¹⁹ Feeling heard and understood is a complex and multi-faceted construct that relates to being seen, acknowledged, treated with dignity, and cared for as a whole person. It is central to achieving goal-concordant care,^{20,21} relief of suffering,²²⁻²⁶ and dignity at the end of life.^{27,28} Systematically measuring, reporting, and responding to how well patients feel heard and understood can improve communication about prognosis and treatment options and adherence to the treatment plan and is crucial to sustaining a health care environment that excels in serious illness care.^{8,28}

Simple and reliable quality measures assessing whether a patient feels heard and understood by their outpatient palliative care providers are lacking. Existing measures are often narrowly focused on communication behaviors and outcomes (e.g., information giving and receiving) rather than on important relational aspects of the overall interaction.²⁹ Measures of therapeutic alliance^{30,31} allude to the construct of feeling heard and understood, e.g., by evaluating whether the physician listens to and understands the patient; but also measure other aspects of the physician-patient bond, which could limit their portability across quality measurement contexts. Moreover, such measures typically assess the patient's perception of the provider's behavior, i.e., whether the provider listened to the patient, rather than the patient's experiential outcome, i.e., whether the patient felt heard and understood.

Prior work has established that a single item assessing feeling heard and understood after inpatient palliative care consultation is a promising self-report quality measure.⁸ However, this item has not been evaluated in ambulatory clinic settings, where lower illness-related distress, death anxiety, and acuity of decision-making might allow for more comprehensive patient-reported assessment. Compared to a single item, a multi-item scale may more reliably reflect the various facets of feeling heard and understood while offering

greater sensitivity to smaller, yet clinically important, change. A reliable measure of feeling heard and understood could be used in accountability programs to incentivize and improve ambulatory palliative care. We sought to develop and test a novel patient-reported scale to measure ambulatory palliative care patients' feelings of being heard and understood by their providers.

Methods

Overview

This study was part of a larger national study funded by the Centers for Medicare & Medicaid Services (CMS) to develop patient-reported outcome measures for use in quality payment and improvement programs (Cooperative Agreement No. 1V1CMS331639-01-00). Here we describe the testing and initial validation of the Feeling Heard and Understood patient-reported scale, a multi-item scale designed to assess patients' interrelated experiences of communication, interpersonal trust, respect, acknowledgment, and therapeutic alliance with their ambulatory palliative care provider and team. We previously identified 10 candidate patient-reported items for testing through a combination of published literature and quality measure searches, patient, caregiver, and provider focus group input, and expert panel ratings, that were determined to reflect aspects of feeling heard and understood.³² Nine of the 10 items were used verbatim or with small wording changes to align with the ambulatory palliative care setting; a single item was constructed *de novo* based on expert panel input [Table 1]. Using these 10 candidate items we conducted a field test and psychometric analyses to identify the best subset of items to efficiently assess patients' experiences of feeling heard and understood by their palliative care provider and team. The study was reviewed and approved by the RAND Human Subjects Protection Committee.

Sampling

Our sample included all patients aged 18 years or older currently receiving ambulatory clinic-based palliative care from one of 44 programs participating in the larger quality measure development study. These programs were purposively sampled from databases maintained by the Center to Advance Palliative Care (CAPC) to ensure representation based on administrative affiliation (i.e., hospice, hospital, ambulatory, and other affiliation) and by geographic location (i.e., U.S. Census Regions). Further details regarding program recruitment and sampling procedures are described elsewhere.³³ As per the design for the larger study, eligible patients were sent a patient experience survey within 6 months of an outpatient palliative care visit with an

Table 1
Description and Source of the 10 Feeling Heard and Understood Candidate Items

