Measuring Goal-Concordant Care in Palliative Care Research

Natalie C. Ernecoff PhD, MPH, Kathryn L. Wessell MPH, Antonia V. Bennett PhD, and Laura C. Hanson MD, MPH

Division of General Internal Medicine (N.C.E.), University of Pittsburgh School of Medicine, Pittsburgh, PA, USA; Cecil G. Sheps Center for Health Services Research (K.L.W., L.C.H.), University of North Carolina at Chapel Hill, NC, USA; Department of Biostatistics (A.V.B.), Gillings School of Global Public Health, University of North Carolina at Chapel Hill, NC, USA; Division of Geriatric Medicine and Palliative Care Program (L.C.H.), University of North Carolina at Chapel Hill, NC, USA

Abstract

>*Goal-concordant care is a priority outcome for palliative care research, yet the field lacks consensus on optimal methods for measurement. We sought to 1) categorize methods used to measure goal-concordant care, and 2) discuss strengths and limitations of each method using empirical examples from palliative care research. We categorized measurement methods for goal-concordant care. We identified empirical examples of each method to illustrate the strengths, limitations, and applicability of each method to relevant study designs. We defined four methods used to measure goal-concordant care: 1) Patient- or Caregiver-Reported, 2) Caregiver-Reported After Death, 3) Concordance in Longitudinal Data, and 4) Population-Level Indicators. Patient or caregiver-reported goal-concordant care draws on strengths of patient-reported outcomes, and can be captured for multiple aspects of treatment; these methods are subject to recall bias or family-proxy bias. Concordance in longitudinal data is optimal when a treatment preference can be specifically and temporally linked to actual treatment; the method is limited to common life-sustaining treatment choices and validity may be affected by temporal variation between preference and treatment. Population-level indicators allow pragmatic research to include large populations; its primary limitation is the assumption that preferences held by a majority of persons should correspond to patterns of actual treatment in similar populations. Methods used to measure goal-concordant care have distinct strengths and limitations, and methods should be selected based on research question and study design. Existing methods could be improved, yet a future gold standard is unlikely to suit all research designs.* J Pain Symptom Manage 2021;62:e305−e314. © 2021 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

EDITOR'S NOTE   *David Casarett, MD, MA*

This review article summarizes what is known about various approaches to measuring goal-concordant care, and identifies important gaps and questions that should be the focus of future research.

Key Message

This article defines four key descriptive categories of methods used to measure goal-concordant care in palliative care research and discusses strengths and weaknesses of each method.

Introduction

Outcome measurement science is an emerging aspect of palliative and end-of-life care research, addressing critical gaps that limit the evidence base for clinical practice.[1] Investigators have developed and validated numerous

measurement instruments for patient and caregiver-reported outcomes, as demonstrated in indexing of these tools by the Palliative Care Research Cooperative (PCRC) group.[2,3] In a recent Delphi consensus process, a large panel of experts identified goal-concordant care as the highest priority outcome for advance care planning.[4]

Investigators have acknowledged a range of conceptual and practical challenges to measuring goal-concordant care. Turnbull and Hartog described measurement methods for ICU care, noting that measurement may require data on patient goals and treatment preferences at multiple time points, and subsequent measurement of receipt or withholding of preference-sensitive treatments.[5] They note challenges to validity including family members who feel unprepared or uncertain of goals, recall bias, social desirability bias in retrospective assessment of goal-concordant care, and poor agreement among clinicians on treatment concordant with goals. Examining goal-concordant care more broadly, Sanders et al. outlined a conceptual framework that proposes causal links between communication quality, goal-concordant care, and other outcomes.[6] Halpern described important conceptual barriers, including the need to establish baseline patient goals, capture data on change of patient goals over time, and difficulties aligning goals with patient treatment experience.[7] Experts have recognized that expressed goals may be aspirational but not realistic, yet this distinction is rarely made.[8] While individual investigators have operationalized goal-concordant care in specific research studies, the field lacks consensus on a "gold standard" or optimal method for its measurement.[9–11]

Acknowledging these challenges, we sought to define optimal methods currently used to measure goal-concordant care. Our objectives were: To 1) categorize methods used to measure goal-concordant care, and 2) discuss strengths and limitations of each method using empirical examples from palliative care research.

