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Quality Measurement and Accountability for Community-Based Serious Illness Care

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Data Needs for a Serious Illness Care Accountability System:
A Framework and Recommendations

Tom Valuck, MD, JD and Russ Montgomery, PhD, MHS

Abstract

Background: Successful implementation of a comprehensive accountability system for community-based serious illness care will require a robust data infrastructure. Data will be needed to support care delivery, quality measurement, value-based payment, and evaluation and monitoring.

Objective: The specific data needs in these areas need to be identified and understood, so that gaps in currently available data may be addressed.

Design: We developed a framework that includes the needed data and data infrastructure to support the features and characteristics of a serious illness care accountability system. Based on this framework, we analyze the current data landscape to identify gaps in available data resources and capacities. This analysis was informed by conducting Internet-based research, interviews with key informants, and a survey of key informants.

Results: Based on the identified gaps, we present a series of priority recommendations for advancing the data infrastructure to support community-based serious illness care. These recommendations include additional measurement of patient-reported outcomes, increasing interoperability among various data sources, increasing development and exchange of patient care plans, leveraging newly standardized data on patient functional and cognitive status, and using patient-reported information for clinical decision support at the point of care.

Conclusion: There are significant unmet data needs for a comprehensive accountability system in serious illness care, but these gaps can be prioritized and addressed through alignment and collaboration across stakeholders.

Keywords: accountability system; care delivery; community-based care; quality measurement; serious illness; value-based payment

Introduction

Robust data are needed for multiple purposes in an accountability system for community-based serious illness care. These purposes include care delivery, quality measurement, value-based payment, and evaluation and monitoring. However, data are often poorly aligned and inaccessible when needed due to fragmentation in our healthcare system. Such fragmentation is particularly severe in serious illness care. In other cases, data are not being generated. It is necessary to identify existing gaps in needed data and ways to fill these gaps.

In this article, we present a framework of the data needs for an accountability system and highlight the gaps in currently available data. We then present a series of recommendations on filling data gaps.

Methods

We conducted an analysis to identify data needs based on a set of design characteristics for a serious illness care accountability system, which builds on the introductory article of Teno et al. in this special issue. This analysis resulted in a framework that presents design characteristics and data
needs, along with data types and sources that may be used to meet these needs. In addition, we conducted an analysis to assess the extent to which existing data meet the needs described in the framework. The analyses were informed by Internet-based research, interviews with key informants, and a survey of a convenience sample of key informants. Figure 1 summarizes the analytic approach.

Data needs framework

Figure 2 is a framework that highlights a set of defining characteristics for a robust accountability system for high quality, affordable, community-based serious illness care. These characteristics are divided across four domains:

1. Care delivery,
2. Quality measurement,
3. Value-based payment, and
4. Monitoring and evaluation.

Based on these characteristics, the framework presents a set of data needs for each of the four domains. These data needs are divided into data processes and end uses of data. In addition, the framework identifies the major types of data and major available data sources that may be used to meet the defined needs.

This framework does not represent the ideal future, but rather what may be possible in the near- to midterm. Below, we review the data sources and types in the framework, and then map them to the identified data needs within each domain. This mapping of data types and sources includes data that are currently being used to meet the defined needs or have the potential to be leveraged in the near- to midterm to meet the needs.

Data sources and types

A range of data sources can be leveraged for care delivery, quality measurement, value-based payment, and monitoring and evaluation. Claims databases aggregate utilization and cost data from payers and purchasers. Electronic health records (EHRs) and paper medical records contain patient-level clinical data, such as diagnoses, histories, symptoms, test results, and medications. In rare cases, they include data on patient functional and cognitive status.

Patients and their families are data sources through surveys, which may be used at the provider-level for quality improvement and aggregated in registries and other repositories for quality measurement, payment, and other uses. Patient-reported outcomes (PROs) focus on outcomes such as symptom management and patient experience, among other types of data. Notably, when a seriously ill patient serves as a data source, steps must be taken to reduce reporting burden. Proxies may be used to alleviate the reporting burden. While studies show that responses from patients and their

FIG. 1. Analytic approach.

FIG. 2. Data needs framework for a serious illness care accountability system.
proxies often differ, particularly on subjective symptoms, a family member is often the best source of information for some seriously ill patients (e.g., individuals with end-stage dementia). Patient assessments include data elements such as functional and cognitive status and patient and family experience, as well as clinical data. To serve as a data source for population health management and other uses, assessments may be aggregated and reported at a population-level. Similarly, clinical registries aggregate a wide range of data at a population-level, including clinical data and functional and cognitive status. Monitoring devices are an emerging source of patient-level data. They may report clinical data such as vital signs or may track functional status and cognition, among other types of data.

**Care delivery**

**Characteristics.** Studies show that seriously ill individuals prefer to receive care at home, rather than in institutional settings. The seriously ill have complex needs—both medical and nonmedical. To most effectively treat their conditions and provide care that is patient-centered, service delivery should be evidence-based and driven by patient preferences. The seriously ill benefit from care that is multidisciplinary, team-based, and well-coordinated across care settings.

**Data needs.** The data types in the framework are used in a variety of ways to support care delivery. At the patient-level, clinical data are used to manage and coordinate care and support clinical decision making. Clinical decision support helps providers make informed decisions at the point of care, and care planning and shared decision-making help ensure that these decisions align with patient preferences. At the population-level, data dashboards present aggregated clinical data as well as other types of data, such as functional and cognitive status, health outcomes, and utilization and cost, to more effectively manage population health and engage in program and system management. Within dashboards and other data tools, risk stratification and predictive modeling may be used to identify and segment patients by acuity or other factors to more effectively target interventions.

**Quality measurement**

**Characteristics.** Effective quality measurement links structure and process measures to outcome measures in accordance with the Donabedian framework. Outcome measures, particularly PROs, should be emphasized. Measure sets should include reliable and valid measures of the factors important to quality care and outcomes for the seriously ill. In addition, measure sets should be parsimonious, with common measures used across care settings and programs where possible, and additional measures specific to the setting and purpose used as needed. The collection and reporting of measures should minimize burden on the provider, patient, and family.

**Data needs.** Nearly each type of data can and should be used for quality measurement. For the serious illness population, PROs and data on patient preference and patient and family experience are particularly important. In addition, quality measures must be specified, including clear numerator and denominator definitions. This requires rich data on characteristics that define the serious illness population, such as diagnosis as well as functional and cognitive status. Once calculated, measures may be used for a variety of purposes, including public reporting, value-based payment, and quality improvement. In addition, performance information may also be used for value-based insurance design by establishing provider networks and cost-sharing adjustments that encourage beneficiaries to choose high-quality providers.

**Value-based payment**

**Characteristics.** Payment should move from fee-for-service, based on the volume of services provided, to the value of care delivered. To support value-based care, provider payment should be tied to performance, with steps taken to ensure fair and timely comparisons across providers. To maximize the ability of clinicians to provide the care needed by the seriously ill when they need it, payment should be flexible and prospective. Simple payment structures help minimize provider uncertainty and administrative burden.

**Data needs.** Historical information on utilization, cost, and quality measure performance are needed to structure value-based payment models and set performance targets. To help ensure fair comparisons and make payment adjustments, measures should be benchmarked and risk-adjusted. Benchmarking allows for comparisons across providers and against targets and trends, while risk-adjustment helps ensure that measures are based on performance and not on other differences in the patient population. Once measures are risk-adjusted and benchmarked, they can be used to adjust payment.

**Monitoring and evaluation**

**Characteristics.** Short-term monitoring and long-term evaluation are needed to assess the real-world impacts of healthcare delivery and payment policy changes on patients. Monitoring and evaluation should focus on the effectiveness of care and payment models, as well as potential unintended consequences, such as restricted patient access to services and technologies. These processes should be ongoing from the initiation of new models.

**Data needs.** For monitoring purposes, real-time data feeds (or close to real-time) are needed to identify issues and address them promptly. For evaluations, data are needed to identify trends, conduct studies that compare treatment and comparison groups, and assess causal relationships between program features and outcomes, including impacts on utilization and cost. The results of these evaluations should be reported to participating providers, who may use them for quality improvement; policymakers, who may use them to improve programs; and patients, who may use them to make more informed care decisions. In addition, results may be used to adjust the design of care models and the incentives that are part of payment models.
Data Gaps and Recommendations

We assessed the extent to which currently available data are meeting the needs described in the framework. Based on this assessment, we identified a series of data gaps and recommendations for filling these gaps. The gaps and recommendations have been grouped together into broad goals for improving data availability and the data infrastructure to support an accountability system.

**Goal 1: Increase patient- and family-centered care**

Providing care that is patient- and family centered is an aim of the National Quality Strategy and has been a goal in the ongoing evolution toward value-based payment. Capturing patient preferences and perspectives on care is even more essential in serious illness care, as patients may not be expected to recover and the goals of care are oriented toward managing symptoms and improving quality of life.

**Recommendation: Increase aggregation of PROs and develop PRO-performance measures.** The collection of true PROs is currently limited in serious illness care, and aggregation of PROs for the development and use of PRO-performance measures is minimal. As new clinical registry capabilities are planned, there is an opportunity to include additional collection and aggregation of PROs. By making registry participation a requirement for participating in an accountability system, small numbers issues can be mitigated, and incentive models can take into account the extent to which providers are addressing patient preferences and experiences.

**Recommendation: Increase collection and exchange of longitudinal care plans and advance directives.** True patient- and family-centered care is not possible if providers do not have access to detailed patient care plans and information on patient preferences for care. Unfortunately, these documents are often not developed during care. When they are developed, they are often not shared and are not available to clinicians when they are needed. Initiatives to increase collection of advance directives and other end-of-life care orders, such as physician orders for life-sustaining treatment (POLST), have been implemented in recent years, largely at the state level.

As of 2017, 48 states have POLST programs, although actual submission of documents to them remains low, and the adequacy of communication during care planning has been questioned. There is an opportunity to build engagement with these programs and help them expand and improve. While these initiatives may increase development of advance directives, the documents are often not made accessible via EHRs. Working with EHR vendors may help address some of the accessibility issues. Importantly, POLST should be reviewed and updated regularly to ensure that they continue to capture patient preferences.

**Goal 2: Reduce data collection and reporting burden**

A major challenge in collecting data about seriously illness is the burden placed on patients, families, and providers. This is true for data entry in EHRs, conducting patient assessments in postacute care settings, data entry into clinical registries, and gathering patient-reported information. Many of the data elements are similar or redundant across these collection methods and data resources.

**Recommendation: Increase data exchange and interoperability.** While strides have been made in recent years, data exchange and interoperability across care settings remain low and inadequate for quality improvement and other uses. As part of IMPACT Act implementation, The Centers for Medicare and Medicaid Services (CMS) is developing a Data Elements Library (DEL) to facilitate interoperability and transferability of data from postacute care data sets. Through the DEL, CMS is mapping the data elements from patient assessments to the Consolidated Clinical Document Architecture, which is a widely used standard that defines many of the types of information built into EHRs. Providers can use the information in the DEL to help establish interoperability for their EHRs.

With the DEL and growing interoperability across care settings, there are new opportunities to exchange data to populate EHRs, assessments, and other data sources. Such data exchange can reduce the frequency of repetitive data collection. Reporting requirements for any new accountability system should harness these advancements in standards for data exchange and interoperability to reduce burden.

**Recommendation: Identify measurement approaches that minimize patient and family burden.** Increased interoperability between assessments, EHRs, and other data sources may also reduce the reporting frequency for patients and families. However, even with decreased frequency, patients and their families will still face reporting burden. Future research on ways to address several critical measurement issues with PROs can help to address many of these issues. These topics include ways to improve the validity of proxy use, provide questionnaires that are more appropriate to differing levels of patient function (e.g., vision and cognition), reduce instances of false representation of symptoms by providers and patients, and elicit patient responses using passive technologies.

**Goal 3: Improve EHR functionality**

Enhanced data exchange and interoperability with EHRs will only advance so far without changes to EHR functionality and interfaces. While standards and language have advanced in some ways, many EHR platforms simply do not have fields or displays for certain types of information, such as care plans and advance directives.

**Recommendation: Work with partners to propose enhanced functions and codes to EHR vendors.** Multiple key informants stated that the terminology used in hospice care and other settings relevant to serious illness is not as well represented in the Logical Observation Identifiers Names and Codes (LOINC), which is a set of code names and identifiers for medical terminology used in EHRs. EHR vendors may be willing to speak with providers on these issues, but without a critical mass of EHR users requesting changes, vendors are unlikely to make significant modifications. There is an opportunity to organize specialty societies and provider trade associations to approach vendors in a unified manner with concrete requests. Such an approach could also help by...
spreading the costs of changes across many different consumers.

As a complementary strategy, a consortium of these organizations could also work to develop lists of priority terms for serious illness and approach the Regenstrief Institute, the organization that oversees LOINC, to request development of additional codes. These codes would permit increased processing of care plans and other open text in EHRs for quality improvement, measurement, and other purposes.

**Goal 4: Define and segment the serious illness population**

Defining the serious illness population and leveraging data related to that definition is necessary for all four domains of data needs. In particular, data on physical and cognitive function are needed to segment the population and define and calculate denominators for quality measures. Moreover, defining and segmenting the population can help to determine which patients should be included in new models of care, as well as value-based payment models and program evaluations.

**Recommendation:** Leverage functional and cognitive status data in postacute care datasets and clinical registries. Functional and cognitive status information is included in the recommended quality measure definitions in the article of Kelley in this special issue. The implementation of the IMPACT Act is bringing much needed standardization to functional status data elements in the postacute care datasets, including the Minimum Data Set, Inpatient Rehabilitation Facility-Patient Assessment Instrument, Outcome and Assessment Information Set, and Long-Term Care Hospital CARE Data Set. Cognition items are also being standardized, including mental status assessment tools such as the Brief Interview on Mental Status. These data can be leveraged to define the serious illness population and calculate measure denominators, as described in the article of Kelley.

**Goal 5: Improve accessibility of data at the point of care**

Clinical decision support can lead to more informed decisions at the point of care. However, due to the need for data from multiple settings of care, clinical decision support in serious illness care has not been as advanced as other areas of healthcare. New technology and the emergence of big data and new data sources are resulting in new capabilities for improving clinical decision support.

**Recommendation:** Build “feed forward” capability into clinical data registries for clinical decision support. The clinical data registries currently in use in serious illness care, including the Global Palliative Care Quality Alliance, Palliative Care Quality Network, and National Palliative Care Registry, are used primarily for local quality improvement and research. They do not have built-in capability to facilitate real-time clinical decision support based on PROs.

A planning process is currently underway to enhance and integrate the existing registries, and there is an opportunity to add “feed forward” capabilities to help inform decision making at the point of care. This approach was pioneered by the Swedish Rheumatology Quality registry. Patients enter, or feed forward, information about their symptoms and quality of life, through a web portal or on registration during an office visit. The provider supplements this information with data from a clinical examination and laboratory tests. A built-in decision support system incorporates these data and shows comparisons to the data of other patients in the registry.

**Conclusion**

Based on our review of the current landscape, additional data and data capabilities are needed to support serious illness care delivery, quality measurement, value-based payment, and evaluation and monitoring. To fill gaps in currently available data, we recommend actions to achieve specific goals.

To support care delivery, EHRs and clinical data registries need additional functionality to inform clinical decision making, and increased use of PROs and advanced care plans will help ensure patient preferences are informing care. To support quality measurement, payment, and evaluation and monitoring, the serious illness population needs to be better defined and segmented. As new data and data infrastructure are developed, efforts should be made to reduce the data reporting burdens on patients, families, and providers. Addressing these recommendations will require new ways of thinking and collaborating among organizations.

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**Author Disclosure Statement**

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**References**


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Identifying the Population with Serious Illness: The “Denominator” Challenge

Amy S. Kelley, MD, MSHS and Evan Bollens-Lund, MA

Abstract

Background: To ensure seriously ill people and their families receive high-quality primary and specialty palliative care services, rigorous methods are needed to prospectively identify this population.

Objective: To define and operationalize a definition of serious illness for the purpose of identifying patients and caregivers who need primary or specialty palliative care services.

Design/Setting: Two stages of work included (1) building expert consensus around a conceptual definition of serious illness and (2) using the National Health and Aging Trends Study linked to Medicare claims data to test a range of operational definitions composed of diagnoses, utilization, and markers of care needs.

Measurements: One-year outcomes included mean total Medicare costs, mortality, and percent hospitalized, as well as those reporting ≥2 measures of need and functional impairment. Sensitivity, specificity, and c-statistics (unadjusted and adjusted for age, sex, race, and Medicaid status) were calculated for each definition across the outcomes.

Results: Conceptually, “Serious illness” is a health condition that carries a high risk of mortality AND either negatively impacts a person’s daily function or quality of life, OR excessively strains their caregivers. The range of operational definitions simulated all had low sensitivity and high specificity across all outcomes. None of the definitions reached an unadjusted c-statistic >0.6 (or adjusted >0.7) for identifying a population with ≥2 indicators of care needs.

Conclusions: Standard administrative data are inadequate to identify this population. Defining the seriously ill denominator with high specificity, as described here, will focus efforts toward the highest-need segment of the population, who may indeed benefit most.

Keywords: denominator populations; health care spending; measures of need; Medicare; serious illness

Introduction

Health care spending is extremely concentrated and high spending is often a marker of low quality care. The top 5% of spenders account for nearly 60% of healthcare costs. This spending is neither easily predictable nor consistent over time. Only 11% of the highest-cost individuals are in the last year of life, while even fewer have predictable prognoses. Despite highly concentrated spending, care of this patient population is frequently of low quality; poorly coordinated with multiple transitions across sites of care; marked by inadequate symptom control and low patient and family perceptions of the quality of care; and potentially discordant with personal goals and preferences.

Healthcare reform aims to improve the value (i.e., raise quality while holding stable or lowering costs) of care for these highest-cost seriously ill patients. In select groups, palliative care interventions (including an interdisciplinary team of physicians, nurses, social workers, and chaplains) have been shown to improve quality of life, manage symptoms, and support patients and families, and lower costs.

Yet, not all patients need all aspects of palliative care services and many patient who could benefit receive no palliative care services at all. Efficiently targeting resources, particularly in...
community settings, to those who need and will benefit from them most before a personal healthcare crisis occurs is a critical step in providing appropriate, value-driven, and patient-centered care to the seriously ill population.

Thus, central to the success of programs that serve high need, high cost patients, such as community-based palliative or serious illness care programs, is accurate identification of those with the greatest need, otherwise the programmatic costs will exceed the potential savings.21 Yet, to date, efforts both to efficiently target specialized clinical interventions and appropriately apply quality metrics for the care of the seriously ill have been hindered by our inability to prospectively identify the high-cost, high-need population.

One commonly used approach to identifying the high-cost population is the Centers for Medicare and Medicaid Services hierarchical condition categories (HCC), which rely on diagnostic codes from claims and a complex statistical algorithm to adjust Medicare Advantage capitation payments.22,23 Yet diagnoses alone fail to adequately predict costs, hospital use, mortality, or, most importantly, unmet care needs.1,3,24,25 The addition of functional status measures and prior healthcare utilization to identification algorithms may add predictive strength, but clearly defined criteria and consistent data are lacking.7,25

This article aims to build upon prior work by conceptually defining serious illness and describing the steps needed to operationalize this definition within a healthcare population.26–30 We align these methods with current alternative payment model (APM) proposals31,32 and highlight critical challenges and tensions in specifying the approach. To illustrate these issues, we also describe simulated examples of population identification methods using a nationally representative cohort of Medicare beneficiaries. Finally, we outline recommendations for next steps.