Data Element	Construct Related to Feeling Heard and Understood	Source/Adapted From
Q12: I felt heard and understood by this provider and team.	Feeling heard and understood	Gramling, Robert et al. "Feeling Heard and Understood: A Patient-Reported Quality Measure for the Inpatient Palliative Care Setting." <i>Journal of pain and symptom management</i> vol. 51,2 (2016): 150-4. doi:10.1016/j.jpainsymman.2015.10.018
Q13: I felt comfortable asking this provider and team questions.	Therapeutic Alliance	Mack, Jennifer W et al. "Measuring therapeutic alliance between oncologists and patients with advanced cancer: the Human Connection Scale." <i>Cancer</i> vol. 115,14 (2009): 3302-11. doi:10.1002/cncr.24360
Q14: I trusted this provider and team.	Trust	Safran, D G et al. "The Primary Care Assessment Survey: tests of data quality and measurement performance." <i>Medical care</i> vol. 36,5 (1998): 728-39. doi:10.1097/00005650-199805000-00012
Q15: I could tell this provider and team anything, even things I might not tell anyone else.	Trust	Safran, Dana Gelb et al. "Measuring patients' experiences with individual primary care physicians. Results of a statewide demonstration project." <i>Journal of general internal medicine</i> vol. 21,1 (2006): 13-21. doi:10.1111/j.1525-1497.2005.00311.x
Q16: I felt this provider and team put my best interests first when making recommendations about my care.	Trust	Safran, Dana Gelb et al. "Measuring patients' experiences with individual primary care physicians. Results of a statewide demonstration project." <i>Journal of general internal medicine</i> vol. 21,1 (2006): 13-21. doi:10.1111/j.1525-1497.2005.00311.x
Q17: I felt this provider and team always told me the truth about my health, even if there was bad news.	Trust	Safran, D G et al. "The Primary Care Assessment Survey: tests of data quality and measurement performance." <i>Medical care</i> vol. 36,5 (1998): 728-39. doi:10.1097/00005650-199805000-00012
Q18: I felt this provider and team saw me as a person, not just someone with a medical problem.	Whole-person orientation; therapeutic alliance	Shi, Leiyou, et al. "Validating the Adult Primary Care Assessment Tool." <i>Journal of Family Practice</i> , vol. 50, no. 2, 2001, p. 161. Accessed 13 Apr. 2021.
Q19: I felt this provider and team knew what worried me most about my health.	Whole-person orientation	Mack, Jennifer W et al. "Measuring therapeutic alliance between oncologists and patients with advanced cancer: the Human Connection Scale." <i>Cancer</i> vol. 115,14 (2009): 3302-11. doi:10.1002/cncr.24360
Q20: I felt this provider and team understood what is important to me in my life.	Whole-person orientation	Safran, D G et al. "The Primary Care Assessment Survey: tests of data quality and measurement performance." <i>Medical care</i> vol. 36,5 (1998): 728-39. doi:10.1097/00005650-199805000-00012
Q21: I felt this provider and team would know what I would want done if I was unconscious or in a coma.	Values alignment	Shi, Leiyou, et al. "Validating the Adult Primary Care Assessment Tool." <i>Journal of Family Practice</i> , vol. 50, no. 2, 2001, p. 161. Accessed 13 Apr. 2021.
		New

eligible provider including physicians and physician-designees, advanced practice nurses, therapists, and clinical psychologists. Greater detail regarding visit eligibility criteria, reference, or "lookback" timeframe, and survey fielding timeframes, are reported elsewhere.³³

Data Collection

Data were collected using a mixed-mode survey administration procedure, i.e., web to mail to telephone follow-up. The survey was fielded from November 2019 through February 2021, with a pause in data collection between April and September 2020 due to the COVID-19 pandemic. The survey oriented the respondent to the eligible palliative care provider and team with an initial question: "Our records show that you got care from the provider and team named below in the last 6 months [Provider Name and team]. Is that right?" with a Yes/No response option. Affirmative responses were then provided additional orientation: "The questions in this survey will refer to the provider

named in Question 1 as "this provider and team". Please think of this provider and team as you answer the survey". Negative responses were skipped to the end of the survey. The survey included the 10 Feeling Heard and Understood candidate items, questions to assess validity of the potential multi-item scale related to patient experiences with communication (four-item Clinician and Group Consumer Assessment of Healthcare Providers and Systems [CG CAHPS®] communication measure¹), emotional support, pain management, and overall care. The instrument also included questions about general physical and mental health,³⁴ mood,³⁵ cognition,³⁶ and demographics (age, gender, race/ethnicity, education).

The mixed-mode procedure included an initial mailed pre-notification letter to inform patients of the study and upcoming survey, with a link to a web-based survey.³⁷ This was followed within a week by a mailed survey (See Appendix A). If the mailed survey was not returned within three weeks, up to eight attempts were

made to contact the patient by telephone and complete the survey via computer-assisted telephone interview (CATI) before the patient was considered a “non-response.” A subset of patient respondents by phone ($N = 437$) were randomly selected for a test-retest analysis. Out of this subset of 437 phone respondents, 235 patients (54%) were successfully reached by phone within 2 days and asked the candidate Feeling Heard and Understood items again.