Methods

Methods Used to Measure Goal-Concordant Care
We first defined descriptive categories of methods used to measure goal-concordant care.[6,12] We characterized each method based on data sources of goals of care (e.g., patient report, family caregiver report, written directives, population survey), data sources of treatments (e.g., patient report, family caregiver report, healthcare record or administrative data), and timing and method for data capture. We identified four descriptive categories of measurement methods based on these characteristics.

Empiric Examples of Research Measuring Goal-Concordant Care
In conjunction, two researchers (N.C.E., K.L.W.) then conducted a targeted literature review to identify empirical examples of each of the four measurement methods for goal-concordant care. We began by searching PubMed and Scopus using the search terms "goal-concordant care," "concordance," and "care consistency." We augmented this review with further search of reference citations in conceptual literature.[6] We included literature searches, expert recommendations, and theory papers. We excluded background papers, and papers containing only utilization outcomes. We used this search to identify published examples of research studies with an operational definition for measuring goal-concordant care. We used these examples to illustrate strengths and limitations of each of the four methods.

Results

We identified 54 papers. After assessing for exclusion criteria, 36 were included for full review. We identified four categories of methods used to measure goal-concordant care: 1) Patient- or Family Caregiver-Reported, 2) Family Caregiver-Reported After Death, 3) Concordance in Longitudinal Data, and 4) Population-Level Indicators. Since research demonstrates a gap between goals defined by patients and those defined by surrogate decision-makers such as family members, we sub-divided the first category based on patient vs surrogate reporting. The temporality of the data sources for each method is illustrated in Fig. 1. Empirical examples of each method are presented in Table 1.
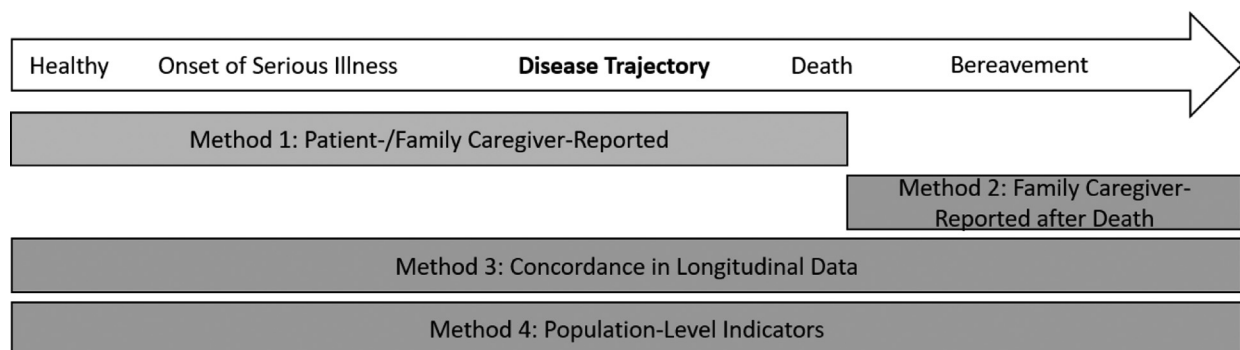

Fig. 1. Temporality of data sources for each method for measuring goal-concordant care.