Defining the Population

We first reviewed a wide range of literature and reports on conceptual and operational definitions of “serious illness,” “advanced illness,” and the “palliative care population.” We then asked a group of expert advisors and palliative care specialists to define serious illness, specifically for the purpose of identifying a population of patients and caregivers who need primary or specialty palliative care services. The group’s iterative work ultimately reached consensus on the following definition (Box 1):

Next, we discussed the steps needed to operationalize this conceptual definition to create a template or algorithm for patient identification. Through this process, we identified several critical areas of tension to be wary of in one’s choice of approach. First, our primary intent is to identify those people and families with unmet palliative care needs, yet this is currently not possible on a population level due to lack of data and measurement challenges. Moreover, to date, there is no “gold standard” prospective measure of care needs amenable to palliative care services. Instead, many existing methods seek to identify those people at risk for high healthcare costs, a marker of potentially burdensome healthcare utilization and proxy indicator of care needs. While palliative care has been associated with reduced costs, this is an indirect result of providing appropriate care before a crisis and thereby reducing use of emergency services or non-beneficial interventions. Cost savings is not a primary intent of palliative care services. Reduction of costs, however, is often one of the key components of risk-sharing payment models in which palliative care programs may participate and cost avoidance may support the business plan for a palliative care program’s sustainability. In our simulations, we attempt to capture both measures of costs, utilization and care needs.

Data availability is central to the second tension identified. Lacking a gold standard, one might seek a range of measures signaling potential care needs or risk of poor outcomes (e.g., symptoms, functional and cognitive impairment, and caregiver strain or distress). These measures are rarely available in administrative data or electronic health records (EHRs), however, and when they are available, they usually have not been rigorously collected and may vary substantially across sites, providers, or populations. One possible solution is to use the Minimum Data Set (MDS) or Home Health (HH) OASIS data, which contain standardized and mandated assessments of cognition and function.33 These assessments are only conducted on the subsets of Medicare beneficiaries accessing skilled nursing facility (SNF) or HH services, thereby excluding many who might otherwise meet the proposed definition. So we aim to highlight the population identified with SNF and HH claims data in comparison to those identified through survey-based functional assessments. By doing so, we may develop an approach based upon currently available data, while recognizing its limitations, and highlighting the need to mandate collection of these critical data elements in the future.

Third, the identification process must consider both sensitivity and specificity. In light of imprecise or inadequate data, accurate identification of the target population would require some component of point-of-care or patient-portal survey screening. Identifying too broad a population (highly sensitive definition) could misdirect finite resources to those with minimal care needs, while a method that identifies too narrow a population (highly specific definition) may result in missing a substantial proportion of those who could greatly benefit from services. Thus, a highly specific population definition may be best for a resource-intensive clinical program, but a more sensitive population definition would be preferred for a standard measure of care quality.

Finally, we considered what role, if any, prognosis should have in identifying the target population. While the last months of life are the highest-cost and highest-need period for many people, only 11% of all high-cost high-need patients are in the last year of life.3,4 Many high-cost patients experience high levels of spending over multiple years.27,34 By purposefully targeting the end of life, programs may miss or curtail the opportunity to meaningfully improve care and reduce burdensome or inappropriate utilization. Furthermore, hospice services are specifically targeted to patients in the last months of life, whereas palliative care services may be appropriate at any stage of illness. For these reasons, our approach does not aim to identify those people in the last year of
life, but we report mortality as a proxy measure of care needs and severity of illness.

In sum, we recognize the inevitable need for a variety of denominator populations. The tensions and challenges described above offer opportunities to simulate and test a range of choices. In the following sections, we describe these preliminary simulations and offer a few specific methods that may fit the purpose of various entities, including community-based palliative care programs, institutions, and payers.

Approach to Identifying the Seriously Ill: Nationally Representative Simulations

Sample and data

Data are drawn from the 2011 National Health and Aging Trends Study (NHATS), linked individual Medicare claims data, and linked caregiver data from the National Study of Caregiving (NSOC).\textsuperscript{35,36} NHATS is a population-based longitudinal survey of individuals aged 65 years and older living in the contiguous United States, drawn from the Medicare enrollment file, which represents 96% of all older adults in the United States. In-person interviews were completed between May and November 2011 and yielded a sample of 8245 persons, with a 71% response rate. Among these, 7609 were community dwelling. Nursing Home residents were enrolled, but did not complete full surveys. Proxy respondents were interviewed when the participant could not respond (6%). Study participants who received assistance with daily needs and activities (e.g., personal care, mobility, household activities, transportation, or medically oriented tasks) provided a roster of helpers who provided assistance. NSOC participants were identified from this NHATS helper roster, thus providing linked NHATS participants and NSOC caregivers. NHATS participants are also linked to individual Medicare claims data. To have complete claims data for these analyses, we limited the sample to those with six months of continuous fee-for-service (FFS) Medicare coverage before the NHATS survey date. All measures are adjusted for survey weights to provide estimates relative to the Medicare FFS population.

Components of the approach

Drawing upon the conceptual definition of serious illness, past literature, and expert consensus about elements to include in operationalizing this definition, we selected the following three components for simulations:

1. Diagnoses: We used two methods to approach serious medical diagnoses (Table 1). The first approach is drawn from the Dartmouth Atlas of Healthcare and identifies nine serious chronic conditions, associated with about 90% of all deaths, by using only diagnosis codes.\textsuperscript{37,38} The second more complex approach is modified from prior work to identify the seriously ill,\textsuperscript{27} and uses diagnosis codes and additional claims-based elements to provide evidence of advanced disease (e.g., COPD only if using home oxygen or as primary diagnosis on hospital admission). In practice, these diagnoses could be identified through claims data, EHR or billing data, or patient report.

2. Utilization: We used measures of healthcare utilization in the past six months as a proxy indicator of higher level of illness severity and care need. We considered acute care hospitalizations, HH and SNF claims, separately and in combination. In addition, we explored durable medical equipment (DME) claims (home oxygen, hospital bed, and wheelchair) as indicators of illness severity and functional impairment.

3. Measures of need: Five domains of potential need were identified through evaluation of current APM proposals and expert panel consensus.\textsuperscript{31,32} No gold standard exists and various measures could be used to assess these domains. In addition, for this study, we are limited to those measures available from the NHATS and NSOC surveys. These include the following: functional dependence (NHATS: activities of daily living or ADL), nutritional decline (NHATS: unintentional weight loss), cognitive impairment (NHATS: probable dementia algorithm), symptoms (NHATS: pain limits activities), and caregiver strain (NSOC: caregiving-related financial, emotional, or physical difficulty). We considered a person to have “high need” if two or more of these domains were positive.

Outcomes

Given the tensions described above and the variety of purposes for which a denominator population may be needed, we present a range of descriptive information for each

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\textsuperscript{a}List of diagnoses from Dartmouth Atlas of Health Care report on Variation in End-of-Life Care.\textsuperscript{37} 
\textsuperscript{b}List of diagnoses from Kelley et al.\textsuperscript{27}
approach. We examined each identified group’s one-year outcomes: mean total Medicare costs, mortality, and percent hospitalized. We report the proportion of the identified group who are within the top 10% of total costs; report two or more measures of need; and are dependent for at least one ADL. Finally, we provide measures of sensitivity, specificity, and c-statistic estimates for each approach across the outcomes. In addition to the unadjusted c-statistic, we also calculated c-statistics adjusted for age, sex, race, and Medicaid status. As a comparator, we provide these performance measures for a group identified by the top 10% of HCC scores. At each step, we note the size of the population identified relative to the FFS Medicare population.

Results

The mean total Medicare spending for the full population was $9,459, with 20% experiencing a hospitalization, and 5% dying within one year of follow-up. The top 10% of patients averaged $53,612 and together accounted for 57% of the observed FFS Medicare costs. Nursing home residents represented 4% of the total population and their average Medicare spending was $21,462, with 39% hospitalized and 30% dying within the year. The community-dwelling population had the following characteristics: 28% hospitalized and 5% died at one year. Thirty-eight percent were in the top 10% of spenders, 89% reported 2 or more measures of need, 15% had ADL impairment, and 8% had HH or SNF claims.

The first identification simulation took a straight-forward approach using only claims data: a combination of chronic condition diagnosis codes, hospital use, and HH/SNF/DME claims over the past six months. This method captured 6% of the total FFS population and selected people with $32,384 average costs, 55% hospitalized and 25% died at one year. Thirty-eight percent were in the top 10% of spenders, 89% reported 2 or more measures of need, and 73% reported ADL impairment (Fig. 1).

In comparison, a more complex approach used claims data to identify serious medical conditions, that is, to limit diagnoses to those with evidence of advanced illness. As above, we then added the claims-based criteria of hospital use and

![Diagram](https://via.placeholder.com/150)

**FIG. 1.** Simulation of denominator definition using chronic conditions and claims. aChronic condition = 9 serious chronic conditions as per the Dartmouth Atlas of Healthcare method. ADL, activities of daily living; DME, durable medical equipment, specifically hospital bed, wheelchair or home oxygen; FFS, fee-for-service; HH, home health; SNF, skilled nursing facility.
HH/SNF/DME claims over the past six months. This method captured 4% of the total FFS population and selected people with $33,994 average costs, 56% hospitalized and 30% died at one year. Forty percent were in the top 10% of spenders, 91% reported two or more measures of need, and 78% reported ADL impairment (Fig. 2).

As a third approach, we used the same serious medical conditions and hospitalization criteria, but substituted self-reported functional impairment, specifically receiving help with one or more ADL. This method captured 4% of the total FFS population and selected people with $34,425 average costs, 58% hospitalized and 30% died at one year. Forty-two percent were in the top 10% of spenders and 95% reported two or more measures of need (Fig. 3). All six simulated serious illness denominator definitions are displayed together in Figure 4.

Next, we considered sensitivity [true positive/(true positive + false negative)], specificity [true negative/(true negative + false positive)], and c-statistics (a more global measure of concordance) for each of the approaches simulated (Table 2). Overall, the range of approaches offered similarly low sensitivity and high specificity across outcomes. None of the methods achieved an unadjusted c-statistic over 0.7, a threshold commonly considered good. Also, none of the methods reached an unadjusted c-statistic >0.6 for identifying a population with two or more indicators of care needs. C-statistics adjusted for age, sex, race, and Medicaid status, particularly those for one-year mortality and spending, resembled those of other published predictive models.39–42

Special subpopulations

We also evaluated those with dementia as a unique subpopulation (6% of the total population). We identified dementia with diagnosis codes and limited the sample to those with a hospital admission and living within the community (1% of total FFS population and 22% of total dementia population). This method captured people with $30,755 average costs, and 54% were hospitalized and 23% died at one year. Forty percent were in the top 10% of spenders, 83% report two or more measures of need, and 77% reported ADL impairment (data not shown).

Finally, those with multimorbidity (three or more severe chronic conditions) were evaluated as another unique subpopulation (11% of the total population). We identified multimorbidity with diagnosis codes and limited the sample...
to those with a hospital admission and living within the community (5% of total FFS population and 47% of total community-dwelling multimorbidity population). This method captured people with $30,291 mean costs, and 57% were hospitalized and 21% died at one year. Thirty-nine percent were in the top 10% of spenders, 73% report two or more measures of need, and 59% reported ADL impairment (data not shown).

**Discussion**

Ensuring the delivery of high-quality care to those with serious illness across all sites of care is inextricably linked to our ability to identify that population. We have refined a conceptual definition of serious illness, that is, the population of patients and caregivers who need primary or specialty palliative care services, and highlighted the current challenges and tensions inherent in operationalizing a definition of this patient population. The greatest barrier is the lack of a "gold standard"—valid and reliable measure of care needs amenable to palliative care services—against which the operational definitions can be tested on a generalizable population. In lieu of a gold standard, we have tested a range of definitions against outcomes that may proxy unmet care needs: hospitalization, costs, mortality, and survey-based measures of potential care need (i.e., functional and cognitive impairment, symptoms, nutritional decline, and caregiver strain). All the tested definitions had high levels of specificity and low sensitivity.

**Recommendations to apply now**

Despite limitations in available data for population identification, there are steps that can be applied now. Furthermore, we recognize that one single denominator definition is not appropriate for all purposes and have laid out the components that should be considered or included in each approach. Based upon the simulations evaluated, we offer the following recommendations for a few targeted purposes.

Community-based palliative care programs functioning with limited resources for screening and aiming to target the highest-cost and highest-need group should apply the most straightforward approach (Fig. 1) using only chronic condition diagnosis codes and past hospital use with or without HH/SNF/DME claims. This errs on the side of specificity over sensitivity and recognizes that programs may have administrative data on diagnoses and hospitalizations, but may not have full claims records, including HH, SNF, and DME.
Risk-bearing entities, institutions with a large at-risk portfolio, such as an Accountable Care Organization (ACO), or payers should consider an approach with greater sensitivity. Such entities are able to access the data needed for the more complex approach to indentifying serious medical conditions and this combined system-wide collection of function data or telephonic screening would replicate the approach with the greatest sensitivity (Fig. 3).

Quality measures will require a range of denominators. Measures intended for use in the accountability sphere require high specificity, to promote high-quality care for those with greatest need, while avoiding unintended consequences for a broader group. Quality improvement metrics, on the other hand, must be sensitive. For example, measures of access to palliative care services should be based upon a denominator with the greatest sensitivity, so that it does not unintentionally exclude patients with unmet care needs. Many other measures should only be applied to highly specific groups or may be applicable only to specific disease or condition subgroups. And yet, others may require further specifying the denominator population (e.g., those with a stated preference to die at home).

Research priorities and recommendation for future

This work reveals several important research priorities. Further research is needed to refine these simulation methods and improve the measurement of need, so that it is better aligned with patient and family concerns that may be modifiable or are specifically addressed by palliative care services. This will encompass several focused areas of research and implementation, as listed below:

1. Establish a “gold standard” measure of care needs amenable to palliative care services and, within a broad population, test the sensitivity and specificity of utilization-based identification criteria against this “gold standard.”
2. Recruit several large healthcare systems to use one of the proposed denominator criteria to conduct recurring assessments of patients’ specialty or primary palliative care needs and observe patients’ outcomes over time.
3. Translate these findings to a comprehensive EHR strategy, perhaps in partnership with major EHR vendors, to identify the “denominator,” expand access to services, and ease quality measurement for accountability.
4. Assess the degree to which a utilization-based denominator definition can be enhanced by function and cognitive status measures, that is, those assessments mandated by the IMPACT Act in the post-acute setting; measure what population is excluded from the denominator because of the lack of these assessments; and estimate the impact of expanding the IMPACT Act assessment mandate to the inpatient acute care setting.
5. Conduct additional identification simulations to identify special subpopulations: advanced dementia, multimorbidity, frailty, and others.
6. Develop a brief screening tool to identify patients’ need for enhanced services, trial its use in patient-facing EHR portals or other modes of data collection, and evaluate the effectiveness and efficiency of additional screening to identify those who would benefit from enhanced services.
<table>
<thead>
<tr>
<th>Condition^a and hospitalization, and HH/SNF/DME</th>
<th>Condition^a and hospitalization, and HH/SNF/DME</th>
<th>Serious Medical Condition^b and hospitalization, and HH/SNF/DME</th>
<th>Serious Medical Condition^b and ADL impairment</th>
<th>Serious Medical Condition^b and ADL impairment</th>
<th>HCC-predicted to be top 10% of costs</th>
</tr>
</thead>
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<tr>
<td>Top 10% spending</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
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<tr>
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<td>0.67</td>
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<td>Hospitalization within one year</td>
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<td></td>
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<td>Sensitivity</td>
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<td></td>
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<tr>
<td>C-statistic, adjusted^c</td>
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<td>615</td>
<td>378</td>
<td>415</td>
<td>287</td>
<td>609</td>
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<td>1,552,984</td>
<td>1,005,124</td>
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<tr>
<td>Medicare FFS population, %</td>
<td>9.9%</td>
<td>5.7%</td>
<td>7.2%</td>
<td>4.2%</td>
<td>9.5%</td>
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</table>

Sensitivity = true positive/(true positive + false negative). Specificity = true negative/(true negative + false positive) for identifying those at risk for being among the costliest 10% of beneficiaries, death and hospitalization in the following year, and reporting two or more care need indicators. Bold = c-statistic ≥ 0.6.

^aChronic condition = 9 serious chronic conditions as per the Dartmouth Atlas of Healthcare method.

^bSerious medical condition = diagnoses and additional claims-based elements to provide evidence of advanced disease.

^cAdjusted C-statistic = adjusted for age, sex, race, and Medicaid status.

ADL, activities of daily living; DME, durable medical equipment, specifically hospital bed, wheelchair, or home oxygen; FFS, fee-for-service; HCC, hierarchical condition categories; HH, home health; SNF, skilled nursing facility.
Conclusions

Serious ill people and their families are at risk of low quality and overly burdensome healthcare, and timely primary or specialist palliative care services may ameliorate this risk. An upstream and proactive approach to meeting the care needs of this vulnerable population requires a method of prospective identification. The primary impediments currently are the lack of a “gold standard” for identification of need and inadequate assessment measures in administrative data. The simulated approaches to defining the seriously ill denominator population described in this work offer high levels of specificity. Clinical programs may choose to focus on this highest-need segment of the seriously ill population and may indeed have the highest positive impact on care for this group now. Further research is needed, however, to improve the sensitivity of the denominator definition, so that providers may be held accountable for providing high-quality care to all people with serious illness in the future.

Acknowledgments

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Achieving Goal-Concordant Care:  
A Conceptual Model and Approach to Measuring  
Serious Illness Communication and Its Impact  

Justin J. Sanders, MD, MSc,1–3 J. Randall Curtis, MD, MPH,4 and James A. Tulsky, MD1,2  

Abstract  

Background: High-quality care for seriously ill patients aligns treatment with their goals and values. Failure to achieve “goal-concordant” care is a medical error that can harm patients and families. Because communication between clinicians and patients enables goal concordance and also affects the illness experience in its own right, healthcare systems should endeavor to measure communication and its outcomes as a quality assessment. Yet, little consensus exists on what should be measured and by which methods.  

Objectives: To propose measurement priorities for serious illness communication and its anticipated outcomes, including goal-concordant care.  

Methods: We completed a narrative review of the literature to identify links between serious illness communication, goal-concordant care, and other outcomes. We used this review to identify gaps and opportunities for quality measurement in serious illness communication.  

Results: Our conceptual model describes the relationship between communication, goal-concordant care, and other relevant outcomes. Implementation-ready measures to assess the quality of serious illness communication and care include (1) the timing and setting of serious illness communication, (2) patient experience of communication and care, and (3) caregiver bereavement surveys that include assessment of perceived goal concordance of care. Future measurement priorities include direct assessment of communication quality, prospective patient or family assessment of care concordance with goals, and assessment of the bereaved caregiver experience.  

Conclusion: Improving serious illness care necessitates ensuring that high-quality communication has occurred and measuring its impact. Measuring patient experience and receipt of goal-concordant care should be our highest priority. We have the tools to measure both.  

Keywords: goal-concordant care; quality measurement; serious illness communication  

Introduction  

High-quality care in serious illness aligns treatment with patients’ known goals and values. Therefore, quality measures should reflect our ability to deliver “goal-concordant” care. When we fail to provide care that matches patients’ preferences, we commit a medical error, no less urgent than any other harmful error. Communication between clinicians and patients or their surrogates (hereafter, “communication”) enables goal-concordant care, thus, measuring communication in serious illness may enhance patient safety. Poor communication can also harm seriously  

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ill patients.\(^1\) Therefore, a healthcare system that endeavors to provide the highest quality care to the sickest patients must ensure that high-quality communication occurs and results in the desired outcomes. This raises several questions: What is high-quality communication? How does it impact seriously ill patients and their families? How does it precipitate goal-concordant care? And, how do we measure it?

This article suggests a conceptual framework for the processes that contribute to goal-concordant care and that may assist in quality improvement, accountability schemes, or both. We identify quantifiable variables for these processes, review challenges and opportunities related to measuring them, and examine how they may be implemented.

**Communication, Shared Decision Making, and Quality Measurement in Serious Illness**

A serious illness carries a high risk of mortality AND either negatively impacts a person’s daily function or quality of life, OR excessively burdens their caregivers.\(^2\) Communication plays several roles in the experience of patients with serious illness. First, serious illness frequently requires complex decision making, which entails communication about the risks, benefits, and uncertainties of treatment. Second, serious illness may not only directly limit one’s cognitive ability, but it also heightens anxiety for patients and families,\(^3\) undermining critical thinking abilities.\(^4\) Clinicians, therefore, must respond to emotion when attempting to convey understandable and actionable care options. Finally, treatment decisions typically involve the risk of hastened mortality or prolonged dying, which raise the stakes of communication.