Candidate Items

All 10 candidate Feeling Heard and Understood items were asked in reference to care received by the patient from their ambulatory palliative care provider and team, i.e., the named eligible provider and associated interdisciplinary palliative care team. All items were assessed using a 5-point response scale (1 *completely true*, 2 *very true*, 3 *somewhat true*, 4 *a little bit true*, 5 *not at all true*) and responses were reverse-coded for analyses so that higher scores were indicative of feeling increasingly more heard and understood. Response frequency distributions for the 10 Feeling Heard and Understood items are displayed in [Supplementary Table 1](#). As with other patient satisfaction measures,³⁸ there was a strong tendency for patients to endorse the highest response category; in consultation with the project expert advisor group, we elected to collapse the responses so that item scores = 1 if the response was *completely true*, and = 0 otherwise.

Analyses

We first sought to evaluate and reduce the item set based on examination of the underlying dimensionality through an Exploratory Factor Analysis (EFA) using Mplus.³⁹ Model fit was evaluated using standard criteria including the Root Mean Square Error of Approximation (RMSEA; values < 0.06 are generally considered good fit), the Comparative Fit Index (CFI) and Tucker-Lewis index (TLI) with values of these two indices >0.95 indicating a very good model fit.⁴⁰ To further inform EFA findings and ensure face validity of a condensed item set, we also conducted an item ranking exercise. Fourteen members of the parent project’s technical expert panel, consisting of palliative care clinicians, measure developers, and psychometricians, were asked to rank the 10 candidate items from one (most representative of “feeling heard and understood”) to 10 (least representative). We calculated the average rank for each item and sorted items in ascending order according to average rank to arrive at a one-10 summary ranking for each item. Items that loaded poorly on the single factor in the EFA and/or were consistently rated lower by experts were removed.

We then calibrated the remaining items using item response theory (IRT) using a unidimensional two-parameter logistic (2PL) model⁴¹⁻⁴³ and the IRTPRO

software⁴⁴ to investigate each candidate item’s psychometric properties (e.g., item parameters) and their functioning together as a test (e.g., test information and precision at different levels of the latent trait). We considered item-level fit based on $S-X^2$ index^{45,46} using a 0.01 significance level to indicate potential misfit and examined the standardized local dependence chi-square statistics⁴⁷ to detect violations of local dependence. We also evaluated the candidate items for differential item functioning (DIF)⁴⁸ or item bias according to survey mode with a two-stage procedure⁴⁹ to test statistical significance. We first evaluated DIF for web vs. mail, then for web and mail vs. phone. In addition to considering the expert rankings of the items as described above, those with stronger psychometric properties and not showing differential item functioning were retained and preferred for creating the scale.

Once the final scale was established, we evaluated test-retest reliability and established preliminary validity by examining scale correlation with the CAHPS Clinician and Group Survey 3.0 provider communication measure and health status variables. We hypothesized that feeling heard and understood and having good patient-clinician communication were related constructs reflective of a larger interpersonal relationship and should thus be positively associated with each other. Finally, we generated scale scores according to patient demographics and health status for descriptive purposes.

Results

Participants

The final sample consisted of 2,804 completed surveys from among the 7,595 patients who were fielded a survey for a response rate of 36.9%. For the purposes of the psychometric analyses in this paper, we elected to exclude 226 patient surveys (8%) that were completed with proxy assistance, resulting in an analytic sample of 2,578. As can be seen in [Table 2](#), the average patient age was 62.7, and the patient sample was 58% female and primarily Non-Hispanic White. Nearly 70% of the sample had at least some college education, and 16% had over a 4-year college degree. Most patients completed the survey by mail (43%) or phone (38%); nearly 20% completed the web survey.

Item Analysis and Reduction

The ten-item EFA yielded strong evidence for a single factor ([Table 3](#)). The fit of the single factor model was good (RMSEA = 0.06, CFI = 0.99, and TLI = 0.99) and 9 of the 10 items had loadings > 0.80 on the single factor (Q21: *I felt this provider and team would know what I would want done if I was unconscious or in a coma had a lower loading*). [Table 3](#) shows the EFA loadings and expert rankings of the 10 items. Considering the EFA