Empiric Examples of Methods for Measuring Goal-Concordant Car

Examples	Data Source: Patient Goals	Data Source: Treatment	Variables of Interest and Primary Findings
Method 1: Patient-/Family Caregiver-Reported			
Curtis et al: Effect of a Patient and Clinician Communication-Priming Intervention on Patient-Reported Goals-of-Care Discussions between Patients with Serious Illness and Clinicians[45]	Patient and family caregiver questionnaire (baseline)	Patient questionnaire (2 weeks, 3 months, and 6 months post-target visit) Family caregiver questionnaire (3 and 6 months post-target visit)	Two questions assessing patient perception of goal-concordant care: 1. "If you had to make a choice at this time, would you prefer a plan of medical care that focuses on extending life as much as possible, even if it means having more pain and discomfort, or would you want a plan of medical care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?" 2. The second question assesses patients' perceptions of their current treatment with the same choices.[46] **Primary finding:** Among patients with stable goals at 3-month follow-up, the proportion of goal-concordant care in the intervention group was significantly higher than in control. (73% vs 57%; $p = 0.03$), but not among those who did not have stable goals over time.
Hanson et al: Effect of the Goals of Care Intervention for Advanced Dementia: A Randomized Clinical Trial[47]	Family caregiver interviews (baseline, 3, 6, 9 months, and after death)	Family caregiver interviews (baseline, 3, 6, 9 months, and after death)	1. Family decision maker's perception of concordance with clinician on primary goal guiding the care of the nursing resident with dementia. 2. Items from the Advance Care Planning Problem Score, modified from the Toolkit After-Death Bereaved Family Member Interview.[48] **Primary finding:** Family caregivers in the intervention group reported greater concordance by the final interview (88.4% vs 71.2%, P = .001).
Johnson et al: A Randomised Controlled Trial of an Advance Care Planning Intervention for Patients with Incurable Cancer[49]	Patient and family caregiver questionnaire (baseline, 6 weeks, and 3-month intervals until patient death)	Family bereavement interview (3-months after death)	1. Family member report that the patient's end-of-life wishes were adequately discussed with the family respondent. 2. Family member's satisfaction that patient's end-of-life wishes were met **Primary finding:** There were no significant differences in the proportion of goal-concordant care between intervention and control groups (43% vs. 33%, $p = 0.27$).
Method 2: Family Caregiver-Reported after Death			
Addington-Hall et al: A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire[50]	Family bereavement interview (3-9 months after death)	Family bereavement interview (3-9 months after death)	Family report of treatment decisions made that the deceased patient would not have wanted. **Primary finding:** There was not a significant difference in treatments decisions made that the patient would not have wanted in hospital versus hospice groups (21.4% vs. 10.7%; p=0.25).
Khandelwal et al: How Often Is End-of-Life Care in the United States Inconsistent with Patients' Goals of Care?[26]	National Health and Aging Trends Study (NHATS) last month of life interview	National Health and Aging Trends Study (NHATS) last month of life interview	Family report of treatment or care decisions that were not consistent with patient's wishes. **Primary finding:** 13% of bereaved family caregivers reported care that was inconsistent with the patient's wishes.
Method 3: Concordance in Longitudinal Data			
Hopping-Winn et al: The Progression of End-of-Life Wishes and Concordance with End-of-Life Care[51] (POLST)	Physician's Order for Life-Sustaining Treatment (POLST) form	Electronic health record (EHR) review	Concordance between the code status and medical intervention category (full treatment, selective treatment, or comfort-focused treatment) indicated on the POLST form and the care the patient rec **Primary finding:** Among cases where concordance was able to be assessed, 99% of reviews showed concordance between preferences and care received.