National consensus bodies promote shared decision making (SDM) as the dominant model for communication in such settings.\(^5,6\) Experts define SDM as “an interpersonal, interdependent process in which the healthcare provider and the patient relate to and influence each other as they collaborate in making decisions about the patient’s healthcare.”\(^7\) Clinicians may influence patients by sharing medical knowledge and experience, and patients may influence clinicians by disclosing values and goals relevant to the application of that knowledge. This patient-centered process intends to support the receipt of goal-concordant care.

Existing national quality frameworks for seriously ill patients inadequately capture this outcome or the communication processes and qualities that likely facilitate it. National Quality Forum-endorsed process measures encourage the documentation of treatment preferences or “care plans,” activities that presuppose, but fail to guarantee, that high-quality communication has taken place (Table 1). Most existing quality measures refer implicitly or explicitly to life-sustaining treatments alone. Several assess the utilization of hospice or of potentially nonbeneficial treatments near the end of life (EOL).

Recognizing these shortcomings, several national organizations promote goal-concordant care as a quality indicator for seriously ill patients.\(^8–10\) Yet, measuring goal-concordant care directly poses formidable methodological challenges, including documentation of nonspecific or potentially irrelevant treatment preferences, poor documentation of those preferences, instability of preferences over time, and challenges related to determining “agreement” between preferences and outcomes.\(^11\) Because of these challenges, healthcare systems may consider measuring indicators that either predict goal concordance or result from it.

The complexity of measuring the quality of serious illness communication and goal-concordant care cannot be underestimated, and are evident from clinical experience. Figure 1 highlights two prototypical cases that illustrate this complexity. For example, patients like the man in Case A may have several markers of what might be considered high-quality care by traditional measures, but receive care that is perceived as discordant and results in poor bereavement outcomes. The converse, as in Case B, may also be true. Understanding the relationship between communication and goal-concordant care may support quality improvement efforts by identifying the most appropriate targets for quality measurement.

**A Conceptual Model of the Relationship Between Communication and Goal-Concordant Care**

A conceptual model illustrating the relationship between high-quality communication and goal-concordant care (Fig. 2) suggests candidate quality measurement domains. Communication quality in serious illness comprises at least four mutually reinforcing processes: information gathering, information sharing, responding to emotion, and fostering relationships.\(^12\) These elements directly shape patient experience and, when done well, help patients feel known, informed, in control, and satisfied, thus improving well-being and quality of life.\(^12–14\) Good communication also enhances trust and therapeutic alliance,\(^15–17\) which lay the groundwork for SDM.\(^18\)

SDM may occur in anticipation of future medical decisions during a time of decisional incapacity, known as advance care planning (ACP), or “in the moment,” when there is an immediately relevant decision to be made for a patient with capacity. ACP may result in goal-concordant care indirectly through either patient–surrogate communication and informed surrogate decision making at the time of critical illness, or clinician interpretation of an advance directive (AD).\(^19\) By contrast, in-the-moment decision making may lead directly to goal-concordant care.

The receipt of goal-concordant care likely shapes the bereaved caregivers’ experience as well. The perception that their loved one received care aligned with their values mitigates anxiety, depression, trauma, and regret, and enhances trust, peacefulness, and satisfaction with care.\(^20\) When care is perceived as misaligned, the opposite may be true.

**Measuring Communication and Its Outcomes: Challenges and Opportunities**

Our model recognizes that multiple factors affect goal-concordant care. Table 2 presents a taxonomy of potential measures that correspond to these factors. Many are supported by evidence, some are currently used as quality indicators, and others are theoretical.

Criteria for assessing quality measures include their importance, validity, usefulness, and feasibility.\(^21\) While we believe that these measures meet the threshold of importance, many require further testing for validity, usability, and feasibility. Common measurement challenges include the so-called “denominator problem,”\(^22\) that is, uncertainty about which population should be measured, and the timing of measurement—at what points in the disease trajectory or post death should we survey patients or caregivers?
Table 1. National Quality Forum Endorsed Quality Measures That Relate to But Do Not Ensure That High-Quality Communication Has Occurred

<table>
<thead>
<tr>
<th>NCP guideline (cite)</th>
<th>Program</th>
<th>Measure name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.2: The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family and is developed with professional guidance and support for patient–family decision making. Family is defined by the patient.</td>
<td>Hospice QRP&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Treatment preferences (NQF no. 1641)</td>
<td>Percentage of patients with chart documentation of preferences for life-sustaining treatments.</td>
</tr>
<tr>
<td></td>
<td>PQRS&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Advance care plan (NQF no. 0326)&lt;sup&gt;c&lt;/sup&gt;</td>
<td>Percentage of patients aged 65 years and older who have an advance care plan or surrogate decision maker documented in the medical record or documentation in the medical record that an advance care plan was discussed, but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan.</td>
</tr>
<tr>
<td></td>
<td>Home Health Quality Reporting, Home Health Value-Based Purchasing</td>
<td>HHCAHPS communications between providers and patients (NQF no. 0517)</td>
<td>Multi-item scale with multiple measures accounting for elements and qualities of communication between home health provider and patient.</td>
</tr>
<tr>
<td></td>
<td>n/a</td>
<td>Patients admitted to ICU who have care preferences documented (NQF no.)</td>
<td>Percentage of vulnerable adults admitted to ICU who survive at least 48 hours who have their care preferences documented within 48 hours OR documentation as to why this was not done.</td>
</tr>
<tr>
<td>7.2 The IDT assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential symptoms, patient and family preferences for site of care, attendance of family and/or community members at the bedside, and desire for other treatments and procedures.</td>
<td>n/a</td>
<td>Proportion… receiving chemotherapy in the last 14 days of life. (NQF no. 0210)</td>
<td>Percentage of patients who died from cancer receiving chemotherapy in the last 14 days of life.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>… with more than one emergency room visit in the last day of life. (NQF no. 0211)</td>
<td>Percentage of patients who died from cancer with more than one emergency room visit in the last 30 days of life.</td>
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<tr>
<td></td>
<td></td>
<td>… with more than one hospitalization in the last 30 days of life. (NQF no. 0212)</td>
<td>Percentage of patients who died from cancer with more than one hospitalization in the last 30 days of life.</td>
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<td>… admitted to the ICU in the last 30 days of life. (NQF no. 0213)</td>
<td>Percentage of patients who died from cancer admitted to the ICU in the last 30 days of life.</td>
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<td></td>
<td></td>
<td>… dying from Cancer in an acute care setting. (NQF no. 0214)</td>
<td>Percentage of patients who died from cancer dying in an acute care setting.</td>
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<tr>
<td></td>
<td></td>
<td>… not admitted to hospice. (NQF no. 0215)</td>
<td>Percentage of patients who died from cancer not admitted to hospice.</td>
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<td></td>
<td></td>
<td>… admitted to hospice for less than 3 days (NQF no. 0216)</td>
<td>Assesses families’ perceptions of the quality of care that Veterans received from the VA in the last month of life. The BFS consists of 19 items (17 structured and 2 open-ended).</td>
</tr>
</tbody>
</table>

<sup>a</sup>Quality reporting program.  
<sup>b</sup>Physician quality reporting system.  
<sup>c</sup>This measure is also included in NCP domain 7.2  
BFS, bereaved family survey; HHCAHPS, Home Health Consumer Assessment of Healthcare Providers and Systems; ICU, intensive care unit; IDT, interdisciplinary team; PQRS, physician quality reporting system; QRP, quality reporting program; VA, Department of Veterans Affairs.
Communication quality and processes

Barriers to collecting and analyzing the content of clinical encounters, through recordings or medical record documentation, impede the goal of directly measuring the quality of communication. An audio- or video-recorded medical encounter permits unfiltered analysis of communication content and is thus the measurement gold standard. To date, privacy concerns and logistical complexities have limited recording of communication to research studies. However, as

<table>
<thead>
<tr>
<th>Measure</th>
<th>Source</th>
<th>Description</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication processes and quality</td>
<td>Recorded or documented communication</td>
<td>Assessment of illness understanding; elicitation of patient concerns; exploration of patient goals and priorities</td>
<td>25,28,90</td>
</tr>
<tr>
<td>Information sharing</td>
<td>Delivery of serious news; discussion of prognosis; sharing of risks and benefits</td>
<td>91,92</td>
<td></td>
</tr>
<tr>
<td>Responding to emotion</td>
<td>Response to emotional cues; empathic statements</td>
<td>1,26–28,90,93–95</td>
<td></td>
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<tr>
<td>Fostering relationships</td>
<td>Patient and clinician description of therapeutic relationship</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Global Communication timing and setting</td>
<td>Patient-reported quality of communication</td>
<td>35,36</td>
<td></td>
</tr>
<tr>
<td>Communication processes and quality</td>
<td>Claims or administrative data</td>
<td>When and where communication took place</td>
<td>25</td>
</tr>
<tr>
<td>Patient experience&lt;sup&gt;a&lt;/sup&gt; Known</td>
<td>Patient or surrogate survey</td>
<td>Feels known (heard and understood)</td>
<td>96</td>
</tr>
<tr>
<td>Informed</td>
<td>Feels adequately informed about their or loved ones' care</td>
<td>97,98</td>
<td></td>
</tr>
<tr>
<td>In control</td>
<td>Feels in control of decision making and/or disease trajectory</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>Satisfied</td>
<td>Satisfaction with care</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>Quality of life</td>
<td>Quality of life</td>
<td>36,46,99–101</td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td>Trust in clinician or healthcare system</td>
<td>102,103</td>
<td></td>
</tr>
<tr>
<td>Therapeutic alliance</td>
<td>A sense of mutual understanding, caring, and trust with their physician</td>
<td>104</td>
<td></td>
</tr>
<tr>
<td>Shared decision making (inclusive of its direct outcomes)</td>
<td>Chart review, recorded or observed communication</td>
<td>Use of tools that promote shared decision making (e.g., best case/worst case, SHARE approach) or documented features of shared decision making</td>
<td>105–107</td>
</tr>
<tr>
<td>Advance directive or POLST completion</td>
<td>Chart review, registry data or patient or surrogate survey</td>
<td>Completion of advance directive, POLST or similar documentation to reflect their preference for future medical treatments</td>
<td>74,108,109</td>
</tr>
<tr>
<td>Family communication</td>
<td>Patient or surrogate survey</td>
<td>Patient reported communicated with family members about their future healthcare goals</td>
<td>62,110,111</td>
</tr>
<tr>
<td>Goal-concordant care Patient-reported outcomes</td>
<td>Patient survey</td>
<td>Trust or confidence that future care will be goal concordant</td>
<td>n/a</td>
</tr>
<tr>
<td>Patient-specific outcomes</td>
<td>Patient, advance directives or POLST registries, claims data</td>
<td>Utilization at the end of life reflects patient or surrogates previously stated or documented care goals (specific or general) or location of death</td>
<td>21,25,38,75,112–115</td>
</tr>
<tr>
<td>Population-specific outcomes</td>
<td>Claims or administrative data</td>
<td>Utilization of given therapies, care settings (including hospice), or location at the end of life; or utilization that may reflect care that is insensitive to patient or family goals and values (e.g., hospice use &lt;3 days or frequent transitions in last days of life)</td>
<td>76,116–119</td>
</tr>
<tr>
<td>Rhino care</td>
<td>Medical care</td>
<td>Patient received care in alignment with preferences, whether or not those preferences were known and/or discussed</td>
<td>62,87,110,120,121</td>
</tr>
<tr>
<td>Bereaved caregiver experience Quality of care</td>
<td>Bereaved caregiver survey</td>
<td>Quality of care across a number of domains, including symptom control and communication</td>
<td>21,84,122</td>
</tr>
<tr>
<td>Decisional conflict or regret</td>
<td>Decisional conflict or regret related to end-of-life care</td>
<td>75,123,124</td>
<td></td>
</tr>
<tr>
<td>Quality of life</td>
<td>Quality of life, including depression, anxiety, complicated grief, or post-traumatic symptoms</td>
<td>125–129</td>
<td></td>
</tr>
</tbody>
</table>

EOL, end of life; n/a, not applicable; POLST, physician’s orders for life-sustaining treatment.

**Communication quality and processes**

Barriers to collecting and analyzing the content of clinical encounters, through recordings or medical record documentation, impede the goal of directly measuring the quality of communication. An audio- or video-recorded medical encounter permits unfiltered analysis of communication content and is thus the measurement gold standard. To date, privacy concerns and logistical complexities have limited recording of communication to research studies. However, as
the boundaries of private and public communication increasingly blur, and personal recording devices proliferate, we might soon easily record all clinical encounters. Advances in natural language processing and machine learning offer the hope of analyzing recorded encounters at scale.

As an alternative to direct observation, these same technologies also make analysis of electronic health record (EHR) data increasingly feasible. Currently, EHR documentation poorly approximates actual communication, yet health systems can mitigate this challenge by implementing documentation templates that capture key domains of communication. For example, documentation of illness understanding, information preferences, prognostic communication, and patient goals, values, and treatment preferences suggest high-quality communication by recording elements of SDM.

Survey instruments to assess patients or family members’ perspectives on the quality of communication have been used as outcomes in randomized trials, but may be difficult to implement in clinical practice. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys and Family Evaluation of Hospice Care measures also assess communication, although in a limited way. More robust communication-focused instruments could be systematically deployed to seriously ill patients at key inflection points in the serious illness trajectory, including at the time of diagnosis, and enrollment in post-acute and hospice care. Cross-validation of these with direct communication measurements will contribute to our understanding of their respective validity.

One need not measure communication quality to measure its occurrence. Quality improvement programs, such as the Serious Illness Care Program, have demonstrated the feasibility of measuring the timing and setting of communication among seriously ill patients; researchers in Canada have

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**FIG. 1.** Cases illustrating the complexity of quality measurement of communication and goal-concordant care.

**Case A.**
Mr. A is a 67 yo man with NYHA Class IV congestive heart failure, hypertension, and type II diabetes who was admitted to the hospital an acute exacerbation of his chronic heart failure complicated by acute kidney injury. Despite multiple prior hospitalizations, and recent enrollment by his insurance company in a community-based palliative care program, he had never spoken with his physician or visiting nurse about his wishes should an acute illness be refractory to medical treatment. He was instructed shortly after admission for acute respiratory failure. In accordance with his religious faith, Mr. A’s wife, his healthcare proxy, believes that life should be prolonged at all lengths. Against the recommendation of the consulting nephrologist, she requested initiation of hemodialysis. Mrs. M. and Mr. A’s children, arriving from out of state, and hearing from the ICU team that he was not likely to recover from his illness, felt that his care should transition to a focus on comfort alone. Under pressure from their children and the medical team, Mrs. A changed her husband’s code status to DNR/DNI and Mr. A was extubated. Surprisingly, he survived removal of the ventilator and was transferred home on hospice, where he died peacefully 8 days later. Mrs. A remains angry and resentful, convinced that her husband might have survived longer had they pursued more aggressive treatment. She feels that his end-of-life care was not aligned with his goals. Unknown to her, Mr. A had completed a living will with his lawyer 6 months prior saying that he wouldn’t want any “extraordinary measures” to prolong his life. He kept it in his bedside drawer.

**Summary points:**
- No communication
- ACP (not shared)
- No shared decision making
- Hospice care
- Death at home
- Narrow bereavement outcomes

**Observations**
Cases A and B demonstrate the likely correlation between communication, goal-concordant care, and bereavement outcomes. Additionally, Case A, characterized by absent communication, unrecognized advance care planning, coercive decision making, and late bereavement outcomes resulted in positive utilisation outcomes, including hospice enrollment and death at home. By contrast, Case B, characterized by good communication, shared decision making and advance care planning, resulted in negative utilisation outcomes, including a late transition of care and death.

**FIG. 2.** Clinician–patient communication improves patient and caregiver experience enables shared decision making, and mediates goal-concordant care. Adapted from Street et al.
recently validated a set of quality indicators that include communication processes.40

Patient experience

Prospective or retrospective surveys may be used to directly or indirectly assess patient or family experience of communication quality.41–43 Patient ratings of communication and experience overlap conceptually and in practice, but are not the same. Therefore, it is important to assess both. Patient experience measures have driven improvement in care quality by enhancing adherence to recommended treatment processes, and are associated with improved outcomes and patient safety.44,45 Quality of life measures may also reflect patient experience, but most focus predominantly on the physical illness experience, which may respond less to communication.35,46,47 Ideally, clinician–patient communication helps patients feel known as people, informed, and in control of their care, measures of which remain underdeveloped.

Depression and anxiety commonly burden seriously ill patients and their families.48–51 Poor clinician communication can inadvertently contribute to these symptoms and interventions to improve communication have reduced symptoms of depression and anxiety.52,53 Conversely, well-intentioned communication may result in unintended consequences, including increased patient or family distress.54,55 For these reasons, a comprehensive assessment of communication outcomes and goal-concordant care should include measurement of anxiety, depression, or complicated grief as markers of the distress that poor communication or goal discordant-care may cause.

Shared decision making

Systematic and expert reviews highlight the difficulties of promoting, participating in, and measuring SDM.56–59 Systems may more feasibly measure the processes and anticipated outcomes of SDM, such as ACP or ACP engagement, than patient perceptions regarding the collaborative nature of their communication experience.60 Studies measuring ACP processes demonstrate mixed outcomes. For example, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) study showed no meaningful improvements in care among patients randomized to an intervention that included ACP.61 However, the Respecting Choices model of ACP has been shown to decrease hospitalizations and to improve caregiver awareness of patient wishes and perceived goal-concordant care.62,63

Patient–surrogate communication

Measuring patient–surrogate communication also carries benefit.24 First, uninformed surrogates complicate end-of-life decision making. Second, surrogates commonly assess patient’s wishes incorrectly and apply them inconsistently; neither surrogate assignment nor prior discussion of patient treatment preferences improve alignment on treatment choices in hypothetical scenarios.64 Finally, patients vary in how much leeway they wish to give surrogates, with some deferring to surrogates even when decisions contradict previously stated preferences.65 Furthermore, factors unrelated to clinician–patient communication (such as the patient–surrogate relationship) determine patient–surrogate communication. Despite these complexities, measuring patient–surrogate communication may facilitate quality improvement efforts to improve surrogate understanding of patient’s wishes and may address gaps in our understanding of the mechanism by which ACP results in goal-concordant care.

AD completion

Several quality frameworks support documentation of treatment preferences in an AD.9,66,67 However, AD completion remains a problematic quality indicator for several reasons. First, ADs do not always reflect SDM.68–70 Second, patients’ preferences may change as their illness progresses making previously completed AD no longer accurate.71,72 Third, ADs inconsistently demonstrate their impact on the delivery of goal-concordant care, with a majority of studies showing little association between the two.73 Finally, limited portability and inconsistent interpretation by family and clinicians limit implementation of ADs.70,73 Legal documents, such as living wills, are not universally accessible. Portable medical orders, such as Physician’s Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST), have been shown to influence location of death in accordance with stated preferences,74 but patient selection remains unclear and some have raised concerns about their interpretability and degree of patient centeredness.75 Because they are increasingly utilized and will remain part of the complex landscape of serious illness care,76 we should measure their completion and impact on goal-concordant care.

Goal-concordant care

Healthcare systems can assess goal-concordant care in four ways (Fig. 3): (1) patient- or surrogate-reported outcomes of goal-concordant care, (2) patient-specific care indicators, (3) population-specific care indicators, and (4) bereaved caregiver reports of whether end-of-life care was goal concordant.

While not widely used, patient-reported assessments of goal-concordant care present an opportunity to measure goal-concordant care before death. The SUPPORT investigators measured goal-concordant care by assessing agreement between patient preference for care focused on life extension or comfort, and patient assessment of whether or not current care aligned with that preference.61 Patients frequently value conflicting or contingent goals equally,77 making such a “forced choice” to some degree a false one. However, it may help clarify a patient’s highest priority, and whether or not a health system helps meet it. There may be other ways to prospectively assess goal-concordant care, including a single-item measure to assess confidence that a patient’s current or future care aligns, or will align, with their goals and values.