Table 2
Patient Demographic Characteristics

Characteristic	Summary	S.D.	Percent Missing
Number of Observations	N = 2578		
Age (Mean)	62.73	13.08	0.04%
Gender (Male %)	42.03%		0.04%
Race	N=2529		1.90%
White	87.50%		
Black or African American	6.05%		
Asian	0.87%		
Multi-racial	2.93%		
American Indian or Alaska Native	0.47%		
Native Hawaiian or other Pac. Islander	0.20%		
Other	1.98%		
Hispanic	N = 2522		2.18%
Yes, Hispanic or Latino	4.36%		
No, not Hispanic or Latino	95.64%		
Education	N = 2558		0.76%
More than 4-year college degree	16.30%		
4-year college graduate	15.83%		
Some college or 2-year degree	35.42%		
High school graduate or GED	24.98%		
Some high school but did not graduate	6.18%		
8th grade or less	1.29%		
Survey mode	N = 2578		
Mail	43.25%		
Phone	38.01%		
Web	18.74%		

results and expert rankings together, we elected to remove items 15 and 21 from further consideration at this stage.

The IRT calibration of the remaining eight items yielded the item parameters shown in Table 4. All eight items had high slopes (range 2.66 – 5.18) with Q16 (*I felt this provider and team put my best interests first when making recommendations about my care*) having the highest slope. Location parameters, which are interpreted on the scale of the underlying measured construct with mean = 0 and standard deviation = 1, were all negative

Table 4
IRT Parameter Estimates and Diagnostics for Eight Feeling Heard and Understood Items

Item number	Slope (se)	Location (se)	P(S-X ²)	LD pairs
Q12	2.66 (0.14)	-0.58 (.032)	0.04	a
Q13	3.81 (0.23)	-0.74 (.031)	0.00	a
Q14	3.52 (0.21)	-0.90 (.033)	0.04	
Q16	5.18 (0.36)	-0.67 (.028)	0.33	
Q17	3.30 (0.19)	-0.80 (.032)	0.43	
Q18	4.24 (0.27)	-0.80 (.03)	0.02	
Q19	3.98 (0.24)	-0.36 (.027)	0.00	b
Q20	3.97 (0.24)	-0.36 (.027)	0.02	b

(range -0.90 - -0.36), indicating that the items are relatively 'easy' to endorse.

The S-X² indexes for items 13 and 19 displayed significant ($P < 0.01$) misfit to the 2PL model. Further, examination of the local dependence (LD) indices revealed two LD pairs, items 12 and 13, and items 19 and 20. Based on these two diagnostic metrics we elected to remove items 13 and 20 from further consideration.

We examined information functions from the IRT model for various item subsets and determined that a minimum of four items is required to achieve a target reliability ≥ 0.7 across a sufficiently wide range of scores. Combining the psychometric information with the expert ratings, we selected items 12, 16, 18 and 20 to comprise the final four-item Feeling Heard and Understood scale. Item 12 was selected based on its expert rating and preferred content, item 16 was selected because it had the strongest psychometric performance (i.e., highest slope), and items 18 and 20 were selected based on combined performance and rankings. Fig. 1 displays the IRT-based reliability and standard error estimates of the Feeling Heard and Understood scores across the score continuum. The x-axis in this figure represents the range of the IRT-based HU score which is standardized to have a mean of 0 and a standard deviation of 1. The reliability of the score is well above 0.7 across a wide range of the score continuum from 1.6 standard deviations below the mean to 0.8 standard deviations above the mean.

Table 3
Factor Loadings and Expert Rankings for 10 Feeling Heard and Understood Candidate Items

Item Number	Data Elements	EFA Factor Loading	TECUPP Ranking
Q12	I felt heard and understood by this provider and team	0.83	1
Q13	I trusted this provider and team	0.91	4
Q14	I felt comfortable asking this provider and team questions	0.90	5
Q15	I could tell this provider and team anything, even things I might not tell anyone else	0.83	9
Q16	I felt this provider and team put my best interests first when making recommendations about my care	0.94	7
Q17	I felt this provider and team always told the truth about my health, even if there was bad news	0.88	8
Q18	I felt this provider and team saw me as a person, not just someone with a medical problem	0.92	2
Q19	I felt this provider and team knew what worried me most about my health	0.92	6
Q20	I felt this provider and team understood what is important to me in my life	0.92	3
Q21	I felt this provider and team would know what I would want done if I was unconscious or in a coma	0.65	10