Table 1
Continued

Examples	Data Source: Patient Goals	Data Source: Treatment	Variables of Interest and Primary Findings
Song et al: Determining Consistency of Surrogate Decisions and End-of-Life Care Received with Patient Goals-of-Care Preferences[27]	Written goals-of-care tool and surrogate bereavement interview (two weeks after death)	Medical record review and surrogate bereavement interview (two weeks after death)	1. Concordance between the patient's written preferences and treatment received at the end-of-life. If the patient was able to participate in decision making: 2. Concordance between patient's written and verbally stated preferences/decisions at end-of-life. 3. Concordance between the patient's and treatment decisions. 4. Concordance between patient's verbally stated preferences and care received at end-of-life. If the patient was unable to participate in decision making. 5. Concordance was between patient's written preferences and treatment decisions made by the surrogate. **Primary finding:** 53.3% of patients received care concordant with their written preferences. Concordance was higher when patients were able to participate in decision making at the end of life (81%).
Ernecoff et al: Concordance between Goals of Care and Treatment Decisions for Persons with Dementia[52]	Family caregiver interviews (baseline, and 9 months or after death)	Family caregiver interviews (baseline, and 9 months or after death)	1. Family decision maker's perception of concordance with nursing home (NH) staff on primary goal guiding the care of the nursing resident with dementia. 2. A question from the Advance Care Planning Problem Score, modified from the Toolkit After-Death Bereaved Family Member Interview addressing goal-concordant treatment.[48] **Primary finding:** Family caregiver report of goal concordance with NH staff improved from baseline to the final interview (49% vs. 69%).
Method 4: Population-Level Indicators			
Pivodic et al Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries[14]	Population surveys	Death certificate data	Place of death, based on previous studies indicating home is the preferred place of death for most people[15] **Primary finding:** Between 53% (Mexico) and 13% (Canada) of deaths occurred at home.
Teno et al: Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009[34]	Population surveys	Medicare Part A and Part B claims and the Residential History File	Place of death, based on surveys indicating the majority of respondents with serious illness prefer to die at home.[53,54] Burdensome transitions defined as transitions in the last 3 days of life and/or 3 or more hospitalizations in the last 90 days of life.[55] **Primary finding:** There was a trending increase in the proportion of Medicare decedents who died at home (30.7% to 33.5%), had at least 1 transition in the last 3 days of life (10.3% to 14.2%), and had 3 or more hospitalizations in the last 90 days of life (10.3% to 11.5%) 2000 and 2009 respectively.

Methods to Measure Goal-Concordant Care

Method 1: Patient-/Family Caregiver-Reported.

(a) *Patient-Reported:* This method for measuring goal-concordant care allows patients to report how well current care or care within a specific reference period is or was concordant with their goals, *or* to report their confidence that future care will reflect goals and values. In this method, goals and treatments are being asked about at the same time, and both are either retrospective or prospective. Because this method is specifically *patient*-reported, it requires that the data source be patient survey or interview while living with serious illness. The researcher may know, but does not need to know, *which* goals or treatments the patient is considering, just *whether* they perceived their care to be concordant with their goals.

(b) *Family Caregiver-Reported:* Similar to Patient-Reported Goal-Concordant Care, this method addresses goal-concordant care for patients who are alive but lack capacity to self-report on goal-concordant care. Family Caregiver-Reported Goal-Concordant Care allows family caregivers or closely involved surrogate decision-makers to report how well current care or care within a specific reference period is or was concordant with patient goals, *or* to report their level of confidence that future care will reflect patient goals and values. Again, goals and treatments are being asked about at the same time: both are either retrospective or prospective.

Method 2: Family Caregiver-Reported After Death. Family caregiver-reported goal-concordant care after a patient's death is used to address care during the dying process. This method, conceptually, uses a reference period looking back from the time of a patient's death, and can be used to assess, for example, quality of care during active dying or the final phase of a serious illness. In these cases, family members report the degree to which they believe that care before death, including at the end of life, reflected patient's goals and values.

Method 3: Concordance in Longitudinal Data.
Concordance between stated goals and subsequent treatment is a measure that maps treatments received onto previously expressed preferences. In this category of measurement, the statement of goals occurs chronologically before the treatment is received. The data source for goals and preferences must represent the patient perspective, but could include a written advance directive, documentation of stated preferences in the healthcare record, patient response in a survey or interview, or surrogate response in a survey or interview. Data about treatments may also come from varied

sources such as patient report, surrogate report, healthcare records, or administrative data. Statements of preferences or goals from these data sources will then require a systematic and reproducible process by which investigators map treatments received as concordant or discordant with expressed preferences.