Patient-specific outcomes compare a known preference, usually communicated through an AD or portable medical order, and an end-of-life outcome, including care utilization or location of death. Uncertainty about the timing of preference measurement and methodological constraints related to identifying deceased patients and collecting utilization data from multiple settings complicate these approaches. Additionally, patients may provide general guidance for care that may not easily translate into specific care options.

Population-specific outcomes include trends in healthcare utilization over time and location of deaths.78,79 Comparison to survey data about care preferences may suggest a population-level goal concordance of care.80 Such measures
may help shape policy, and a recent study suggests that they may be meaningful for individuals, as less hospital care and more hospice care relate to higher caregiver-reported EOL care-quality outcomes.

Measuring bereaved caregiver’s perceptions regarding the goal concordance of their loved one’s end-of-life care remains an untapped domain of quality assessment. While surrogates commonly predict patient’s wishes inaccurately in hypothetical scenarios, their shared experience with the dying patient may be the closest thing we have to the patient’s own voice. Because preferences can change as illness progresses, surrogates’ beliefs about patient’s goals may be more accurate than those previously recorded by patients. A recent study found that, when compared with caregivers who reported goal-concordant care, those reporting goal-discordant care rated the quality of communication and quality of care lower. Limitations of this approach include the potential for multiple biases and challenges identifying surrogates. However, the Veterans Affairs administration’s Bereaved Family Survey and several mortality follow-back studies have demonstrated the feasibility of this approach.

**Bereaved caregiver experience**

Finally, measuring the bereaved caregiver’s experience represents an important quality measurement opportunity. When patients die, their loved ones are left to grieve, cope, and reconsider the care that took place over the patient’s illness trajectory. Healthcare resulting in bereaved caregivers feeling more anxious, depressed, traumatized, or regretful may reflect poor-quality EOL care and communication. We do not know if a lack of perceived goal concordance predicts complicated grief, or other negative outcomes, but such a relationship is plausible and should be investigated.

**Recommendations**

The cases in Figure 1 demonstrate the likely correlation between communication, goal-concordant care, and bereavement outcomes. The measurement challenges illustrated by these scenarios inform our recommendations for quality measures that should be implemented now in the care of seriously ill patients, and recommendations for the future. Specifically, they illustrate the need for specific goal-concordant care measures.

### Implementation-ready measures

Three quality indicators appear ready for implementation in cohorts of seriously ill patients: (1) timing and setting of serious illness communication; (2) patient (or surrogate) experience of communication and care; and (3) caregiver bereavement surveys that include assessment of perceived goal concordance of end-of-life care.

First, we advocate for measurement of when, where, and with whom communication happens, because it has the potential to drive improvement in the frequency, timing, and quality of communication. Communication is a prerequisite for delivering goal-concordant care, and sufficient evidence exists to suggest the benefit of timely, high-quality communication. Measuring this process is likely to have greater impact than measurement of AD completion alone.

Second, measurement of patient experience of communication and care will reflect the quality of communication and serious illness care as a whole. Some patient experience measures remain underdeveloped; others, including quality of life are valid, reliable, and meaningful.

Third, we advocate measurement of goal-concordant care through caregiver bereavement surveys, specifically by asking questions to assess whether caregivers believe that their loved one received care consistent with their values and preferences.

### Future measurement candidates

We recommend prioritizing three quality indicators for further development: communication quality, prospective patient or family assessment of goal-concordant care, and the bereaved caregiver experience. First, applying existing tools and technology to the direct measurement of communication remains limited by data access and privacy concerns. These obstacles are surmountable. Doing so could revolutionize serious illness care by placing the clinician–patient communication in a position that reflects its primacy in patients’ illness experiences. Second, prospectively assessing patient or surrogate-reported goal-concordant care may present real-time opportunities to improve communication and care. Preliminary findings from ongoing studies suggest that this outcome may be responsive to communication interventions. Third, attending to bereaved caregivers’ experiences will shape our understanding and delivery of serious illness care. Some aspects of their experience may reflect neither communication quality nor goal-concordant care. The experience of the bereaved matters. If the deceased could speak, this would likely be the thing that many would say matters most.

The proposed quality measures highlight research priorities in serious illness communication, particularly as we consider their applicability to accountability programs. We must understand the responsiveness of these measures to interventions; assess at multiple time points the relationship between current, prospective, and retrospective reports of goal-concordant care and actual care outcomes; and assess the relationships between and relative impact of clinician–patient communication on patient–surrogate communication, AD completion, and goal-concordant care.

### Conclusion

As we consider opportunities for systematic quality measurement in seriously ill patients, we advocate for ensuring that
communication has occurred, and for measuring its impact. The most important outcomes of communication, and indeed all of serious illness care, are the patient experience and the receipt of goal-concordant care. We have the tools to measure both.

Future research can address knowledge gaps. Yet, the lack of complete data should not stop implementation in the short term. Negative patient experiences and the delivery of goal-discordant care currently cause harm to patients and families. Our intolerance of these outcomes must be matched by our willingness to measure them.

Acknowledgments

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Author Disclosure Statement

No competing financial interests exist.

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Measuring Patient-Centeredness of Care for Seriously Ill Individuals: Challenges and Opportunities for Accountability Initiatives

Rebecca Anhang Price, PhD1 and Marc N. Elliott, PhD2

Abstract
Patient- and family-centeredness of care is particularly important for individuals with serious illness. In this article, we describe methodological challenges of using measures of patient- and family-centeredness in accountability initiatives such as public reporting and pay for performance. We begin with background on measuring patient- and family-centered care using standardized surveys, describe evidence of the use of these measures for quality improvement, and highlight methodological challenges in the development and implementation of these measures for use in accountability. To ensure that patient- and family-centeredness is the cornerstone of public and private accountability initiatives designed to promote high-quality care to seriously ill patients, we recommend development of (1) a nationally endorsed survey instrument that assesses patient and family experiences of serious illness care across the full range of patient trajectories and care settings in which this care is provided; (2) administrative data infrastructure that allows for identification and outreach to the most knowledgeable respondents for the survey, regardless of the patient’s setting of care; and (3) a broad toolkit of quality improvement approaches to ensure that as the emphasis on accountability grows, providers across settings have access to tools that can help them improve patient- and family-centeredness of care for the seriously ill.

Keywords: accountability initiatives; family-centeredness; patient-centeredness; quality improvement approaches

Introduction
Increasingly, national, state, and provider-level accountability initiatives, including public reporting and pay-for-performance, are being implemented to promote transparency and quality improvement across a range of health care settings. Evidence suggests that when these programs use a simple design with sufficiently large incentives, apply quality measures with a strong tie to evidence, and target a focused set of areas in greatest need for improvement, they can promote improvements in care.1-4

Patient-centeredness is a core element of high-quality health care,5 and accordingly, measures of patient-centeredness are increasingly included in national public reporting and pay-for-performance programs as complements to clinical process and outcomes measures. For seriously ill individuals, care is provided to both the patient and his or her family as a unit, and therefore, the goal is patient- and family-centered care, “…an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families…”6 in which “patients and families…determine how they will participate in care and decision-making.”6

Patient- and family-centered care—which can be directly measured through surveys of patients and their family caregivers—is associated with higher levels of adherence to
recommended prevention and treatment processes, better clinical outcomes, better patient safety within hospitals, and less health care utilization.2,7

Patient- and family-centeredness is particularly important for seriously ill patients, given great variability across patients with regard to both preferences for care intensity and tradeoffs between quality and length of life. In this article, we describe methodological challenges of using measures of patient- and family-centeredness in accountability initiatives such as public reporting and pay-for-performance. We begin with some background on measuring patient-centered care using standardized surveys, describe evidence of the use of these measures for quality improvement, and highlight methodological challenges in the development and implementation of these measures for use in accountability.

Measuring Patient-Centered Care with Standardized Surveys

The Agency for Healthcare Research and Quality (AHRQ)’s Consumer Assessment of Healthcare Providers and Systems (CAHPS) family of surveys includes standardized tools for assessing the experience of consumers receiving different types of health care, including ambulatory care delivered by health plans, physicians and physician groups, accountable care organizations, and facility-based care in hospitals and nursing homes, among several other settings and patient populations.

Most recently, the Centers for Medicare and Medicaid Services commissioned the development of the CAHPS Hospice Survey, which covers the domains of communication, timeliness of care, emotional and religious support, symptom management, respect, provision of hospice care training to family members, as well as overall ratings of care and willingness to recommend the hospice.21

Numerous other surveys have been developed and implemented to assess patient and family experiences with care at the end of life in particular (Table 1).22 Experiences in developing and implementing these surveys are instructive for future measure development that aims to assess care experiences of seriously ill adults, children, and infants across a range of disease trajectories and care settings.

<table>
<thead>
<tr>
<th>Table 1. Frequently-Cited, Validated Survey Instruments for Assessing Experiences with Care for the Seriously Ill</th>
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<tr>
<td>The Family Evaluation of Hospice Care survey, an after-death survey designed to report hospice quality from the perspective of the patient’s family or other informal caregiver. The most recent version of the survey, in use by hospices nationwide until 2015, included 10 sections with 55 questions (including 54 closed-ended questions and one open-ended) addressing care coordination, attention to family needs, symptom management, and communication. Survey results have been used by the National Hospice and Palliative Care Organization (NHPCO) to feedback information regarding hospice care quality to their provider members.39,45–51</td>
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<tr>
<td>The After-Death Bereaved Family Interview, a 74-item tool, includes questions related to information and care planning, symptom management, spiritual and religious support, and psychosocial and personal care. It can be used to assess care across settings.52–59</td>
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<tr>
<td>The View of Informal Carers—Evaluation of Services (VOICES) questionnaire asks caregivers about the problems they or the patient faced during the last three months of life, and about the care they received in different settings (i.e., home, nursing home, hospital, and hospice). In four of the five sections, respondents answer questions about the type and frequency of pain the care recipient experienced as well as therapies, communication with staff, quality and the type of care that the care recipient received, and overall satisfaction in these care settings. The last section consists of items not specific to the care setting related to patient/caregiver—provider communication, socioeconomic issues, and stress.60–63</td>
</tr>
<tr>
<td>The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments used an eight-item questionnaire to measure satisfaction with (1) patient comfort and (2) patient—provider communication and decision making. Family members answer questions on if more could have been done to make the patient comfortable during the last weeks of life, how well medical staff was able to explain the patient’s condition, if staff provided moral support to family members, and if staff carried out their decisions about patient care.54</td>
</tr>
<tr>
<td>The Family Assessment of Treatment at the End of Life is an after-death survey that assesses experiences of end-of-life care for Veterans. The 32-item questionnaire includes questions regarding communication, care around time of death, emotional and spiritual support, symptom management, and respect for treatment preferences.64,65 The FATE was shortened to the FATE-S, later referred to as the Bereaved Family Survey (BFS).66,67 The BFS contains only 14 questions to limit the time of interview, but still captures the majority of pertinent information collected for the FATE. The BFS is now completed for all inpatient Veteran Administration deaths in an effort to measure and improve quality of end-of-life care in this population.</td>
</tr>
<tr>
<td>The Quality of Dying and Death survey was developed at University of Washington, Seattle after literature review and qualitative study identifying the following six domains of care: symptoms and personal care, preparation for death, moment of death, family, treatment preferences, and whole person concerns. The entire survey is 31 questions and is intended for after-death interviews with family members.68–73</td>
</tr>
<tr>
<td>The Family Satisfaction with Advanced Cancer Care is a 16-item instrument designed to measure experiences with cancer care.74–82</td>
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experiences with physicians significantly improved following the introduction of statewide measurement, reporting, and performance-based financial incentives tied to scores on the CAHPS Clinician & Group Survey.\(^{23}\) Hospitals succeeded in improving Hospital CAHPS scores in response to required survey administration and public reporting,\(^{24,25}\) although additional improvements may not be attributable to introduction of value-based purchasing.\(^{26}\) Although there has been limited empirical study of the effects of quality improvement initiatives targeting patient-centeredness, case studies are instructive.\(^{27}\) Table 2 presents highlights of case studies describing successful initiatives targeted at improving patient- and family-centeredness.

**Methodological Challenges in Development and Implementation of Measures of Patient-Centeredness for Use in Accountability**

For use in accountability, quality measures must have several important features. They must (1) be “measures that matter” to the consumers who will use them to select among providers and to the providers being evaluated; (2) be collected and calculated in such a way as to be representative and valid assessments of care within a given provider; (3) have sufficient ability to distinguish between the performance of providers (i.e., adequate interprovider reliability); (4) leave room for improvement (i.e., not be “topped out”); and (5) allow for fair comparisons across providers. In this section, we highlight challenges to each of these criteria for development and implementation of measures of patient- and family-centeredness for the seriously ill.

**Measures that matter**

Seriously ill individuals, families, and providers must be integrally involved in development of survey measures to ensure their relevance. Seriously ill individuals vary greatly with regard to primary diagnosis, disease trajectory, and acuity of illness; these factors also affect patients’ likelihood of receiving care at home, in an acute care hospital, or a skilled nursing facility. Measures developed for use across these diverse patient subgroups and settings must therefore address goals of care that are common to all patient populations (regardless of the setting in which they receive care), such as symptom management, emotional support, and provider communication.

**Representative and valid**

Declining response rates to patient surveys have led to concern regarding representativeness of those who do respond, and in particular, whether nonrespondents differ from respondents in ways that are associated with how they respond to a given survey, resulting in nonresponse bias. Achieving the highest possible response rates is critical to reduce the perception and possibility of nonresponse bias, and to maximize the number of providers for whom scores can be stably estimated. Evidence to date suggests that mixed-mode administration (mail with telephone follow-up) produces the highest response rates on care experience surveys,\(^{28}\) although mixed-mode data collection is expensive relative to other modes.

Alternative, potentially less-costly modes, such as Internet-based platforms and point-of-service surveys, should be investigated carefully. Internet surveys may actually result in worse response rates than traditional modes,\(^{29}\) and it may not be possible to survey a representative sample, which is needed for accountability. Internet surveys yield their highest response rates when survey links are delivered by email; however, prior studies have shown great variability in comprehensive availability of valid email addresses across health care providers.\(^{30}\)

Point of service survey administration (i.e., surveying patients or family members at the location of care) faces a similarly important barrier in the context of accountability: ensuring that all (or a random sample of) eligible patients are invited to participate. This has proved challenging to achieve even in experimental settings,\(^{30,31}\) introducing potentially systematic bias to the survey sample. In particular, when staff members from the health care provider are responsible for recruiting respondents, they may (intentionally or unintentionally) bias who is sampled and how they respond. An experiment comparing point-of-service administration to other modes found that patients invited to participate in a survey by clinic staff at the point of service gave more favorable responses than patients responding via other modes.\(^{30}\)

Lower response rates to high-quality surveys based on probability samples are not consistently related to nonresponse bias;\(^{32}\) to address the possibility of biased comparisons,
however, results can be adjusted using available data. For example, case-mix adjustment models (described in more detail below) that include factors such as age and health status that are related to nonresponse help to compensate for bias associated with these factors when comparing health care providers; some patient survey analyses further adjust for possible nonresponse bias resulting from differential response rates across hospitals.

An additional challenge to representativeness of survey results for the seriously ill is that direct reports from such patients may not be feasible because of illness acuity and speed of clinical decline. Patients who are able and willing to participate in surveys therefore are not broadly representative of all seriously ill patients. For patients with dementia and other diagnoses and disease progressions that impact cognitive function, family caregivers are critical informants for understanding care experiences. Regardless of diagnosis, the role of family caregivers tends to increase over the trajectory of the illness. To ensure that surveys capture the care experiences of seriously ill patients regardless of their ability to participate, family caregivers must be allowed to act as proxy respondents for surveys administered during the course of patient care. In addition, family caregivers are the only available respondents for after-death surveys that assess care in the final days of life.

As members of the unit of care, family caregivers can provide direct reports of their own experiences with the care team and provide proxy reports of their family members’ experiences. When acting as proxies, family caregivers’ responses have moderate-to-high agreement with patient responses regarding observable symptoms, such as fatigue or shortness of breath, and quality of care, such as being kept informed by health care providers; however, family caregivers’ responses to questions regarding less observable symptoms, such as pain, anxiety, and depression, exhibit lower agreement with patient responses. This suggests that survey questions should be designed with the respondents’ role as an “expert observer” in mind—that is, question content should be framed to capture reports of observed experiences rather than inferences regarding patient experiences.

Although proxy respondents may sometimes answer differently than patients would have, there is no reason to believe that these differences reduce the validity of comparisons of care experiences by proxies across provider organizations. Survey results can be statistically adjusted to address the effects of proxy responses; such adjustments address both the systematic differences in response tendencies resulting from proxy response, as well as the underlying differences in health that result in proxies responding rather than patients.

**Distinguishing between providers**

Many health care providers are either too small, or care for too few patients at the end of their lives, to generate a sufficient number of completed surveys to promote adequate measure reliability. Reliability is the ability of a measure to distinguish between the performances of health care providers; reliability generally improves when sample sizes increase. When reliability is poor, measure scores are of limited value for comparing and rewarding the performance of providers or informing consumer choice.

The most direct approach to addressing the small numbers problem is to pool measure data in various ways. Pooling survey measure data over longer time periods, for example, improves the overall number of surveys used to compute the measure scores. The downside of this approach is that it includes data from a considerable lag, forgoing some responsiveness and immediacy; however, that tradeoff is usually worthwhile, since change is often slower to take place than might be anticipated. Statistically smoothing techniques allow for data to be pooled over time, but still to be used to predict current performance without masking improvements or declines occurring over the whole period.

Alternatively, survey measure data can be pooled across small facilities or facilities with common characteristics. The appropriateness of this pooling can be assessed empirically. For example, if a parent provider organization has many sites providing care to the seriously ill, is the organization-level driving performance or perhaps are setting-specific factors more dominant such that performance measurement should be aggregated within setting, then within the organization?

**Topped-out measures**

When a measure has low reliability (i.e., it does not have strong ability to distinguish the performance of one hospice from another), and its mean is near the top of the scale (i.e., near 100 for a top-box score), it has little to no room for quality improvement and may be deemed “topped-out.” Patients report very favorable care experiences at the end of life, perhaps reflecting better access to care; nonetheless, capturing variation in care experiences for seriously ill patients is critical for making comparisons across providers and identifying areas in need of further quality improvement.

Topped-out measures are often retired and replaced in accountability programs, although continued incentives may be important to maintain high performance on these measures. As an alternative to retiring topped-out measures, high-performing measures can be used to identify problems rather than to compare performance for all entities. Although it may be difficult to distinguish exceptional hospices or capture improvement in the context of topped-out measures, there may be better power to identify providers that are problematic. From the perspective of payers, policy makers, and patients and families, being able to flag problematic providers actually may be of higher priority than differentiating between excellent and very good providers.

Care experiences vary substantially by setting; Teno et al. reported that family members of those who received care from hospice at home more likely to report favorable experiences than those whose family members received care in nursing homes or hospitals, particularly with regard to emotional support, for example. Consequently, measures may be topped-out in some settings of care, but not others. Such measures are still valuable in accountability programs. Variability in measure scores across settings can help providers and payers to steer patients toward settings most likely to meet their needs. In addition, measures with lower scores in a given setting represent opportunities for improvement within that setting.

**Fair comparisons between providers**

As noted above, relevant topical domains, patient populations, and caregiver familiarity with care may vary considerably across settings of care. To ensure that survey scores
can be fairly compared across providers, despite differences in the types of patients they care for and the settings in which they provide care, survey scores must be adjusted for factors that influence how patients and family caregivers respond to survey questions, but are (1) not within the providers’ control, and (2) not associated with the quality of care provided.

Case-mix adjustment uses statistical models to predict what each provider’s score would have been for a standard patient population, thereby removing from comparisons the predictable effects of differences in patient characteristics that vary across providers. A case-mix adjusted measure score for a provider, therefore, can be interpreted as what we would expect that provider’s score to be if it had a patient population with characteristics that were the same as the standard patient population (e.g., the national average).