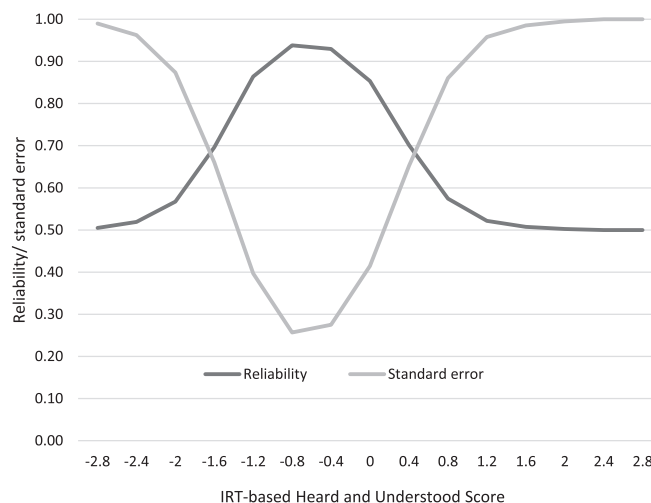


Fig. 1. IRT-based reliability and standard error of final 4-item Feeling Heard and Understood scale.

Characteristics of 4-item HU Scale

Classical test statistics also provide support for the reliability of the observed four-item HU scale scores. Cronbach's alpha for the four-item set was 0.84, and test-retest reliability (i.e., polychoric correlation coefficient) for the HU total score was 0.72. Results of validity testing provide evidence supporting the use of the HU score. As hypothesized, higher scores on the HU scale were associated with higher CAHPS communication scores ($r = 0.45$, $P < 0.001$), greater self-reported physical ($r = 0.09$, $P < 0.001$) and mental ($r = 0.15$, $P < 0.001$) health, and lower self-reported depression ($r = -0.13$, $P < 0.001$) and cognitive function ($r = -0.13$, $P < 0.001$) scores. Taken together, these results support the convergent validity of four-item HU scale.

Discussion

J. Randall Curtis, a palliative care clinician researcher living with ALS recently noted on a GeriPal podcast⁵⁰ that being diagnosed with a serious illness reaffirmed “that what I care most about my providers is that they care about me as a person. . . it is a surprise to me how powerful that is”. A central tenet of palliative care is to care for the person, not the disease, and ensuring that patients feel heard and understood by their palliative care providers can be a useful measure of this patient-centered principle. We developed a novel multi-item scale with strong psychometric properties for measuring ambulatory palliative care patients' experience of feeling heard and understood by their provider and team. This multi-item construct goes beyond existing related palliative care measures of communication and information-giving to assess a more holistic, interpersonal, and relational construct of feeling seen, acknowledged and understood. Measuring and ensuring that palliative care patients feel

heard and understood by their care team sets the foundation for ongoing trust and can help to establish a care plan that is truly patient-centered and preference-concordant. The strong psychometric properties demonstrated by this scale in a nationally representative sample of patients underscores its value and potential for use in quality measurement programs.

An important strength of our study is that we integrated psychometric performance with systematically gathered expert input to ensure the face validity and usability of the final scale. This is particularly important given the number of measurement scales that are developed with strong properties but that have limited use and utility in practice. The design of our study also had several strengths including its large sample size, which is unusual and difficult to obtain in this patient population, our inclusion of useful measures to evaluate validity, and our ability to confirm that the scale behaves similarly across three data collection modes (mail, web, phone). We believe the Feeling Heard and Understood scale can provide important and actionable information to improve the quality of the patient-provider relationship in palliative care, as well as be used to incentivize higher quality care overall when incorporated into pay-for-performance programs.

We developed this multi-item scale specifically for ambulatory, clinic-based settings. Prior work^{8,51} describes the development and use of a single item “feeling heard and understood” measure to assess inpatient palliative care experience and found it to be a useful and promising patient-reported quality measure. Building on this to develop a multi-item measure significantly strengthens its measurement. In addition to being able to compute an estimate of internal consistency reliability, the use of a multi-item scale allows for greater content heterogeneity covering a broader and full range of the construct as well as improving

sensitivity to pre-post change and clinically smaller differences. Moreover, this measure has important utility in outpatient settings, where patients are typically earlier in their disease trajectory and likely to build a longer-term relationship with their palliative care provider and team, allowing more opportunity for quality improvement and improving the patient-provider relationship and trust.

Our work establishes the psychometric strength of a brief patient-reported scale to assess feeling heard and understood. Though our findings support the use of this scale in the context of quality measurement of ambulatory palliative care, future work should focus on understanding optimal implementation of this scale into practice, to improve care for patients with serious illness. For example, identifying feasible ways to administer the patient survey such as via tablet in waiting rooms might increase its use and application, but would require further validation. Evaluating how survey results might be acted upon to improve patient experience; for example, through communication skills training, is another critical research avenue to ensure consistent use of this measure. Importantly, understanding how the experience and reporting of feeling heard and understood varies across cultural and linguistic backgrounds will establish the generalizability of this scale across patient populations and enhance its usability.