Method 4: Population-Level Indicators. Population-level indicators of goal-concordant care use aggregate-level survey data on prevalent goals, compared to treatments received by a similar population. For example, in population surveys, a majority of people report a preference to die at home over a clinical setting; this population-level data on preferences can be compared to population-level data on actual site of death.[13-15] As another example, robust research have identified other preferences during serious illness such as relief from pain and assurance of personal cleanliness; these preferences can be compared to the frequency of effective pain treatment or attention to personal care during active dying.[16] For population-level studies, both the data source and the population for goals (e.g., survey in a comparable population) differ from the data source and population used to describe treatments. Types of care are often characterized with utilization metrics (e.g., health record or administrative data on hospitalizations, ED visits, chemotherapy, hospice use, or location of death). While useful for identifying how patterns of care match with societal perspectives on optimal care, this method is fundamentally unable to assess patient-level *goal-concordant* care.

Strengths and Considerations of Measurement Methods for Goal-Concordant Care

Method 1: Patient-/Family Caregiver-Reported.
Strengths. Patient-reported perceptions of goal-concordant care, both reporting of goals and perception of treatment alignment with goals, is the most person-centered way of measuring goal-concordant care. Family caregiver-reports of goal-concordant care by individuals who best know the patient still offer a more patient-centered perspective than other methods of measuring goal-concordant care.[17-19] This method also allows for gathering more nuanced information about goals and treatment preferences directly from patients or family caregivers.

Potential Bias and Rationalization in Patient and Family Reports. Patients' goals, treatments, treatment outcomes, and health status all change over time, as do their perceptions, and retrospective memory may be dependent on the outcomes that ensued. Biases, including recall bias or social desirability bias, can change perceptions of both goals and concordance of

goals with treatments, and differentially so over time.[12,20] With prospective reporting of the perceived concordance between goals and treatment, social desirability bias and rationalization may drive patients toward reporting concordance. Further, assessing prospective confidence in future receipt of goal-concordant care is difficult to disentangle from trust in light of personal and societal medical histories. With retrospective reporting, patient and family reports are subject to more general limitations in recall: patients may not recall specific dates or quantities of treatments, particularly when they experience high treatment burden; goals and values do, indeed, change over time, and reporters may not remember their perceptions at a specific point in time.[21,22] Importantly, these changes in perceptions over time may unintentionally capture the intersection of what the patient experienced and their perception of that experience in hindsight, including decisional regret, potentially skewing the perception of concordance or discordance that occurred during decision making and treatment.[23] These changes in perception may be so dramatic that researchers are essentially measuring retrospective satisfaction with the experience and outcomes. While potentially related, satisfaction may stand in stark contrast to decision making and treatment that were goal-concordant in real time, and be particularly dependent on outcomes. Further, even when patients and their caregivers are asked about their current treatment, they may not be capable of evaluating goal-concordance of care because they do not necessarily know what specific care they are receiving, or what that treatment is meant to achieve clinically.[24] To these points, others have demonstrated how humans have selective memory against adverse events and, separately, rationalize decisions to reduce cognitive dissonance, or in our case, *post hoc* perception of goal-concordance.[20,25]

Of note, family-reports are reflected through several shifting lenses over time, all with imperfect information: their perception of the patients' goals, values, and treatments over time; their relationship to and perception of the patient; their own experience with the treatments; and the patients' outcomes, including whether the patient died (examined in more detail below). In a systematic review, Shalowitz et al. found that surrogate decision makers matched patient reports for their own care one-third of the time.[21] Family decision-makers report more accurately on more directly observable experiences, such as quality of service, and less accurately for more subjective aspects of care such as patient pain, depression, and anxiety.[17] It is plausible that complex or philosophical issues related to a patient's goals may be particularly difficult for a family member to report accurately.

Method 2: Family Caregiver-Reported After Death. *Strengths.* After-death assessment of receipt of goal-concordant care combines the strengths of direct report with timing focused on the dying process. This method provides a full retrospective picture of goals and treatments received at the end of life.[26] This is important because treatment and goals can change quite dramatically near or at the end of life, and these changes may not be fully captured by written preferences or patient reports before death.[27]

Limitations Specific to After-Death Family Caregiver Reports. Concerns about recall bias may be particularly salient in after-death surveys due to the dynamic nature of memory and processing emotions and perspectives at the time of recall.[28] When studies are limited to these reports, they do not encompass those who survived, and may demonstrate a dramatically low response rate.[29] Particular concern is raised when studies include both after-death family caregiver reports and reports by patients or family members of living patients; in those cases, the different data sources may present systematic differences between reporters. A feature of after-death family caregiver reports is that inclusion is not contingent on a specific treatment experience, yet all responses are normalized by the same outcome (death).