Importantly, adjustments should not be made for factors that might be a consequence of the care provided or are within the control of the provider. For example, as noted above, care experiences vary by care setting; thus, survey scores should not be adjusted for care setting, since doing so would mask true differences in care quality across settings within a provider. Similarly, since family involvement in care may be somewhat in the control of health care providers, scores should not be adjusted for level of caregiver involvement, lest these adjustments mask true differences in care quality between providers.

While some measures assess content that is broadly applicable across settings, other survey content might be applied only for a subset of settings for which they are relevant. Regardless of whether setting-specific measures are included in accountability measure sets, these measures can serve as important guides to quality improvement within given settings of care. Setting-specific measures can be operationalized by either (1) asking questions only of those respondents who had experience with the given setting or (2) asking questions of all respondents, regardless of setting, but calculating measure scores only for those with experience in the relevant setting(s).

In addition, linear mixed-effect models allow for assessment of how a provider may perform differently on a given measure across the settings, in which it provides care.

Priorities for Research and Practice

Attention to several priorities is needed to ensure that patient-centeredness is the cornerstone of public and private accountability initiatives designed to promote high-quality care to seriously ill patients.

First, there must be a nationally endorsed survey instrument that assesses patient and family experiences of serious illness care across the full range of patient trajectories and care settings in which this care is provided. Such an instrument could be built off the extensive effort that has gone into development of existing surveys, such as those described in Table 1, with refinements based on new qualitative inquiry with patients, families, and providers in each relevant setting to ensure that the instrument reflects the highest-priority care domains and those most amenable to quality improvement at each stage of care, from enrollment through ongoing care, care at times of crisis, and the actively dying phase.

Development work conducted to inform the development of existing surveys suggests that domains likely to be of greatest importance are communication and shared decision making, physical comfort, dignity and respect, emotional support, and educating family caregivers to care for their family member at home, among others. In addition, particular attention will need to be paid to development of measures in the domains of consistency of care with patient preferences and shared decision making.

Second, administration of surveys to family caregivers requires consistent and comprehensive methods and data systems to identify the most knowledgeable respondent for the survey, regardless of the patient’s setting of care. The CAHPS Hospice Survey relies on hospice administrative records to identify the primary caregiver most knowledgeable about the care received by the decedent; to apply a similar approach to surveys of care in other settings and programs that provide care to the seriously ill, providers would need to maintain current and accurate records for family caregivers, specifically identifying caregivers who are most involved in the care of the patient, as well as up-to-date contact information, including email addresses and mobile telephone numbers, to open the possibility of alternative modes of survey administration.

Finally, the literature on quality improvement initiatives aimed at experiences of care among seriously ill patients and their families is limited. In tandem with development of new tools to measure care experiences of these groups, development of a broad toolkit of quality improvement approaches to address key domains of patient- and family-centeredness is a key priority to ensure that as the emphasis on accountability grows, providers across settings have access to tools that can help them improve.

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Changing Structures and Processes to Support Family Caregivers of Seriously Ill Patients

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Abstract

Background: Although family caregivers provide a significant portion of health and support services to adults with serious illness, they are often marginalized by existing healthcare systems and procedures. Objective: We examine the role of caregivers in existing systems of care, identify needed changes in structures and processes, and describe how these changes might be monitored and assessed and who should be accountable for implementing them. Design: Based on a broad assessment of the caregiving literature, the recent National Academy of Sciences Report on family caregiving, and descriptive data from two national surveys, we describe structural and process barriers that limit caregivers’ ability to provide effective care. Subjects: To describe the unique challenges and impacts of caring for seriously ill patients, we report data from a nationally representative sample of older adults and their caregivers (National Health and Aging Trends Study [NHATS]; National Study of Caregiving [NSOC]) to identify the prevalence and impact on family caregivers of seriously ill patients who have high needs for support and are high cost to the healthcare system. Measurements: Standardized measures of patient status and caregiver roles and impacts are used. Results: Multiple structural and process barriers limit the ability of caregivers to provide effective care. These issues are exacerbated for the more than 13 million caregivers who provide care and support to 9 million seriously ill older adults. Conclusions: Fundamental changes are needed in the way we identify, assess, and support caregivers. Educational and workforce development reforms are needed to enhance the competencies of healthcare and long-term service providers to effectively engage caregivers.

Keywords: family caregiver training; financial concerns; role of family caregivers; support for family caregivers

Introduction

Nearly 18 million family caregivers, broadly defined as relatives, partners, friends, or neighbors, provide care and support to older adults because of limitations in their physical, mental, or cognitive functioning. 1 Millions more provide care and support to younger individuals with serious illness and disability. Family caregivers arrange and attend medical appointments, participate in routine and high-stakes treatment decisions, coordinate care and services, help with...
daily tasks such as dressing and bathing, manage medicines, obtain and oversee the use of medical equipment, and ensure that needs for food and shelter are met. Family members have always been the primary source of support and assistance to older parents, grandparents, and other family members during times of illness and when they can no longer function independently. What has changed in the last few decades is that this job has become more complex and longer lasting because of medical advances, shorter hospital stays, and increased longevity.

The goal of this article is to examine the role of caregivers in existing systems of care, identify needed changes in structures and processes, how these changes might be monitored and assessed, and who should be accountable for these changes. We begin by identifying structural and process barriers that limit caregivers' ability to provide effective care to caregivers of all older adults with illness and disability, including those with serious illness. We argue that addressing these barriers will require fundamental changes in the way we (1) identify and assess caregivers; (2) support them; and (3) train healthcare and long-term service and support (LTSS) providers to effectively engage caregivers.

To better understand the role of caregiving for seriously ill patients, we also focus on caregiving for three types of high-needs and high-cost patients—those with multiple chronic conditions, dementia, and/or are at end of life. These individuals fit the definition for serious illness, “a condition that carries a high risk of mortality and either negatively impacts a person’s daily function or excessively strains their caregivers”,”2 and represent subgroups of patients for whom the stakes for caregivers, patients, and society are especially high. We describe the prevalence of these populations using recent national data and describe how they affect caregiving roles and outcomes. Note that we use the terms high need and seriously ill interchangeably in this article, and we acknowledge that the three patient groups we focus on do not represent all seriously ill patients.

Structural and process barriers to effective care

To fulfill their roles, caregivers serve as the glue that connects healthcare and social service providers to the individual in need of care. They interact with physicians, nurses, social workers, psychologists, pharmacists, physical and occupational therapists, direct care workers, and others. In addition to being direct care providers for the patient, they also serve as the primary source of information about the patient’s health history, abilities, and preferences. Yet, family caregivers are often marginalized in the delivery of healthcare and LTSS.

A confluence of structural and process barriers impedes effective partnerships between family caregivers and other providers of care. The prevailing emphasis on supporting individual autonomy and safeguarding the privacy of personal health information limits family caregivers’ access to information that is appropriate and beneficial when they are responsible for coordinating care or managing treatments. Medical providers are not compensated for time spent educating family caregivers about patients’ medical conditions and treatments, nor are they trained to have those conversations. Although clinical assessments used to formulate treatment plans commonly include questions for patients about the availability of help, caregivers are not asked about their ability to provide care or their relevant knowledge, and receipt of training in performing caregiving tasks is inconsistent at best. The availability and adequacy of family caregiving are simply assumed.1

Guidance on how to address these issues is provided by the recent National Academies of Sciences, Engineering, and Medicine report on family caregiving,1 which calls for transformation in the policies and practices affecting the role of families in the support and care of older adults, stating that today’s emphasis on person-centered care needs to evolve into a focus on person- and family-centered care. Although focused specifically on caregiving for older adults, the recommendations apply equally well to caregiving for adults of all ages. We focus, in this study, on those policy recommendations relevant to the key structures and processes of care that need to be changed to fully integrate caregivers into healthcare and LTSS systems.

Identifying and assessing caregivers

Caregivers’ circumstances vary widely and in ways that affect their availability, capacity, and willingness to assume critical responsibilities. Evidence from randomized clinical trials indicates that most effective interventions begin with an assessment of caregivers’ risks, needs, strengths, and preferences.3,4 Yet most health and LTSS providers do not assess the health, skills, employment, and willingness of family caregivers and provide them little, if any, training to carry out the complicated medical procedures, personal care, and care coordination tasks they are expected to provide. Indeed, the lack of systematic assessment of family participation in health and LTSS not only affects the experience of family caregivers and care recipients but also precludes knowledge of how their involvement influences the quality of clinical care and social services, and undermines credible accounting of the value family caregivers bring to the healthcare delivery system and society.

Optimizing the role of family caregivers will minimally require systematic attention to the identification, assessment, and support of family caregivers throughout the care delivery process. How might this be achieved? First, caregivers need to be identified in both the care recipient’s and the caregiver’s medical record (Table 1). This acknowledges their role as part of a care team and sensitizes providers to the importance of engaging the caregiver when making patient treatment plans. Second, caregivers should be screened to identify those at risk for adverse health outcomes and whose circumstances may place the person they care for in harm’s way. Achieving this goal will require new tools that assess caregivers’ strengths, limits, needs, and risks in relationship to the range of tasks they are expected to perform. Assessments should minimally include caregivers’ health and functional status, their level of stress and well-being, their ability to perform required tasks, and the types of training and supports they might need to enact their role. These assessments should occur during all key provider patient/caregiver encounters, including wellness exams, physician visits, admission and discharge from hospitals and emergency rooms, and chronic care coordination and care transition programs.

Key initial steps to implementing this recommendation will require identification and refinement of caregiver assessment tools appropriate to the care delivery context of the care recipient, identification and training of assessors, and evaluation of provider work flow to determine where and when assessments take place. The health, functional ability,
and care needs of the patient should be a key factor in determining the fit between patient needs and caregiver capacity, which in turn should inform the training and support needs of the caregiver.

With few exceptions, there are no financial incentives for providers to identify, assess, or support family caregivers or penalties for not doing so. For example, the Caregivers and Veterans Omnibus Health Services Act of 2010 established a mechanism for reimbursement/workload credit for services provided to family caregivers, but the focus is primarily on caregivers of younger veterans. The Centers for Medicare and Medicaid Services should be charged with developing testing and implementing provider payment reforms that motivate providers to engage family and support caregivers. Payment reforms should include clearly articulated performance standards that hold providers accountable for caregiver engagement, training, and support by explicitly including caregiver outcomes in quality measures. Outcome measures should include caregiver satisfaction with provider encounters, adequacy of training and instructions provided, caregivers’ confidence and efficacy in performing required tasks, and the adequacy of support services provided.

Both process measures identified in Table 1 and outcome measures listed above should receive high priority for further development with the goal of meeting the standards and endorsement of the National Quality Forum. We envision a measurement strategy that includes a common core that can be used across care settings along with a set of context-specific measures that capture the unique caregiving challenges for patients in hospital, nursing home, hospice, and home care settings.

The recommendations made above stand in sharp contrast to the current reality of caregiver assessment in our healthcare system. The Caregiver Advise, Record, Enable (CARE) Act enacted in more than 20 states is one small step in the right direction as it encourages hospitals to (1) record the name of the family caregiver at the time of hospital admission of their loved one; (2) provide family caregivers with adequate notice before hospital discharge; and (3) provide simple instruction of the medical tasks they will be performing when their loved one returns home. Proposed national legislation such as the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act is a bipartisan bill that would create a national plan to support the more than 40 million Americans caring for older adults, spouses, children with disabilities, veterans, and other people who need care to live independently.

Supporting caregivers

Guidance on how best to support caregivers can be gleaned from a large body of intervention research aimed at improving caregiver and patient outcomes. Education and skills training improve caregiver confidence and the ability to manage daily care challenges. Training strategies that involve active participation of the caregiver are particularly effective in achieving positive outcomes. Counseling, self-care, relaxation training, and respite programs can improve caregivers’ and patients’ quality of life. Technology-based caregiver support, education, and skills training can be an effective and efficient alternative for enhancing caregiver knowledge and skills.

Despite the demonstrated effectiveness of a wide range of caregiver services and supports, few of these intervention strategies have moved from research settings to everyday health and social service programs. Key questions that need to be addressed in pursuing widespread implementation of proven interventions include who should deliver these support strategies, where and when should they be delivered, how can they be integrated into the existing workflow of provider organizations, and who should pay for their delivery and evaluation? The National Family Caregiver Support Program (NFCS) of the Administration for Community Living is one example of a federal program that incorporates elements of evidence-based caregiver interventions into broad-based service programs for caregivers. These relatively modest efforts should be scaled up and expanded. At the same time, we should continue to support efficacy trials aimed at developing and refining support strategies for caregivers.

Enhancing competencies of healthcare and LTSS providers to engage caregivers

Providers should see family caregivers not just as a resource in the treatment or support of a person, but rather as a partner in that enterprise who may need information, training, care, and support. Achieving and acting on that perspective require that providers have the skills to recognize a caregiver’s presence, assess whether and how the caregiver can best participate in overall care, engage and share information with the caregiver, recognize the caregiver’s own healthcare

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### Table 1. Caregiver Assessment

<table>
<thead>
<tr>
<th>Who</th>
<th>When</th>
<th>What</th>
<th>Where</th>
<th>Assessor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify primary caregiver responsible for patient care, entered in patient and caregiver medical record</td>
<td>• Wellness/follow-up visits for patient/caregiver</td>
<td>• Health/functional and emotional status of caregiver</td>
<td>• Physician offices</td>
<td>• Primary care provider</td>
</tr>
<tr>
<td></td>
<td>• Care transitions (admission/discharge from hospitals, emergency rooms/ rehab facilities to home)</td>
<td>• Knowledge and skills for required care tasks</td>
<td>• Receiving/discharge facility</td>
<td>• Discharge planners</td>
</tr>
<tr>
<td></td>
<td>• Chronic care transitions/ change in patient status</td>
<td>• Willingness to carry out required tasks</td>
<td>• Caregiver/patient home</td>
<td>• In-home assessors</td>
</tr>
<tr>
<td></td>
<td>• Regular follow-up monitoring</td>
<td>• Financial and human support resources available to caregiver</td>
<td>• Hospital</td>
<td>• Caregiver specialists</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Training and support needed</td>
<td>• Nursing home</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Hospice</td>
<td></td>
</tr>
</tbody>
</table>
and support needs, and refer the caregiver to needed services and supports. A wide range of professionals and direct care workers are likely to interact with family caregivers—physicians, nurses, social workers, psychologists, pharmacists, occupational therapists, physical and other rehabilitation therapists, certified nursing assistants, physician assistants, and others. Professional organizations in nursing and social work have led the way in taking steps to establish standards for person- and family-centered care that include the caregiver. Similar efforts are needed across the healthcare and social service professions. Federal support is needed from the U.S. Department of Health and Human Services (HHS) for the development and enforcement of competencies for identifying, assessing, and supporting family caregivers by healthcare and human service professionals. Achieving this goal requires that specific competencies are identified by provider type, including competencies related to working with diverse family caregivers. These competencies should in turn shape the development of educational curricula and training programs designed to teach them. Professional societies and accrediting bodies should develop educational curricula and support their systematic evaluation and implementation, and should convene and collaborate with state agencies and professional organizations to incorporate competencies into standards for licensure and certification.

**Seriously ill patients and their caregivers**

Although the preceding recommendations apply to caregiving broadly defined, they take on special significance when caring for seriously ill high-need/high-cost patients where the intensity, duration, and adverse impact of caregiving reach extreme levels. To better understand the impact of seriously ill patients on caregivers, we analyzed the National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC) data to identify the types of tasks performed by caregivers and caregiver outcomes for three types of patients: (1) patients who have three or more chronic diseases and a functional limitation in their ability to care for themselves or perform routine daily tasks; (2) patients with a diagnosis of probable dementia; and (3) patients at the end of life, defined as individuals who died within one year of baseline assessment. Together, these three groups represent some of the highest cost patients in the United States, accounting for majority of health and long-term care expenditures. In addition, family caregivers provide billions of hours of unpaid care to these populations annually. For example, the Alzheimer’s Association estimated that in 2015, 15.9 million family and friends provided 18.1 billion hours of unpaid care to those with Alzheimer’s and other dementias, an economic value of $221 billion.

Inasmuch as there is overlap among the three groups, we also examined all possible combinations of these three groups to explore the additive effects of, for example, caring for patients who have multiple chronic conditions, dementia, and are at end of life. This overlap is clearly illustrated in Figure 1 with corresponding population estimates based on NHATS (patient population, N = 7609). In this nationally representative sample of adults (NHATS) aged 65 and over, 35% of 35.3 million older adults met criteria for at least one of the three groups of interest. Six percent met criteria for at least two categories, and slightly less than 1% (290,000 persons) met criteria for all three; they had dementia, at least three chronic conditions and a functional limitation, and died within a year. We also show in Figure 1 the proportion of patients in each group who received help from an unpaid caregiver, ranging from 75% of patients at the end of life to 97% for patients who met criteria for all three groups.

Table 2 provides context information about caregiving, including the duration and number of hours of care provided per month, and Table 3 summarizes the types of tasks performed by caregivers for each of the three groups and their combinations. As shown in Table 2, caregivers of patients who meet...
multiple high-need categories provide considerably more hours of care than caregivers of low-need patients. For example, 33% caregivers of patients with chronic conditions, dementia, and who are at end of life, provided more than 100 hours of care per month compared to 14% of caregivers caring for low-need patients. Table 3 shows that caregivers of high-need patients are more likely to provide help with virtually all types of tasks when compared to caregivers of low-need patients. With a few exceptions, the level of caregiver help provided is highest among caregivers caring for individuals who meet criteria for all three groups, followed by caregivers caring for persons meeting criteria for two of the three groups.

### Table 2. Caregiving Context by Patient Category

<table>
<thead>
<tr>
<th>Sample size</th>
<th>444</th>
<th>714</th>
<th>49</th>
<th>274</th>
<th>47</th>
<th>53</th>
<th>326</th>
<th>89</th>
</tr>
</thead>
</table>

| Weighted population estimates (millions) | 4.30 | 6.80 | 0.41 | 2.20 | 0.37 | 0.60 | 2.60 | 0.70 |

<table>
<thead>
<tr>
<th>Relationship to CR (%)</th>
<th>Spouse</th>
<th>26.3</th>
<th>13.7</th>
<th>18.0</th>
<th>13.7</th>
<th>23.1</th>
<th>24.0</th>
<th>15.1</th>
<th>8.9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter/daughter-in-law/stepdaughter</td>
<td>27.7</td>
<td>28.5</td>
<td>35.9</td>
<td>24.0</td>
<td>30.7</td>
<td>38.1</td>
<td>42.0</td>
<td>52.7</td>
<td></td>
</tr>
<tr>
<td>Son/son-in-law/stepson</td>
<td>22.0</td>
<td>20.5</td>
<td>20.5</td>
<td>35.1</td>
<td>19.7</td>
<td>10.3</td>
<td>22.0</td>
<td>25.7</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>24.0</td>
<td>37.3</td>
<td>25.6</td>
<td>27.1</td>
<td>26.5</td>
<td>27.6</td>
<td>20.8</td>
<td>12.8</td>
<td></td>
</tr>
</tbody>
</table>

| Lives with CR (%) | 41.4 | 47.2 | 39.3 | 41.2 | 46.3 | 56.8 | 46.6 | 41.5 |

| CR has paid help (%) | 18.1 | 18.6 | 18.6 | 18.6 | 18.2 | 17.6 | 28.3 | 26.2 |

<table>
<thead>
<tr>
<th>Years of caregiving (%)</th>
<th>1 or less</th>
<th>18.6</th>
<th>11.5</th>
<th>11.8</th>
<th>8.4</th>
<th>14.8</th>
<th>31.2</th>
<th>12.6</th>
<th>14.9</th>
</tr>
</thead>
<tbody>
<tr>
<td>2–4</td>
<td>30.5</td>
<td>36.9</td>
<td>41.1</td>
<td>29.7</td>
<td>34.7</td>
<td>36.9</td>
<td>35.6</td>
<td>36.0</td>
<td></td>
</tr>
<tr>
<td>5–10</td>
<td>32.6</td>
<td>34.5</td>
<td>32.1</td>
<td>59.8</td>
<td>33.9</td>
<td>25.9</td>
<td>41.6</td>
<td>36.8</td>
<td></td>
</tr>
<tr>
<td>&gt;10</td>
<td>18.3</td>
<td>17.1</td>
<td>15.0</td>
<td>2.0</td>
<td>16.7</td>
<td>6.0</td>
<td>10.3</td>
<td>12.4</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hours of caregiving per month (%)</th>
<th>1–16</th>
<th>41.2</th>
<th>30.7</th>
<th>30.4</th>
<th>27.0</th>
<th>36.4</th>
<th>17.5</th>
<th>21.3</th>
<th>24.7</th>
</tr>
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<tbody>
<tr>
<td>17–40</td>
<td>23.0</td>
<td>33.4</td>
<td>26.8</td>
<td>20.0</td>
<td>24.7</td>
<td>19.6</td>
<td>28.6</td>
<td>17.0</td>
<td></td>
</tr>
<tr>
<td>41–100</td>
<td>21.7</td>
<td>23.6</td>
<td>24.5</td>
<td>21.0</td>
<td>22.4</td>
<td>38.8</td>
<td>23.1</td>
<td>24.8</td>
<td></td>
</tr>
<tr>
<td>&gt;100</td>
<td>14.1</td>
<td>12.3</td>
<td>18.3</td>
<td>32.1</td>
<td>16.5</td>
<td>24.1</td>
<td>27.0</td>
<td>33.5</td>
<td></td>
</tr>
</tbody>
</table>

National Study of Caregiving (NSOC, 2011).
*Patient does not meet high-need patient criteria, but has limitations in IADL and/or ADL.