Our study has some limitations. We developed and tested this scale using data collected as part of a larger quality measure development effort, which provided us with a large, nationally representative sample of patients. However, based on the limited administrative data we received from participating programs, our sample represented little racial or ethnic diversity, which likely reflects the limited diffusion and accessibility of palliative care across diverse populations generally.⁵² Future studies should consider examining whether there is differential item functioning by race/ethnicity to determine whether the measurement properties are invariant across groups and thus whether racial/ethnic comparisons can be made in terms of feeling heard and understood by palliative care providers and teams. We also did not have consistent or reliable data on other patient characteristics such as diagnosis, which could have impact on item responses. We did not have information on type of visit, e.g., initial vs. established visits and thus could not analyze potential differences in responses relative to an established provider relationship. There is also the possibility for recall bias in patients' reported experiences though we attempted to minimize the length of time between the reference visit and survey fielding by using the most recent eligible visit.

Ensuring that patients feel heard and understood is a central tenet of palliative care and is the foundation

for a trusted patient-provider relationship. Routine use of this scale in ambulatory palliative care practice can generate important insights into patient experiences of feeling heard and understood by their providers and guide improvements in palliative care delivery. Given the strong psychometric properties of this scale, we believe it is a useful measurement tool for use in accountability initiatives and publicly reported performance programs. It might also be considered for broader use among seriously ill patients in other ambulatory settings. Future work might examine its ability to distinguish performance between ambulatory palliative care programs.

Disclosures

This work was supported by the Centers for Medicare and Medicaid Services under a cooperative agreement referred to as the "Palliative Care Measures Project." The cooperative agreement number is [1V1CMS331639-01-00](#). The authors have no conflicts of interest, financial or otherwise, to disclose.

References

1. Ahluwalia SC, Chen C, Raaen L, et al. A systematic review in support of the national consensus project clinical practice guidelines for quality palliative care, Fourth Edition. *J Pain Symptom Manage* 2018;56:831–870.
2. Kavalieratos D, Corbelli J, Zhang D, et al. Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. *Jama* 2016;316:2104–2114.
3. Gramling R, Stanek S, Han PKJ, et al. Distress due to prognostic uncertainty in palliative care: frequency, distribution, and outcomes among hospitalized patients with advanced cancer. *J Palliat Med* 2018;21:315–321.
4. Gramling R, Straton J, Ingersoll LT, et al. Epidemiology of fear, sadness, and anger expression in palliative care conversations. *J Pain Symptom Manage* 2021;61:246–253.
5. Tarbi EC, Gramling R, Bradway C, Broden EG, Meghani SH. "I Had a Lot More Planned": the existential dimensions of prognosis communication with adults with advanced cancer. *J Palliat Med* 2021;24:1443–1454.
6. Schneider E, Abrams M, Shah A, Lewis C, Shah T. Health care in America: the experience of people with serious illness. The Commonwealth Fund; 2018.
7. Quinn KL, Shurrab M, Gitau K, et al. Association of receipt of palliative care interventions with health care use, quality of life, and symptom burden among adults with chronic noncancer illness: a systematic review and meta-analysis. *Jama* 2020;324:1439–1450.
8. Gramling R, Stanek S, Ladwig S, et al. Feeling heard and understood: a patient-reported quality measure for the inpatient palliative care setting. *J Pain Symptom Manage* 2016;51:150–154.
9. Frosch DL, May SG, Rendle KAS, Tietbohl C, Elwyn E. Authoritarian physicians and patients' fear of being labeled