Method 3: Concordance in Longitudinal Data. *Strengths.* This method often relies on data from the healthcare record, which corresponds to information available to clinicians for treatment decision-making.[27] This method can provide a more complete and detailed picture of treatments received.[30] Varying sources of information, including but not limited to: written advance directive, documentation in the healthcare record, patient/family caregiver response in a survey or interview, healthcare records, or administrative data also allow investigators to operationalize measurement based on available data sources.

Limitations Related to Temporal Gap Between Goals and Treatments. Goals can be defined during treatment, before the start of treatment, and even prior to diagnosis or onset of illness. It is ethically appropriate to acknowledge that goals can change over time.[22] Interpretation of whether care was goal concordant likely depends in part on the length of time between when goals were stated and when treatment occurred. As the length of time increases, disease trajectories and treatment goals may have changed. When explicitly comparing previously expressed goals to treatments received, it is essential to acknowledge both the variation in data sources for the two types of information and when in time they were measured.

Limitations When Mapping Treatments Onto Goals. Limitations related to temporal gap between

goals and treatment are particularly salient when researchers attempt to map treatments and values onto one another. Assumptions used in mapping may introduce systematic bias into assessment of goal-concordant or goal-discordant care. Increasingly, researchers and clinicians are building a more nuanced understanding of the ways treatments traditionally associated with one goal can be consistent with other goals for individual patients.[11,31,32] For example, rehospitalization of someone with a primary goal of comfort, enrolled in hospice, may still be reasonable in cases in which the purpose of the hospitalization was for complex symptom management. Additionally, some treatments may not clearly default to a specific goal of care, as in the case of palliative radiation to reduce cancer metastases and to alleviate pain. There is also significant variability among physicians about whether goals are achievable, and whether specific interventions and treatments increase the chance a goal will be reached.[33] The resulting variation in how studies map specific treatments on to goals limits the comparison of goal-concordance across studies.

Method 4: Population-Level Indicators. *Strengths.* Large administrative and claims-based datasets provide information about treatment and utilization patterns. While lacking granularity and individual patient goals, these data can provide a full picture of treatments received over time for populations, including those near the end of life. Because patient-level goals are not available in these types of data, aggregate patient goals must be imputed to make any claims of goal-concordance or non-concordance. However, these data are valuable if assumptions are kept in mind during interpretation of findings. For example, although patients on hospice may reasonably need hospitalization for complex symptom management, or their goals may change, assuming those treatments are generally discordant allows administrative data to highlight potentially burdensome treatment.[34] This method is not generally limited by response rate or reporter bias.

Lack of Patient-Level Linkage of Goals to Treatments. When using this method, investigators must be careful to compare goals and preferences to treatments received by a clearly comparable population. For example, if a survey of a population in one geographic area indicates 40% of people wish to die at home and national mortality statistics indicate that 40% deaths occur at home, the characteristics of these two populations are likely to differ in important ways. Further, even within two comparable populations, it is conceivable that the individuals who expressed a preference to die at home are not similar to those who actually did so − further information about age, ethnicity, insurance status, or health status might be necessary for interpretation.

Erasure of Minority Preferences. The population-level measures for goal-concordant care have the potential to erase minority-held goals within a population, which may impact racial, ethnic, religious, and cultural minorities, who may disproportionately have the lesser-held goal within a larger population.[35–37] Goals that are less prevalent at the population level are often neglected when rates of treatment delivery at the population level are used as proxies for goal-concordant care. For example, compared to non-Hispanic whites, more Black and Hispanic patients would rather die in the hospital.[38] When population-level treatments rates (e.g., hospice enrollment; hospitalizations) are used to evaluate goal-concordant care, it is important to explicitly address that those treatments are not necessarily concordant with the minority-held goal within the population.