### Table 3. Types of Caregiving Tasks by Patient Category

<table>
<thead>
<tr>
<th>CG tasks</th>
<th>Low need*</th>
<th>Chron cond Died</th>
<th>Dementia</th>
<th>Dementia+ died</th>
<th>Chron cond+ dementia</th>
<th>Chron cond+ dementia+ Died</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often did you help... (every day or most days) (% yes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With chores</td>
<td>39.2</td>
<td>43.0</td>
<td>44.9</td>
<td>44.3</td>
<td>43.3</td>
<td>62.3</td>
</tr>
<tr>
<td>With personal care</td>
<td>9.3</td>
<td>14.7</td>
<td>20.0</td>
<td>22.9</td>
<td>33.7</td>
<td>36.6</td>
</tr>
<tr>
<td>Drive CR places</td>
<td>22.8</td>
<td>26.3</td>
<td>17.7</td>
<td>23.8</td>
<td>18.2</td>
<td>22.5</td>
</tr>
<tr>
<td>Help CR get around his/her home</td>
<td>13.1</td>
<td>19.2</td>
<td>11.9</td>
<td>20.3</td>
<td>37.8</td>
<td>41.2</td>
</tr>
<tr>
<td>Did you help... (% yes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keep track of meds</td>
<td>38.8</td>
<td>43.0</td>
<td>39.9</td>
<td>58.8</td>
<td>50.2</td>
<td>48.5</td>
</tr>
<tr>
<td>CR take shots or injections</td>
<td>4.7</td>
<td>8.8</td>
<td>3.1</td>
<td>7.7</td>
<td>11.7</td>
<td>8.2</td>
</tr>
<tr>
<td>Manage medical tasks</td>
<td>4.1</td>
<td>11.3</td>
<td>11.2</td>
<td>9.9</td>
<td>15.9</td>
<td>8.0</td>
</tr>
<tr>
<td>With special diet</td>
<td>19.5</td>
<td>31.8</td>
<td>25.6</td>
<td>22.9</td>
<td>16.6</td>
<td>27.8</td>
</tr>
<tr>
<td>With skin care wounds</td>
<td>18.3</td>
<td>24.2</td>
<td>24.2</td>
<td>17.2</td>
<td>19.2</td>
<td>20.7</td>
</tr>
<tr>
<td>Make medical appointments</td>
<td>50.1</td>
<td>55.7</td>
<td>64.3</td>
<td>75.9</td>
<td>79.4</td>
<td>48.9</td>
</tr>
<tr>
<td>Speak to medical provider</td>
<td>42.8</td>
<td>51.3</td>
<td>48.8</td>
<td>68.4</td>
<td>78.2</td>
<td>54.9</td>
</tr>
<tr>
<td>Add/change health insurance</td>
<td>22.3</td>
<td>23.1</td>
<td>16.9</td>
<td>31.2</td>
<td>35.0</td>
<td>28.5</td>
</tr>
<tr>
<td>With other insurance matters</td>
<td>27.6</td>
<td>31.7</td>
<td>30.3</td>
<td>42.8</td>
<td>52.4</td>
<td>18.0</td>
</tr>
</tbody>
</table>

*Patient does not meet high-need patient criteria, but has limitations in IADL and/or ADL.

CG, caregiver.
An extensive literature shows that caregivers are at increased risk of physical and psychiatric morbidity. They experience emotional distress, depression, anxiety, and social isolation. When the intensity and duration of caregiving is high, self-care and physical health of the caregiver may be impaired. In the NSOC sample, nearly half of all caregivers report emotional difficulty in caring for their loved one, and one fifth report financial and physical difficulty in providing care. These rates are consistently higher among caregivers of high-need patients.

In sum, these data show that caregivers of high-need patients provide large amounts of care over extended periods of time and they are at risk for adverse outcomes jeopardizing their own and the care recipient’s well-being. Identifying, assessing, and supporting these caregivers will be essential to a healthcare system that depends on them to provide the lion’s share of the care for these patients. Accomplishing these goals will require assessment tools tailored to these populations, support options that address the unique challenges faced by these caregivers, and new training programs that prepare providers to effectively engage caregivers of these populations.

Because seriously ill patients are likely to experience more rapid changes in symptomatology and functional status than other patients, it will be important to closely monitor patient status and the caregiver’s ability to address changing patient needs. The high intensity of caregiving demands also puts the caregiver at risk for adverse health outcomes, making it all the more important to monitor caregiver stress and emotional and physical well-being. Frequent and effective communication between caregivers, patients, and the healthcare team will be essential to achieving these goals. Supporting caregivers of seriously ill patients should focus on their role in managing pain and other symptoms, teaching them the philosophy and “how to” of providing comfort care, negotiating care transitions, and addressing the psychological distress and physical health needs of caregivers.

Conclusion

The availability of family caregivers in the future is threatened by the higher rates of childlessness among baby boomers, smaller and more geographically dispersed families, and increasing participation of women in the labor force. At the same time, advances in medicine that save and extend lives increase the duration, complexity, and technical difficulty of care required by individuals with serious illness and disability. Family caregivers will continue to play a vital role in existing healthcare and LTSS systems. However, their willingness to provide care and their effectiveness in doing so will depend on fundamental changes in the extent to which we formally recognize them as key contributors to the health of their relatives, integrate them into the formal provider systems, and support them to do their job. The stakes are high, particularly for high-need, high-cost patients whose quality of life critically depends on the availability of a family caregiver, and for society as a whole responsible for providing high-quality and cost-effective care.

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17. National Study of Caregiving: Produced and distributed by www.nhats.org with funding from the U.S. Department of Health and Human Services’ Office of the Assistant Secretary for Planning and Evaluation in cooperation with the National Institute on Aging (Grant Number NIA U01AG32947).


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Measurement of Chronic Pain and Opioid Use Evaluation in Community-Based Persons with Serious Illnesses

Kathleen Puntillo, RN, PhD1 and Ramana K. Naidu, MD2

Abstract

Background: Chronic pain associated with serious illnesses is having a major impact on population health in the United States. Accountability for high quality care for community-dwelling patients with serious illnesses requires selection of metrics that capture the burden of chronic pain whose treatment may be enhanced or complicated by opioid use.

Objective: Our aim was to evaluate options for assessing pain in seriously ill community dwelling adults, to discuss the use/abuse of opioids in individuals with chronic pain, and to suggest pain and opioid use metrics that can be considered for screening and evaluation of patient responses and quality care.

Design: Structured literature review.

Measurements: Evaluation of pain and opioid use assessment metrics and measures for their potential usefulness in the community.

Results: Several pain and opioid assessment instruments are available for consideration. Yet, no one pain instrument has been identified as “the best” to assess pain in seriously ill community-dwelling patients. Screening tools exist that are specific to the assessment of risk in opioid management. Opioid screening can assess risk based on substance use history, general risk taking, and reward-seeking behavior.

Conclusions: Accountability for high quality care for community-dwelling patients requires selection of metrics that will capture the burden of chronic pain and beneficial use or misuse of opioids. Future research is warranted to identify, modify, or develop instruments that contain important metrics, demonstrate a balance between sensitivity and specificity, and address patient preferences and quality outcomes.

Keywords: accountability; chronic pain; opioid use; serious illness; symptom assessment; symptom control

Introduction

Approximately 100 million adults in the United States, or from 11% to 40%, report chronic pain.1,2 The estimated economic cost is from $560 to $635 billion for necessary healthcare and lower worker productivity.3,4 Chronic pain is often associated with serious illnesses: conditions associated with a high risk of mortality, impaired quality of life, restricted function, high symptom and/or treatment burden, and caregiver stress.5 Using pain assessment information, treatment decisions are made, preferably within the context of the patient’s associated illnesses, functional status, and quality-of-life goals.

One standard analgesic treatment for moderate-to-severe pain is use of opioids. While opioids are often successful in minimizing pain, it is incumbent upon treating health

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professionals to be concerned about their potentially serious adverse consequences such as injury, dependence, addiction, and death. Indeed, the current opioid epidemic and associated increased death rates have highlighted these concerns. Consideration of opioid use risk is an essential element for determining accountability for high-quality care delivery to community-dwelling patients with serious illnesses. This article has three aims: (1) to present options for assessing pain in seriously ill community-dwelling adults according to their ability to communicate by proposing pain metrics that are effective representations of the patient’s condition; (2) to discuss the use of opioids, as appropriate, and their intended and unintended consequences, in patients with serious illnesses; and, (3) to suggest accountability measures for use during pain treatment that can promote quality care and minimize adverse consequences in seriously ill patients.

Assessing and Recording Chronic Pain Metrics

Defining and classifying chronic pain through use of pain metrics

Metrics that define and classify chronic pain provide a focus for professional interventions and evaluation of quality of care. Selecting quality pain metrics requires answers to these questions: (1) what pain metrics are necessary for a screening examination to identify pain? (2) will the patient have the capacity to provide information about the pain metrics, or will input from a patient’s family member, surrogate, or health professional be necessary? (3) if a screening examination is positive for chronic pain, what pain metrics are necessary to capture the dimensions, burdens, and impact of pain on the seriously ill patient and response to treatment? The definition of pain has evolved over the years but still retains the characteristic of being a distressing experience associated with actual or potential tissue damage. (See Table 1 for a glossary of terms.) Pain is recognized as having sensory, emotional, cognitive, and social components, the latter making pain a shared experience. Chronic pain, when described by a time frame, is that which persists past the normal time of healing or lasting at least three months. When chronic, or persistent, pain is associated with substantial restriction of participation in work, social, and self-care activities for six months or more, it is identified as high impact chronic pain. However, looking beyond a time framework for classifying chronic pain, consideration must be given to the mechanisms and burden of pain and recognize that pain classification can evolve over time and new discoveries. Indeed, a new classification is currently under development.

Pain metrics

The important characteristics and domains of pain are identified by instruments and systems with specific pain metrics. (See Table 2 which outlines the relationship among pain domains, metrics, and instruments.) Pain domains as targets for assessment can include pain’s sensory and affective qualities, its temporal characteristics, its location and bodily distribution, pain behaviors, and psychological impact on function. Ascertaining the details of a patient’s pain relies on a patient’s ability to reliably communicate their pain experience and to access individuals and systems that capture pain information. A comprehensive pain assessment would optimally include use of metrics for each domain, while a screening pain assessment would be more focused. Providers are required to gather “enough information” to make treatment decisions and evaluate outcomes for which they are

<table>
<thead>
<tr>
<th>Table 1. Glossary of Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition</strong></td>
</tr>
<tr>
<td>Serious illness: “Serious illness” is a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress.</td>
</tr>
<tr>
<td>Pain: An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.</td>
</tr>
<tr>
<td>Pain (updated): An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment.</td>
</tr>
<tr>
<td>Pain (suggested modification): Pain is a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive, and social components.</td>
</tr>
<tr>
<td>Chronic pain, when described by a time frame, is that which persists past the normal time of healing or lasting at least three months.</td>
</tr>
<tr>
<td>High impact chronic pain: persistent pain with substantial restriction of participation in work, social, and self-care activities for six months or more.</td>
</tr>
<tr>
<td>Nociceptive pain: Pain that arises from actual or threatened damage to non-neural tissue and is due to the activation of nociceptors.</td>
</tr>
<tr>
<td>Neuropathic pain: Pain resulting from a lesion or dysfunction of the peripheral or central nervous systems.</td>
</tr>
<tr>
<td>Pain behaviors: Various actions observed in an individual by others that may indicate that pain is present. These may include language, vocalizations, facial expression, body posture, and escape or avoidance actions.</td>
</tr>
<tr>
<td>Medication addiction is defined as a primary chronic disease of brain reward, motivation, memory, and related circuitry. Dysfunction in these circuits leads to characteristic biological, psychological, social, and spiritual manifestations. This is reflected in an individual pathologically pursuing reward and/or relief by substance use and other behaviors. Addiction is characterized by inability to consistently abstain, impairment in behavioral control, craving, diminished recognition of significant problems with one’s behaviors and interpersonal relationships, and a dysfunctional emotional response. Like other chronic diseases, addiction often involves cycles of relapse and remission. Without treatment or engagement in recovery activities, addiction is progressive and can result in disability or premature death.</td>
</tr>
</tbody>
</table>
### Table 2. Clinimetrics for Chronic Pain Assessment

<table>
<thead>
<tr>
<th>Tools with specific metrics</th>
<th>Sensory&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Temporality&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Relief&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Location&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Interference/functional impact&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Affective</th>
<th>Evaluative</th>
<th>Psychosocial impact</th>
<th>Behavioral&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>VAS, NRS, VRS</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>BPI-SF</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>MPQ-SF</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>PEG</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PROMIS</td>
<td>x (6 items)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x (7 items)</td>
<td></td>
<td></td>
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<tr>
<td>PD-Q</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x radiating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAINAD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PACSLAC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
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</tr>
<tr>
<td>DOLOPLUS-2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
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</tr>
<tr>
<td>MOBID</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NATIONAL HEALTH INTERVIEW</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SURVEY</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PROMIS</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RAI</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup>The first five domains on left represent those deemed most important, in order of importance, by Palliative Care clinician experts.<sup>28</sup>

<sup>b</sup>Behaviors for nonself-reporting patients.

BPI-SF, Brief Pain Inventory-Short Form; DOLOPLUS-2, Abbreviation for a French-language scale; MOBID, Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale; MPQ-SF, McGill Pain Questionnaire-Short Form; NRS, numeric rating scale; PACSLAC, Pain Assessment Checklist for Seniors with Limited Ability to Communicate; PAINAD, Pain Assessment in Advanced Dementia Scale; PD-Q, painDETECT questionnaire; PEG, Pain Intensity, Enjoyment, General Activity; PROMIS, Patient-Reported Outcomes Measurement Information System; RAI, Resident Assessment Instrument; VAS, visual analog scale; VRS, verbal rating scale.
accountable. Gathering pain data from community dwelling individuals with serious illnesses may require a triaging process that begins with more simple interrogations.

Unidimensional pain measures and short questionnaires

Simple interrogations generate data from use of unidimensional measures and brief questionnaires by patients who can self-report and/or self-record. Well validated unidimensional numeric rating scale (NRS) and visual analog scale (VAS) are often used to quantify degree of pain intensity and, less often, degree of pain distress. However, simply focusing on a pain intensity number provided by patients with chronic pain can be problematic since one number does not reflect the total burden of chronic pain. A decrease in a number may not serve as a metric of treatment outcome success; nor can chronic pain treatment be unsuccessful even when a pain intensity number does not change.

There are a number of brief questionnaires that focus on multidimensional domains of pain: the Brief Pain Inventory (BPI), the Short Form-McGill Pain Questionnaire (SF-MPQ), the PEG, and the painDETECT. The BPI is a short self-administered questionnaire that assesses pain severity, as well as its impact on function. The BPI-Short Form (BPI-SF) has been used to identify characteristics of breakthrough pain in patients with cancer-related pain in remission. The SF-MPQ is also a self-administered questionnaire that addresses sensory, affective, and cognitive (evaluative) domains of pain and correlates highly with the well validated Long Form-MPQ. The PEG is a 3-item scale that measures pain intensity (P), interference with enjoyment of life (E), and interference with general activity (G). It has been tested against the BPI for reliability and content validity and has been shown responsive to clinical interventions. Recent Center for Disease Control (CDC) Guidelines offer the PEG as one example of an instrument to assess treatment outcomes. Finally, the painDETECT questionnaire (PD-Q) evaluates symptoms associated with neuropathic versus nociceptive pain. Since patients with neuropathic pain often suffer more severely than patients with nociceptive pain, a tool such as the PD-Q may help with better diagnosis and treatment.

Behavioral pain measures

Some patients with serious illnesses are unable to self-report their pain due to impaired cognitive capacity associated with delirium, dementia, and/or somnolence. Assessing behavioral indices as proxy measures of pain can help to identify people with chronic pain and make them more likely to receive therapeutic interventions.

Pain behaviors noted by healthcare workers in patient medical records in a palliative care center included patient vocalizations such as moans or groans or crying out; facial expressions such as grimaces and winces; and actions such as holding a body part and clenching fists. Recognition of these behaviors in a palliative care population may assist with development and validation of a pain behavior tool for seriously ill patients in those and other settings. One such tool is the MOBID scale (Mobilization-Observation-Intensity-Dementia Pain Scale). The MOBID has been tested in non-delinquent, non-psychotic nursing home patients with dementia suspected to have chronic pain of >3 on a 0–10 NRS intensity scale. Researchers identified the following: pain behaviors were more frequently observed during mobility than rest; observer-generated NRS pain intensity scores and number of behaviors observed were positively correlated; and the best agreement between the testers was for pain noises, although facial expression was demonstrated most frequently. Observation and recording of behaviors by family members or health professionals that may indicate pain deserve careful consideration as a metric-generating activity in seriously ill community-based patients unable to reliably self-report.

Several other pain behavior scales have been developed for older persons with severe cognitive impairment, such as the PAINAD, PACSLAC, and the DOLOPLUS-2 (see footnote of Table 2 for full name of scales). Psychometric properties of these three scales were tested in Dutch nursing home residents. The PACSLAC had better psychometric attributes and was found to be more “user friendly” to raters than the other two scales. However, the testing paradigm was acute (vaccination) pain rather than chronic pain. Items on the PACSLAC and PAINAD could be examined for their applicability to a newly constructed behavioral assessment scale that may reflect chronic pain in persons with serious illnesses.

Use of electronic healthcare data to assess pain and its impact on the person

von Korff et al. pilot tested a 25-item electronic pain survey in a sample of patients in a large group health plan in Washington, with most items derived from established questionnaires. Answers to three specific questions allowed for categorization of respondents as persons with high-impact chronic pain (14% of 365 respondents) versus those with moderate-impact chronic pain (19% of respondents.) There were clear differences between the two groups in responses to survey questions regarding frequency of healthcare use, level of pain intensity, level of life interference, and higher number of painful body sites. This led to researcher confidence that responding to questions on an electronic health survey would be feasible and beneficial in identifying primary care, population-based patients with moderate-to-high impact chronic pain.

A second electronic database, Patient-Reported Outcomes Measurement Information System (PROMIS), was developed by academic scientists, primarily for research purposes, from several institutions and the NIH as a computerized bank of measures of patient symptoms, functional status, and quality of life. There is a pain intensity question as part of a global health scale, and there are two pain measures, pain behavior (a 7-item short form) and pain interference (a 6-item short form), that showed good reliability and validity. The PROMIS short form was a less sensitive measure of pain interference than the BPI or the PEG when used with patients with moderate musculoskeletal pain. Nevertheless, PROMIS has shown to be efficient, flexible, and precise; its item bank is available for public use and items can be made part of an Internet survey platform.