- 'difficult' among key obstacles to shared decision making. *Health Affairs* 2012;31:1030–1038.
10. Committee on Approaching Death: Addressing Key End of Life Issues. Dying in America: improving quality and honoring individual preferences near the end of life. Institute of Medicine. Washington (DC): National Academies Press (US) Copyright 2015 by the National Academy of Sciences; 2015 All rights reserved.
11. Lakin JR, Block SD, Billings JA, et al. Improving communication about serious illness in primary care: a review. *JAMA Intern Med* 2016;176:1380–1387.
12. Rosenberg LB, Greenwald J, Caponi B, et al. Confidence with and barriers to serious illness communication: a national survey of hospitalists. *J Palliat Med* 2017;20:1013–1019.
13. Bernacki RE, Block SD. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med* 2014;174:1994–2003.
14. Anderson RJ, Bloch S, Armstrong M, Stone PC, Low JT. Communication between healthcare professionals and relatives of patients approaching the end-of-life: a systematic review of qualitative evidence. *Palliat Med* 2019;33:926–941.
15. Bennett F, O'Conner-Von S. Communication Interventions to improve goal-concordant care of seriously ill patients: an integrative review. *J Hosp Palliat Nurs* 2020;22:40–48.
16. Sanders JJ, Curtis JR, Tulskey JA. Achieving goal-concordant care: a conceptual model and approach to measuring serious illness communication and its impact. *J Palliat Med* 2018;21(S2):S17–S27.
17. Khandelwal N, Curtis JR, Freedman VA, et al. How often is end-of-life care in the United States inconsistent with patients' goals of care? *J Palliat Med* 2017;20:1400–1404.
18. Teno JM, Freedman VA, Kasper JD, Gozalo P, Mor V. Is care for the dying improving in the United States? *J Palliative Med* 2015;18:662–666.
19. Staudt C. Whole-person, whole-community care at the end of life. *AMA J Ethics* 2013;13:1069–1080.
20. Elwyn G, Lloyd A, May C, et al. Collaborative deliberation: a model for patient care. *Patient Educ Couns* 2014;97:158–164.
21. Epstein RM, Street Jr RL. Patient-centered communication in cancer care: promoting healing and reducing suffering. 2007.
22. Boston P, Bruce A, Schreiber R. Existential suffering in the palliative care setting: an integrated literature review. *J Pain Symptom Manage* 2011;41:604–618.
23. Krikorian A, Limonero JT, Maté J. Suffering and distress at the end-of-life. *Psychooncology* 2012;21:799–808.
24. Wachholtz AB, Fitch CE, Makowski S, Tjia J. A comprehensive approach to the patient at end of life: assessment of multidimensional suffering. *South Med J* 2016;109:200–206.
25. Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med* 1982;306:639–645.
26. Cassell EJ. Diagnosing suffering: a perspective. *Ann Intern Med* 1999;131:531–534.
27. Houmann LJ, Chochinov HM, Kristjanson LJ, Petersen MA, Groenvold M. A prospective evaluation of dignity therapy in advanced cancer patients admitted to palliative care. *Palliat Med* 2014;28:448–458.
28. Chochinov HM, McClement S, Hack T, et al. Eliciting personhood within clinical practice: effects on patients, families, and health care providers. *J Pain Symptom Manage* 2015;49:974–980.
29. Lendon JP, Ahluwalia SC, Walling AM, et al. Measuring experience with end-of-life care: a systematic literature review. *J Pain Symptom Manage* 2015;49:904–915.
30. Mack JW, Block SD, Nilsson M, et al. Measuring therapeutic alliance between oncologists and patients with advanced cancer: the Human connection scale. *Cancer* 2009;115:3302–3311.
31. Mack JW, Nilsson M, Balboni T, et al. Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE): validation of a scale to assess acceptance and struggle with terminal illness. *Cancer* 2008;112:2509–2517.
32. Chen EK, Ahluwalia SC, Shetty K, et al. Development of Palliative Care Quality Measures for Outpatients in a Clinic-Based Setting: A Report on Information Gathering Activities: RAND Corporation; 2020.
33. Ahluwalia SC, Vegetabile BG, Edelen MO, et al. MACRA palliative care quality measure development testing summary report: measure name: feeling heard and understood. Santa Monica, CA: RAND Corporation; 2021.
34. Hays RD, Spritzer KL, Thompson WW, Cella DUS. General population estimate for "Excellent" to "Poor" self-rated health item. *J Gen Intern Med* 2015;30:1511–1516.
35. Gilbody S, Richards D, Brealey S, Hewitt C. Screening for depression in medical settings with the Patient Health Questionnaire (PHQ): a diagnostic meta-analysis. *J Gen Intern Med* 2007;22:1596–1602.
36. Fieo R, Ocepek-Welikson K, Kleinman M, et al. Measurement equivalence of the patient reported outcomes measurement information system[®] (PROMIS[®]) applied cognition - general concerns, short forms in ethnically diverse groups. *Psychol Test Assess Model* 2016;58:255–307.
37. Dillman DA, Smyth JD, Christian LM. Internet, phone, mail, and mixed-mode surveys: the tailored design method. John Wiley & Sons; 2014.
38. Mercer LM, Tanabe P, Pang PS, et al. Patient perspectives on communication with the medical team: Pilot study using the communication assessment tool-team (CAT-T). *Patient Educ Counsel* 2008;73:220–223.
39. Muthén LK, Muthén BO. Mplus: Statistical Analysis with Latent Variables: User's Guide (Version 8). Los Angeles, CA.
40. Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria vs. new alternatives. *Structural Equation Modeling: A Multidisciplinary J* 1999;6:1–55.
41. Hambleton RK, Swaminathan J, Rogers HF. Fundamentals of item response theory. Newbury Park, CA: Sage; 1991.
42. Lord FM. Applications of item response theory to practical testing problems. Hillsdale, NJ: Lawrence Erlbaum; 1980.
43. Lord FM, Novick MR. Statistical theories of mental test scores (with contributions by A. Birnbaum). Reading, MA: Addison-Wesley; 1968.
44. Cai L, Thissen D, du Toit SHC. IRTPRO for Windows [Computer Software]. Lincolnwood, IL: Scientific Software International; 2011.