Discussion

We defined, assessed, and provided examples for four methods currently used to measure goal-concordant care: Patient-/Family Caregiver-Reported, Family Caregiver-Reported Goal-Concordant Care after Death, Concordance in Longitudinal Data, and Population-Level Indicators. Each method has strengths and limitations that should be considered when selecting a method for a new study or evaluating the design of a prior study. Use of patient or family caregiver-report of goal-concordant care draws on all the strengths of patient-reported outcomes, and can be captured for multiple aspects of treatment; these methods are subject to recall bias or family-proxy bias. Goal concordance in longitudinal data is optimal when a specific treatment preference can be mapped reliably to actual treatment; the method is limited to common life-sustaining treatment choices and validity may be affected by temporal variation between preference and treatment. Population-level indicators allow pragmatic research including large populations without individual report of preferences; its primary limitation is assumption that preferences held by a majority of persons will be reflected in use of treatment for populations.

Future improvements in informatics and documentation may strengthen measurement of goal-concordant care. Some of the current limitations in measuring goal-concordant care, including difficulty determining and assessing previously expressed goals and values, may be overcome with improvements in electronic health record (EHR) application and documentation. Clinical and administrative initiatives are increasingly common to improve consistency of documentation of goals-of-care discussions.[39,40] More frequent and thorough documentation and updating of patient goals and advance care planning not only improves data available to the care team for clinical

decision making, but improves researchers' ability to map goals to treatments. Longitudinal measurement in real time will support accurate mapping of goals and treatment when using that method (Method 3), thereby increasing the likelihood of accurate assessment when determining whether care was concordant or discordant at the time it was delivered. Incorporating technologic and informatics methods—including natural language processing and machine learning—has the potential to improve EHR queries and capture nuance for research purposes will likely become more feasible and accurate.[41,42]

Investigators can augment these methods by engaging in measure development, refinement, and validation during the conduct of palliative care research. They should consider and select the best measurement method approach for their study design. Additionally, they can advance measurement science by publishing clear operational definitions and reports of data they generate on measure reliability and validity, including comparison of two different measurement methods. Future insights on measurement of goal-concordant care may result from triangulation across methods of measurement. For example, comparing patient perception of goal-concordance (as in Method 1) with actual goals and treatment (as in Method 3), will provide information about the level of agreement between these types of assessment and about instances where agreement is more likely to be present or absent. Further, published results for measures of goal-concordant care help to set benchmarks, tempered by understanding of the limitations of any given method. While clinicians aspire for goal-concordant care 100% of the time, observed rates rarely reach this level. Barriers include 1) sources of measurement error for each of these methods of assessment, and 2) gaps between aspirational goals and attainable outcomes.

We built upon previous work describing a conceptual model of goal-concordant care by defining and discussing the theoretical methods for measuring goal concordance in research and practice.[6] Further, the operational and conceptual definitions of goal-concordant care have implications for health systems and payers in terms of shifting reimbursement as systems work to define value-based care.[43] To that end, establishing a framework for defining and measuring goal-concordant care may have implications for solving broader questions in our healthcare systems.

Conclusions

Palliative care interventions have demonstrated positive effects on important outcomes, including patients' quality of life, symptom distress, and advance care planning, while reducing intensity of treatment.[44] However, in the absence of rigorous, widely-adopted methods to measure goal-concordant care, it remains unclear if observed changes in treatment intensity are consistent with patient goals and preferences. The methods for measuring goal-concordant care and corresponding tradeoffs should be thoughtfully selected based on each study's goals and study design, and biases clearly acknowledged. Ultimately, each of these methods evaluates goal-concordance from a particular perspective, and thus there is not one method that can be considered the "gold-standard." Existing methods can and should be augmented with new methods and innovations, some of which we outline here, in order to more precisely assess goal-concordant care in palliative care research.

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