A third large electronic database is one used in nursing homes certified by Medicare and Medicaid to assess residents’ strengths and needs through comprehensive
assessments to help ensure that a resident’s quality of life is maintained or improved through quality care. The Long-Term Care Facility Resident Assessment Instrument (RAI) 3.0 contains one section, “Section J, Health Conditions in the Minimum Data Set,” which includes questions about pain that require self-report by the resident: pain presence, intensity, frequency, and effect on function. When residents are unable to self-report, staff complete questions about behavioral indicators of pain or possible pain. These data are used to identify interventions to meet the resident’s individual needs and to monitor the quality of care provided. However, these metrics are specific to pain that the resident experienced over a previous five-day period of assessment, not necessarily chronic pain.

A palliative care perspective on assessing pain

Pain metrics deemed important to assess in patients with advanced cancer receiving palliative care were identified during a systematic search of pain assessment literature. Six pain and palliative care physician experts ranked pain dimensions for relevance and importance. The first five of a list of 10 in order of deemed importance were the following: pain intensity, temporal pattern, treatment and exacerbating/relieving factors, location, and interference. In an update to this work, 11 new tools were identified in the literature, but none was found to be inclusive. Experts (n = 32) again ranked the five most relevant dimensions of pain to be assessed within a 24 hour time window, with the substitution of pain quality for interference (No. 6 on this list).

Despite the work described above, no one pain instrument has been identified as “the best” to assess pain in seriously ill patients. However, consideration of the “right metrics” for capturing a seriously ill individual’s experience of chronic pain is based on an understanding of the possibilities. These data may lead the healthcare provider to conduct a more comprehensive assessment to consider factors that may be influencing current and proposed pain treatment.

Treatment of Chronic Pain Through Use of Opioids

One important avenue of exploration is the role of opioid therapy for seriously ill patients with chronic pain. It is essential to consider that all pains are not equal; there are some conditions that are opioid responsive; some that may be; and others for which opioids are not indicated. Recent CDC Guidelines recommend that prescribers reconsider the use of opioids for chronic noncancer pain, leading to an increased awareness of patients of the dangers of opioids. However, they fall short in providing guidance for use in patients with cancer or other serious illnesses. In addition, Baker warns that care should be taken in establishing new standards, as is being done by The Joint Commission, to avoid the risk of moving the care pendulum away from good pain management. Decreased opioid prescribing may leave a subset of patients, such as those who are seriously ill, with no effective options to manage their unique chronic pain. For this reason, it is important that we continue to gather evidence to determine condition-specific guidelines for pain management. According to recent Clinical Practice Guidelines from the American Society of Clinical Oncology, consideration

FIG. 1. Algorithm for pain screening metrics in the setting of Potential Opioid Misuse, Abuse, and Addiction. In this figure, we present a decision tree highlighting the interplay among pain assessment, pain management, opioid risk assessment, opioid benefit, and opioid management for community-based care. BPI-SF, Brief Pain Inventory-Short Form; COMM, Current Opioid Misuse Measure; MOBID, Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale; MPQ-SF, McGill Pain Questionnaire-Short Form; NRS, numeric rating scale; ORT, Opioid Risk Tool; PAINAD, Pain Assessment in Advanced Dementia Scale; PACSLAC, Pain Assessment Checklist for Seniors with Limited Ability to Communicate; PD-Q, painDETECT questionnaire; PROMIS, Patient-Reported Outcomes Measurement Information System; RAI, Resident Assessment Instrument; SISAP, Screening Instrument for Substance Abuse Potential; SOAPP-R, Screener and Opioid Assessment for Patients with Pain—Revised.
should be given to the use of nonopioid and adjuvant analgesics for chronic pain in patients with cancer. The Guidelines note that, for patients who do not respond to these more conservative measures and have continued distress and impairment of function, a trial of opioids can be considered. While they are not effective for many conditions, there is evidence to identify when opioids should and should not be used, even within the context of serious illness. It is essential to consider metrics to evaluate the effectiveness of opioids, as well as the risks of their use, especially considering the current opioid epidemic.

Balancing the use and misuse of opioids

Determining if an opioid is effective and if a patient is using an opioid appropriately requires considerable vigilance and time. While opioids can diminish suffering for those in pain, their abuse, misuse, and addiction potential can impact community and population health. Figure 1 provides an algorithm for a screening or a comprehensive assessment of pain and opioid use. The CDC has demonstrated that opioid-related deaths have been increasing over the past 10 years (Fig. 2) with much of the increase attributable to increasing opioid prescriptions. Currently, the estimation is that 3–20% of patients prescribed an opioid will be addicted. However, rather than stigmatizing individuals who are susceptible to opioid addiction, monitoring and instituting a shared plan for aiding individuals who do become addicted is necessary.

Assessing the risk/benefit ratio of treating pain with opioids

Provider education of patients regarding the myriad risks of opioids is time consuming. The patient–provider relationship in American medicine has been affected by multiple forces, including managed care, medicine as a business, and shortened physician visits leading to quick decision making. Yet a shared decision-making model of medicine is paramount when it comes to the complex issue of opioid management. Assessing risk for opioid misuse can help providers understand how their patients may fare with potentially abusive and addictive substances. Guidelines suggest that clinicians take a “universal precautions” approach to minimize adverse consequences of opioid use (p. 3339). The beneficial effects of opioids are important to note: improved function in activities of daily living, decreased pain severity, decreased pain interference, and improved quality of life. Clinicians must also recognize the risks of opioid therapy with an individual patient. Table 3 provides a checklist of opioid therapy risks. In addition, clinicians can use specific opioid risk screening tools to assess risk based on substance use history, general risk taking, and reward-seeking behavior. There are several screening tools specific to the assessment of risk in opioid management that can be incorporated into a community-based assessment of chronic pain and opioid use (Table 4). Research is still needed on continued psychometric evaluation of these existing and newly developed instruments and the effects of their use in evaluating clinical outcomes.

Determining Accountability for Quality Care: Selecting Pain and Opioid Metrics

Determining accountability for quality care of patients with serious illness who have chronic pain is complex. Selection of pain metrics is a context-dependent process depending on the patient’s ability to report their pain; whether patients are in primary care, managed care, or residential care and; what type of data is required by health systems and...
funding agencies to address their outcomes of interest. Quality outcomes of interest would include whether pain was identified through proper screening and comprehensive assessments and that the patient’s relief from pain and their quality of life and functional capacity are improved with pain treatment.\textsuperscript{31} Table 2 provides a grid of pain instruments that can be considered according to whether pain self-report is an option or whether proxy observation of patients’ behaviors is required. Quality outcomes would include assessment of the appropriateness of pain treatment and treatment results. Ineffective or adverse results from treatment require accountability.

Measures of accountability regarding the use and effectiveness of opioids must take the particular patient’s situation in mind. Clinician concern about the use of opioids can sometimes depend on their estimates of the patient’s life expectancy, being less concerned with patients in hospice settings and more concerned with patients who have a longer course of treatment. Nevertheless, clinicians’ decision making regarding opioid use, especially with their attendant risks and ongoing monitoring of the balance of their effectiveness and risks, should be transparent. Table 4 suggests opioid risk tools that can be used on an ongoing basis for patients with chronic pain receiving opioids, to identify special needs. Identifying, intervening, and evaluating intervention results can improve accountability and quality care. Figure 1 offers an algorithm for screening patients’ pain and opioid use while identifying instruments for consideration.

**Conclusion**

Accountability for high quality care for community-dwelling patients with serious illnesses requires selection of metrics that will capture the burden of chronic pain whose treatment may be enhanced or complicated by opioid use. Community-based care will need to be accountable through selection of, and attention to, appropriate pain and opioid metrics. Future research is warranted to identify, modify, or develop instruments that contain important metrics, demonstrate a balance between sensitivity and specificity, and, importantly, speak to the preferences of patients with serious illnesses.

**Author Disclosure Statement**

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**References**


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Using Electronic Health Records for Quality Measurement and Accountability in Care of the Seriously Ill: Opportunities and Challenges

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Abstract

Background: As our population ages and the burden of chronic illness rises, there is increasing need to implement quality metrics that measure and benchmark care of the seriously ill, including the delivery of both primary care and specialty palliative care. Such metrics can be used to drive quality improvement, value-based payment, and accountability for population-based outcomes.

Methods: In this article, we examine use of the electronic health record (EHR) as a tool to assess quality of serious illness care through narrative review and description of a palliative care quality metrics program in a large healthcare system.

Results: In the search for feasible, reliable, and valid palliative care quality metrics, the EHR is an attractive option for collecting quality data on large numbers of seriously ill patients. However, important challenges to using EHR data for quality improvement and accountability exist, including understanding the validity, reliability, and completeness of the data, as well as acknowledging the difference between care documented and care delivered. Challenges also include developing achievable metrics that are clearly linked to patient and family outcomes and addressing data interoperability across sites as well as EHR platforms and vendors. This article summarizes the strengths and weakness of the EHR as a data source for accountability of community- and population-based programs for serious illness, describes the implementation of EHR data in the palliative care quality metrics program at the University of Washington, and, based on that experience, discusses opportunities and challenges. Our palliative care metrics program was designed to serve as a resource for other healthcare systems.

Discussion: Although the EHR offers great promise for enhancing quality of care provided for the seriously ill, significant challenges remain to operationalizing this promise on a national scale and using EHR data for population-based quality and accountability.

Keywords: accountability in care; electronic health records; palliative care; quality metrics; seriously ill patient population

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The field of palliative care has grown substantially over the past three decades. High-quality specialty palliative care has resulted in improved quality of life and symptoms for patients with serious illness and their families, as well as decreased healthcare costs attributed to lower intensity treatments at the end of life—treatments that match patients’ goals of care. Despite these successes, effective implementation of high-quality primary and specialty palliative care has been challenging. Some well-designed palliative care interventions have not resulted in significant improvements in patient or family outcomes and, in some cases, have been associated with worsened outcomes.

Given the increasing interest in developing interventions, payment plans, and policies that enhance palliative care, it is important to document that such interventions, plans, and policies improve quality of care without unintended consequences. There is also increasing interest in ensuring high-quality, population-based care for seriously ill patients and their families across settings, including hospital, clinical, long-term care facility, and home, and using quality measurement to ensure accountability for this care. In this context, it is critical that we develop and validate quality metrics that facilitate implementation and evaluation of clinical and policy programs that improve palliative care and enhance accountability for serious illness care across diverse settings.

Quality metrics for palliative care have been developed and implemented for specialty palliative care programs, primarily using data entry completed by palliative care specialists during their clinical work. Although these programs have tremendous potential, they are limited to the minority of seriously ill patients seen by palliative care specialists and sometimes require that busy clinicians input quality data in addition to their clinical workload. Quality metrics for palliative care have also been developed and implemented in the Veterans Health Administration, but require manual chart abstraction and may be challenging to scale to other healthcare systems.

In the search for feasible, reliable, and valid palliative care quality metrics, automated methods of using the electronic health record (EHR) are an attractive option. However, the EHR has often not delivered on its potential. In this article, we identify strengths and weaknesses of using EHR data for quality metrics for serious illness care and review our experience developing and implementing an EHR-based quality metrics program for primary and specialty palliative care, that is, care for seriously ill patients and their families delivered by all clinicians in the healthcare system (primary) as well as palliative care specialists (specialty). We also describe the key domains and individual metrics that we focused on after feedback from diverse stakeholders, including patients, families, clinicians, administrators, quality improvement staff, and information technology experts. Finally, we describe lessons learned through this program and identify opportunities and challenges for moving this work forward.

**Strengths and Weaknesses of the EHR for Palliative Care Quality Metrics**

As the organized repository for information about both intended healthcare and actual healthcare, the EHR has strengths that are important to understand and capitalize on. The EHR is a comprehensive record of clinical and administrative data on all individuals cared for within our healthcare systems. As such, it offers a repository with sufficient size and scope to support analyses of detailed clinical care and assessments of important subgroups of patients, such as those with serious illness, including “high-cost, high-need” patients who particularly benefit from palliative care.

In addition, EHR data are recorded directly from documentation of healthcare delivery and utilization without requiring additional data entry beyond that accompanying routine care. The EHR also captures social determinants of health, which are important to the delivery of high-quality, accountable care for the seriously ill.

Alongside these strengths, the EHR has important limitations. First, information obtained from the EHR reflects care documented rather than care delivered or care perceived by patients and families. Goals-of-care discussions offer a good example of this potential mismatch: clinicians may report having these conversations with patients, but either fail to document them or document them in ways that are not easily retrievable. Conversely, aspects of care may be documented in the EHR but not actually delivered; the frequency of duplicative documentation by “copy-and-paste” makes it difficult to determine how many goals-of-care conversations really occurred.

Second, the diverse range of purposes for which EHR data are collected may compromise its validity for use in quality and accountability. Purposes include documentation of care delivered, communication between clinicians, billing, care coordination, quality improvement, and administrative reporting. Each of these purposes introduces idiosyncrasies in the data that may undermine reliability and validity for quality metrics. One example is the widespread use of flowsheets documenting that patients were asked about advance directives, as mandated by the Patient Self-Determination Act. At the University of Washington, these forms were often erroneously uploaded into the same data field that records actual advance directives, making it difficult to distinguish what the record contains. Since the EHR was not designed for assessment of palliative care quality metrics, such metrics need to be adapted to the information available and then psychometric properties need to be validated. Alternatively, modifications to the EHR may help capture data relevant to high-quality palliative care.

A third limitation of the EHR is the absence of key outcomes essential to high-quality serious illness care. The EHR generally lacks systematic, structured assessment of outcomes such as patients’ and families’ experiences of care, physical and psychological symptoms, quality of life, spiritual needs, or functional status. As these represent essential domains of serious illness care, any EHR-based metrics program must be supplemented by patient and family reports. Novel approaches to include systematic assessment of patient-reported outcomes in the EHR are in development and offer promise for addressing this shortcoming.

Fourth, the lack of interoperability between EHRs from different healthcare organizations and different vendors creates challenges to developing quality metrics that span multiple EHRs and can be used to assess population-based care or accountability. Efforts to unify data from different EHR systems are hampered by both technical challenges in aggregating data from multiple platforms and idiosyncrasies in how the same data are stored in different EHRs. Without access to data with consistent meaning, metrics from different
<table>
<thead>
<tr>
<th>Domain/measure no.</th>
<th>Numerator</th>
<th>Denominator</th>
<th>Importance(^a) (%)</th>
<th>Feasibility(^b) (%)</th>
<th>Difficulty(^c)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Service utilization</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>No. of emergency room visits</td>
<td>Serious illness and last month of life</td>
<td>32</td>
<td>68</td>
<td>Low</td>
</tr>
<tr>
<td>2</td>
<td>No. of hospitalizations</td>
<td>Serious illness and last month of life</td>
<td>36</td>
<td>66</td>
<td>Low</td>
</tr>
<tr>
<td>3</td>
<td>Admitted to the ICU</td>
<td>Serious illness and last month of life</td>
<td>24</td>
<td>56</td>
<td>Low</td>
</tr>
<tr>
<td>4</td>
<td>Received chemotherapy</td>
<td>Metastatic cancer and last two weeks of life</td>
<td>18</td>
<td>44</td>
<td>Low</td>
</tr>
<tr>
<td>5</td>
<td>Readmissions in last 90 days of life (30 days; 7 days)</td>
<td>Serious illness</td>
<td>n/a</td>
<td>n/a</td>
<td>Low</td>
</tr>
<tr>
<td><strong>Circumstances of death</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Died in an acute care hospital</td>
<td>Serious illness decedents</td>
<td>24</td>
<td>56</td>
<td>Low</td>
</tr>
<tr>
<td>7</td>
<td>Died in ICU</td>
<td>Serious illness decedents</td>
<td>24</td>
<td>50</td>
<td>Low</td>
</tr>
<tr>
<td>8</td>
<td>Hospitalized patients who die an unexpected death with an ICD deactivated</td>
<td>Inpatient deaths with an ICD</td>
<td>8</td>
<td>18</td>
<td>Medium</td>
</tr>
<tr>
<td>9</td>
<td>Not admitted to hospice</td>
<td>Metastatic cancer decedents</td>
<td>20</td>
<td>30</td>
<td>Medium</td>
</tr>
<tr>
<td><strong>Screening and assessment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Fewer than three days in hospice</td>
<td>Serious illness decedents</td>
<td>26</td>
<td>32</td>
<td>Medium</td>
</tr>
<tr>
<td>11</td>
<td>Received bowel regimen</td>
<td>Inpatients with serious illness who receive opiates</td>
<td>26</td>
<td>28</td>
<td>Medium</td>
</tr>
<tr>
<td>12</td>
<td>Screened for the presence and intensity of pain using a numeric pain score</td>
<td>Serious illness</td>
<td>52</td>
<td>40</td>
<td>Medium</td>
</tr>
<tr>
<td>13</td>
<td>Had comprehensive assessment completed (includes prognosis, functional assessment, screening for physical and psychological symptoms, and assessment of social and spiritual concerns)</td>
<td>Serious illness</td>
<td>54</td>
<td>14</td>
<td>High</td>
</tr>
<tr>
<td>14</td>
<td>Screened for shortness of breath</td>
<td>Serious illness</td>
<td>22</td>
<td>24</td>
<td>High</td>
</tr>
<tr>
<td><strong>Patient needs and preferences</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Have an advance care plan or surrogate decision maker documented in the EHR or documentation that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan</td>
<td>Serious illness</td>
<td>72</td>
<td>18</td>
<td>Medium</td>
</tr>
<tr>
<td>16</td>
<td>Documentation of patient’s preferences for care (may include code status, preferences for general aggressiveness of care) has been considered or an attempt was made to identify them.</td>
<td>Serious illness</td>
<td>80</td>
<td>16</td>
<td>Medium</td>
</tr>
<tr>
<td>17</td>
<td>Discussion of emotional or psychological needs</td>
<td>Serious illness</td>
<td>48</td>
<td>12</td>
<td>High</td>
</tr>
<tr>
<td>18</td>
<td>Documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss</td>
<td>Inpatients with serious illness</td>
<td>46</td>
<td>14</td>
<td>High</td>
</tr>
</tbody>
</table>

Stakeholders included patients, patient representatives, families, clinicians, administrators, quality improvement staff, and information technology experts.

\(^a\)Importance = Percentage of stakeholders marking this as having high importance, \(n = 50\).

\(^b\)Feasibility = Percentage of stakeholders marking this as having high feasibility, \(n = 50\).

\(^c\)Difficulty = Expectation of difficulty anticipated by team developing metrics.

ICD, implantable cardioverter-defibrillator.
healthcare systems are difficult to compare. 12 Although standards and incentive programs have improved the utility of EHR data for population health, substantial disincentives to the creation of interoperable metrics remain, including incentives to sell and individualize separate modules for particular metrics (e.g., advance care planning) and incentives to allow platforms to import, but not export, data to other systems. 20

Finally, modifications to a healthcare system’s EHR may pose ongoing challenges for the collection of quality metrics. Updates to an EHR system, or a change in vendor, may change the way data are collected or represented, resulting in disruptions in previously successful quality metrics. Periodic validation of EHR-based metrics is essential.

Identifying the Key Domains and Individual EHR-Based Palliative Care Metrics

Key to any quality metrics program is agreement on a set of measures and guidance on how to collect and report the data. A systematic review of palliative care quality metrics for cancer identified 284 metrics. 34 Smaller sets of metrics have been promoted by national programs, including Measuring What Matters (by the American Academy of Hospice and Palliative Medicine), 35 the National Quality Forum, 36 and others. 15–17,37–39 These programs provide important insights into the development of specific metrics and permit benchmarking across programs and settings, but none of these programs focused on using the EHR.

The Cambia Palliative Care Center of Excellence at UW Medicine has developed a series of palliative care quality metrics across UW Medicine’s four hospitals, diverse outpatient clinic network, and comprehensive cancer center. The project systematically evaluates primary and specialty palliative care for patients with serious illness in inpatient and outpatient settings, and has developed a users’ manual to document our process as a resource for other healthcare systems. 40 We are engaging with stakeholders from diverse healthcare systems to guide the implementation and dissemination of this project.