45. Orlando M, Thissen D. Likelihood-based item-fit indices for dichotomous item response theory models. *Appl Psychol Meas* 2000;24:50–64.
46. Orlando M, Thissen D. Further investigation of the performance of S - X2: an item fit index for use with dichotomous item response theory models. *Appl Psychol Meas* 2003;27:289–298.
47. Chen W-H, Thissen D. Local dependence indexes for item pairs using item response theory. *J Educ Behav Stat* 1997;22:265–289.
48. Thissen D, Steinberg L, Wainer H. Detection of differential item functioning using the parameters of item response models. *Differential item functioning*. Hillsdale, NJ, US: Lawrence Erlbaum Associates, Inc; 1993. p. 67–113.
49. Edelen MO, Stucky BD, Chandra A. Quantifying ‘problematic’ DIF within an IRT framework: application to a cancer stigma index. *Qual Life Res* 2015;24:95–103.
50. Widera E, Smith A. GeriPal PodCast. Episode 187: Living with and studying serious illness: Podcast with Randy Curtis; 2021.
51. Ingersoll LT, Saeed F, Ladwig S, et al. Feeling heard and understood in the hospital environment: benchmarking communication quality among patients with advanced cancer before and after palliative care consultation. *J Pain Symptom Manage* 2018;56:239–244.
52. Johnson KS. Racial and ethnic disparities in palliative care. *J Palliat Med* 2013;16:1329–1334.

Supplemental Table 1
Response Frequencies of the 10 Feeling Heard and Understood candidate items

Item Number	Item Content	Not at All True	A Little Bit True	Somewhat True	Very True	Completely True
Q12	I felt heard and understood by this provider and team	49 (1.9%)	41 (1.6%)	124 (4.9%)	577 (22.7%)	1753 (68.9%)
Q13	I trusted this provider and team	23 (0.9%)	33 (1.3%)	103 (4.0%)	469 (18.4%)	1919 (75.3%)
Q14	I felt comfortable asking this provider and team questions	23 (0.9%)	29 (1.1%)	89 (3.5%)	389 (15.3%)	2016 (79.2%)
Q15	I could tell this provider and team anything, even things I might not tell anyone else	83 (3.3%)	68 (2.7%)	272 (10.8%)	603 (23.9%)	1500 (59.4%)
Q16	I felt this provider and team put my best interests first when making recommendations about my care	31 (1.2%)	33 (1.3%)	124 (4.9%)	465 (18.3%)	1890 (74.3%)
Q17	I felt this provider and team always told the truth about my health, even if there was bad news	26 (1.0%)	28 (1.1%)	105 (4.2%)	430 (17.1%)	1930 (76.6%)
Q18	I felt this provider and team saw me as a person, not just someone with a medical problem	24 (0.9%)	40 (1.6%)	106 (4.2%)	406 (15.9%)	1974 (77.4%)
Q19	I felt this provider and team knew what worried me most about my health	39 (1.5%)	31 (1.2%)	214 (8.4%)	648 (25.5%)	1608 (63.3%)
Q20	I felt this provider and team understood what is important to me in my life	41 (1.6%)	37 (1.5%)	220 (8.7%)	635 (25.0%)	1605 (63.2%)
Q21	I felt this provider and team would know what I would want done if I was unconscious or in a coma	190 (7.7%)	68 (2.8%)	353 (14.4%)	560 (22.8%)	1288 (52.4%)