We began the process of identifying palliative care quality metrics by reviewing recommendations from systematic reviews 34,41 and synthesizing these into a list of 17 metrics, which we presented at a stakeholder meeting in May 2015. The meeting involved 105 participants, including patient representatives, family members, clinicians, administrators, information technology specialists, quality improvement staff, and payers. The group reviewed a draft list of metrics, recommended one additional metric, and prioritized each metric. This resulted in 18 metrics in four domains: (1) end-of-life healthcare utilization; (2) circumstances of death; (3) assessing symptoms and social and spiritual needs; and (4) documenting patients’ goals and preferences (Table 1).

Example of Specific Metrics Across a Multihospital Healthcare System

We began implementation of our program at UW Medicine with the domains of healthcare utilization and circumstances of death for a decedent sample with chronic life-limiting illnesses. This initial focus represented a logical starting place because these metrics were relatively easy to obtain and viewed as important by healthcare system leadership. We chose decedents as our initial denominator population because the methodology for analyzing patterns of end-of-life care among decedents is well established. 42–44 Finally, to understand the quality of palliative care received by patients with chronic illnesses, we focused on decedents with at least one of the nine Dartmouth Atlas chronic conditions: cancers with poor prognoses, chronic pulmonary disease, coronary artery disease (CAD), heart failure, severe chronic liver disease, chronic renal failure, dementia, diabetes with end-organ damage, and peripheral vascular disease. 42 We report on some of these metrics here to highlight the potential and the limitations of this approach.

We linked Washington State death certificate data to our EHR data to identify patients who met our criteria of attribution to the UW Medicine system. These criteria were adapted from Dartmouth Atlas: at least one nonsurgical inpatient visit at an affiliated hospital in the two years before death, or at least two outpatient visits from the same site in the last 32 months of life, with at least one visit occurring during

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comorbidities, n (%)</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>11,891 (51.4)</td>
</tr>
<tr>
<td>Chronic pulmonary disease</td>
<td>6052 (26.3)</td>
</tr>
<tr>
<td>Coronary heart disease</td>
<td>6001 (26.2)</td>
</tr>
<tr>
<td>Heart failure</td>
<td>5306 (23.0)</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>2954 (12.6)</td>
</tr>
<tr>
<td>Severe chronic liver disease</td>
<td>2681 (12.8)</td>
</tr>
<tr>
<td>Diabetes with end-organ damage</td>
<td>1983 (8.6)</td>
</tr>
<tr>
<td>Chronic renal failure</td>
<td>4379 (19.0)</td>
</tr>
<tr>
<td>Dementia</td>
<td>2124 (9.2)</td>
</tr>
<tr>
<td>Insurance status, n (%)</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>7988 (34.6)</td>
</tr>
<tr>
<td>Medicare</td>
<td>7892 (34.2)</td>
</tr>
<tr>
<td>Medicaid</td>
<td>5183 (22.4)</td>
</tr>
<tr>
<td>Military</td>
<td>829 (3.6)</td>
</tr>
<tr>
<td>Other insurance type</td>
<td>518 (2.2)</td>
</tr>
<tr>
<td>Uninsured</td>
<td>686 (3.0)</td>
</tr>
<tr>
<td>Male, n (%)</td>
<td>13,163 (57.0)</td>
</tr>
<tr>
<td>Race, n (%)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>17,248 (82.8)</td>
</tr>
<tr>
<td>Black</td>
<td>1190 (5.7)</td>
</tr>
<tr>
<td>Native American/Alaska Native</td>
<td>355 (1.7)</td>
</tr>
<tr>
<td>Asian</td>
<td>1299 (6.2)</td>
</tr>
<tr>
<td>Native Hawaiian/other Pacific Islander</td>
<td>131 (0.6)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>385 (1.8)</td>
</tr>
<tr>
<td>Mixed race</td>
<td>226 (1.1)</td>
</tr>
<tr>
<td>Age, mean (SD)</td>
<td>65.5 (15.1)</td>
</tr>
<tr>
<td>Education, n (%)</td>
<td></td>
</tr>
<tr>
<td>8th Grade or less</td>
<td>918 (4.5)</td>
</tr>
<tr>
<td>9–12 Years, no diploma</td>
<td>1422 (7.0)</td>
</tr>
<tr>
<td>High school graduate or equivalent</td>
<td>6823 (33.4)</td>
</tr>
<tr>
<td>Some college, no degree</td>
<td>4079 (20.0)</td>
</tr>
<tr>
<td>Associate’s degree</td>
<td>1665 (8.1)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>3456 (16.9)</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>1418 (6.9)</td>
</tr>
<tr>
<td>Doctorate or professional degree</td>
<td>659 (3.2)</td>
</tr>
</tbody>
</table>

*The group and total sample sizes were reduced for two variables for which death certificates provided incomplete information. Race was known for 20,834 decedents; education for 20,440 decedents. SD, standard deviation.
the last 24 months of life. Decedents were excluded if they were younger than 18 years or if the cause of death on the death certificate was “injury or poisoning emanating from an accident, suicide, homicide, or an undetermined source.”

Using these criteria, we identified 23,096 decedents with life-limiting illness attributable to UW Medicine who died between January 1, 2010, and December 31, 2015. Overall, 57% of decedents were male and the average age at death was 66.5 years (Table 2). The most common chronic illness was cancer (51%), followed by chronic pulmonary disease (26%) and CAD (26%). The mean number of diagnoses per decedent was 1.9.

From 2010 to 2015, we found decreasing intensity of hospital and ICU care for patients with hospitalizations at UW Medicine’s two largest hospitals during decedents’ last 30 days of life that included a lower proportion with acute care hospitalizations (29% to 24%; \( p < 0.001 \); Fig. 1) and with ICU care (21% to 17%; \( p < 0.001 \); Fig. 2). In addition, a lower proportion of decedents had 30-day hospital readmissions in the last 90 days at UW Medicine hospitals (10% to 8%; \( p = 0.02 \); Fig. 3).

We also explored specific predictors of hospital and ICU utilization at the end of life, identifying decreased hospital utilization for patients with comorbid psychiatric illness raising concerns about inequities in serious illness care. We found that 40% of patients with chronic illness died in a hospital, with almost half of hospital deaths occurring outside the UW Medicine system, highlighting the importance of ensuring that advance care planning is transmitted to other healthcare systems. In addition, we found that the decrease in hospital utilization during the last 30 days of life was consistent for patients older and younger than 65 years, while the decrease in ICU utilization in the last 30 days of life was more prominent for patients older than 65 years. Importantly, one of the
limitations of EHR-based metrics is that utilization data are limited to the healthcare system. For example, regional changes in hospital use (such as changes in market share) could invalidate these findings. These findings need to be validated with population-based data across healthcare systems.

Our stakeholders gave top priority to metrics that reflect documentation of patients’ goals of care and advance care planning (Table 1). We began this work by using available data that recorded the presence of advance directives (including healthcare directives and durable power of attorney for healthcare) and Physician Orders for Life Sustaining Treatment (POLST) forms, as well as upload dates. We found that the proportion of decedents who had either an advance directive or a POLST form in their EHR at the time of death increased significantly from 21% in 2010 to 52% in 2015 ($p < 0.01$; Fig. 4). We validated these utilization and advance directive measures and found strong agreement between manual chart review and our automated methods (with agreement between 75% and 100%). However, these metrics fall short of the charge from the stakeholder group: identification of discussions of advance care planning and goals of care.

Challenges and Lessons Learned from EHR-Based Metrics

In our efforts to use the EHR to assess primary and specialty palliative care, we uncovered specific challenges and lessons. One of our most important challenges was to define the population of interest, or “denominator.” This is a particular challenge for assessing population-based care, since only some healthcare systems provide comprehensive population-based care through accountable care networks or other population-based programs. In addition, the denominator of interest may differ for different stakeholders. The use...
of EHR-based metrics for accountability and value-based purchasing will also need to ensure that metrics cannot be easily gamed. EHR-based metrics will be difficult to use for population-based programs and accountability purposes until EHRs achieve interoperability.

We started with a focus on decedents with at least one of the Dartmouth Atlas chronic conditions for three reasons: (1) diagnostic codes were readily available in the EHR; (2) methods to use these data were well developed; and (3) these conditions account for 90% of deaths among the Medicare population, suggesting many of these patients receive serious illness care.

Examining decedents allows a clear focus on the quality of end-of-life care, but this approach creates a second challenge in that it cannot be used to identify individual patients whose care can be improved, since patients have already died. We are working to define other patient populations with unmet palliative care needs, such as those with psychiatric illness or adult congenital heart disease.

A third challenge is that of benchmarking quality and the related consequence of adjudicating accountability for low or high quality. The most appropriate benchmark may vary by stakeholder group, hospital, or healthcare system because of differences in patient populations. Furthermore, improvements in metrics over time can be difficult to attribute to specific programs or providers. Accountability can be challenging with all forms of quality metrics, but is particularly important for rewarding success in improving palliative care or holding providers or programs accountable for shortcomings.

A fourth challenge is to integrate champions of serious illness care into institution-wide quality improvement efforts, to ensure their efforts are both durable and supported by institutional leadership and system-level quality improvement. Similarly, these champions should be engaged when EHR systems are updated, as such changes can create erroneous data and lead to unexplained variation in quality reports.

A fifth challenge was associated with ensuring that metrics of importance to stakeholders are discoverable in the EHR. Our stakeholders prioritized the assessment of advance care planning and goals-of-care discussions. Although written advance directives may be a marker for these discussions, capturing advance care planning and goals-of-care discussions is more important. Unfortunately, these measures are more difficult to capture. Advance care planning is documented in diverse ways by different clinicians and can be stored in various locations in the EHR that may include a specific EHR module, a specific note type, or a standard clinic or hospital progress note with no overt flags to signal this content. Widespread use of well-designed, comprehensive, and retrievable templates would facilitate documentation of advance care planning and goals-of-care conversations, and could also provide a guide for these discussions.

Natural language processing (NLP) and machine learning also hold promise for facilitating quality metrics related to advance care planning and goals-of-care discussions. Recent studies have shown that NLP approaches can effectively extract meaningful information, such as adverse drug reactions, cancer staging, and disease progression from clinical notes. Preliminary results suggest that NLP can identify documentation of advance care planning. Several groups are currently working on using NLP or machine learning to identify and evaluate these discussions.

Summary

The EHR offers important opportunities to identify seriously ill patients and assess palliative care quality metrics across large numbers of patients with serious illness. Currently, the opportunities are most achievable for assessing intensity of care and some easily captured metrics such as advance directives, POLST forms, and pain assessments. Other metrics, such as documentation of advance care planning and goals-of-care discussions, are not as readily available in most healthcare systems, but the use of EHR modules specific for advance care planning and approaches such as NLP offer potential solutions. However, EHR-based palliative care metrics pose important challenges that must be addressed: lack of interoperability across healthcare systems and, at times, within a single system; absence of systematic documentation of patient- and family-centered outcomes; and difficulties in capturing quality metrics information from data that were collected for other purposes. In this report, we describe a palliative care metrics program to assess serious illness care that can serve as a model and resource for others. Although the EHR offers great promise for measuring, benchmarking, and improving palliative care, these promises are largely unrealized on a national or population-based scale at this time. As EHR-based quality measures are developed, validated, and used to improve serious illness care, their strengths and shortcomings must be assessed and addressed, with adjustments made to ensure that the metrics are feasible, reliable, valid, and meaningful for quality improvement and accountability.

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A Person-Centered, Registry-Based Learning Health System for Palliative Care: A Path to Coproducing Better Outcomes, Experience, Value, and Science

Arif H. Kamal, MD, MBA, MHS, Kathryn B. Kirkland, MD, Diane E. Meier, MD, Tamara S. Morgan, MA, Eugene C. Nelson, DSc, MPH, and Steven Z. Pantilat, MD

Abstract

Background: Palliative care offers an approach to the care of people with serious illness that focuses on quality of life and aligning care with individual and family goals, and values in the context of what is medically achievable.

Objective: Measurement of the impact of palliative care is critical for determining what works for which patients in what settings, to learn, improve care, and ensure access to high value care for people with serious illness.

Methods: A learning health system that includes patients and families partnering with clinicians and care teams, is directly linked to a registry to support networks for improvement and research, and offers an ideal framework for measuring what matters to a range of stakeholders interested in improving care for this population.

Measurements: Measurement focuses on the individual patient and family experience as the fundamental outcome of interest around which all care delivery is organized.

Results: We describe an approach to codesigning and implementing a palliative care registry that functions as a learning health system, by combining patient and family inputs and clinical data to support person-centered care, quality improvement, accountability, transparency, and scientific research.

Discussion: The potential for a palliative care learning health system that, by design, brings together enriched information environments to support coproduction of healthcare and facilitated peer networks to support patients and families, collaborative clinician networks to support palliative care program improvement, and collaboratories to support research and the application of research to benefit individual patients is immense.

Keywords: coproduction; learning health system; palliative care; registry

If you want to go fast, go alone. If you want to go far, go together. A Masai Proverb
Introduction: A Call for a Collaborative Learning Health System in Palliative Care

Healthcare for persons with serious illness in the United States often fails to meet the priorities and needs of patients and families, resulting in suffering, preventable crises, and high use of emergency services.1,2 Palliative care focuses on quality of life and aligning care with individual goals and values in the context of what is medically achievable. Because palliative care interventions match service delivery to the needs and goals of patients and families, quality improves and costly crises and emergencies are often prevented, leading to a higher value of healthcare.

There is increasing awareness across the healthcare system of the necessity of measuring the impact of care that is delivered. Measurement is especially critical in palliative care to determine what works for whom in what settings to improve and ensure access to high value care for people with the most serious illness. Recognizing the need to “measure what matters”3 has led several groups to develop innovative palliative care registries to (1) assess prevalence and quality; (2) enable peer to peer comparisons4; (3) establish research networks to advance science5; and (4) develop community-based collaborative improvement networks to make measurable advances in palliative care quality across geographically diverse settings based on benchmarking, transparency, and sharing effective practices.5,6

There is an opportunity to achieve more by integrating these registries into a single system using two powerful conceptual frameworks to achieve multiple goals. The first framework—the learning health system—was popularized by the Institute of Medicine. “A learning health system … generates and applies the best evidence for the collaborative health care choices of each patient and provider … (and) drives the process of discovery as a natural outgrowth of patient care.”7 The second framework—service coproduction—was developed by thought leaders outside of healthcare, including Fuchs,8 Normann and Ramirez,9 Toffler,10 and Ostrom.11 Essential insights from the coproduction model are that when consumers and providers of services actually work together, they produce value8 and coproduced services are often more attractive, efficient, and sustainable.12

Collaborative design and delivery of care more fully engages healthcare teams, patients, and families, and is associated with a shift from an exclusive focus on disease treatment to expanded attention to the patient’s priorities, concerns, and goals.13 Because palliative care’s focus includes the psychological, social, emotional, and spiritual well-being of both the patient and family, it is ideally suited for coproduction.

Registry creation for palliative care fits naturally together with the learning health system and coproduction frameworks. Drawing on the experience of others and taking into account the unique aspects of palliative care practice, including the inherent heterogeneity of serious illnesses and range of settings where care is delivered, this report describes developing a single palliative care registry that combines patient and family inputs and clinical data to support person-centered care, quality improvement, and scientific research. The design and implementation of such a registry use coproduction principles to bring together patients and families, clinicians and care teams, and researchers to form a sustainable partnership—a collaboratory—for coproducing health and well-being, continuous improvement of care, and research to support learning and guide future investment and practice.14

The Learning Health System Coproduction Model

At the heart of the learning health system coproduction model is a partnership between the patient and family, and the care team. Individualized care pathways produce optimal health and well-being (as defined by the person and family) for individuals and, ultimately, for populations.15 Coproduction relies on an enriched information environment that includes “feed forward” patient generated data available to clinicians in real time along with clinical/biomedical data to provide an ongoing record of the person’s subjective and objective health status and associated treatments (Fig. 1).

This information environment not only allows creation of a patient- and provider-facing dashboard that can be used in real time during care delivery but also serves as a repository of data that can be reused for other purposes, including the following: (1) outcomes research; (2) collaborative clinical improvement networks; (3) facilitated and curated patient networks; and (4) generation of comparative, case-mix adjusted quality and performance reports that can—with proper safeguards for privacy and confidentiality—be shared with clinicians, patients, payers, governmental programs (e.g., Medicare), accreditors (e.g., The Joint Commission), and the public.

The conceptual model is designed as a comprehensive system comprising four inter-related subsystems: (1) the person/family and clinician/care team service delivery system; (2) the patient-/family-facilitated network system; (3) the research collaboratory system; and (4) the collaborative improvement network system. What holds the subsystems together is a set of shared aims, including optimizing the health and well-being of persons and families, continuously improving the value of healthcare service delivery, and building scientific knowledge to measurably improve health outcomes, clinical effectiveness, and value.16

Care models developed in conjunction with patients and families using the learning health system coproduction approach have led to improvements in the outcomes and experiences of patients with rheumatological conditions,17 inflammatory bowel disease,18 and cystic fibrosis.19

Creation of a Registry-Based Learning Health System for Palliative Care

Developing a palliative care registry-based learning health system could proceed in four phases, drawing on principles that come from diverse fields, including service design,20 improvement science,21 change management,22 agile software development,23 and service coproduction.24

Ready! Assemble a codesign team, pausing to clarify aims

First, convene an interdisciplinary design team that includes persons with serious illness and their families, clinicians, and care teams (both palliative care and others who care for people with serious illness), community resource staff, researchers, and IT design experts to develop a set of shared aims. The group starts by asking, “What needs must be met?” Through a series of discussions, the group develops a shared understanding first of key patient and family needs.
and then the needs of other stakeholders. This foundational work defines principles that will guide the learning health system and inform registry development.

**On your mark! Learn from what others have already done**

The codesign team then learns from what has already been accomplished. Three steps are important:

- **Scan the environment** to create an inventory of relevant registries
- **Learn from others**: Study successful pioneering efforts to establish sustainable learning health systems such as the Swedish Rheumatology Quality Registry and Live for Life (also in Sweden); and in the United States, ImproveCareNow, and the Cystic Fibrosis Foundation Patient Registry. Ask questions such as “What worked well?” “What did not work?” “Which aspects are directly applicable to palliative care?” “What adaptations are needed?”
- **Learn from ourselves**: It is imperative to learn from the achievements of existing palliative care national registries: the National Palliative Care Registry (the Registry), the Palliative Care Quality Network (PCQN), the Global Palliative Care Quality Alliance and its data collection system, and the Quality Data Collection Tool (QDACT). These exemplary initiatives (see Appendix 1, which is available at www.liebertpub.com/jpm) are as

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**Table 1. Illustrative Contextual Factors That Must Be Considered in Designing a Registry-Based Palliative Care Learning Health System**

<table>
<thead>
<tr>
<th>Illustrative contextual factors</th>
<th>Potential solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care provides services centered on each individual person and family, and their story, not generic care based on “what most people want.” Palliative care is high-touch, narrative-based care</td>
<td>Measure impact at the level of the individual patient and family, including the degree to which care received is aligned with the changing priorities and concerns of patients and families. Preserve narrative while developing simple metrics reflective of the individual patient’s priorities. Use brief patient surveys and minimize data collection burden. Capture and measure against changing priorities for health outcomes and experience. Focus on limited set of data elements that are needed for decision support, and longitudinal tracking of treatments and associated outcomes. Focus on patient experience, develop core set of metrics for all conditions and create additional disease-specific metrics. Use proxies to provide information on behalf of patient when needed. Create flexible dashboards that can be adapted to and are interoperable across different settings. Provide for multiple users and inputs to the system.</td>
</tr>
<tr>
<td>Time compression associated with limited prognosis Illness trajectory changing</td>
<td></td>
</tr>
<tr>
<td>Burden, intensity, and complexity of serious illness for patients and caregivers</td>
<td></td>
</tr>
<tr>
<td>Highly heterogeneous set of diseases with varying trajectories, prognoses, symptoms, and treatments Frequency of functional and cognitive impairment in serious illness Multiple sites of palliative care delivery (home, office, emergency department (ED), inpatient, outpatient, etc.) Broad scope of palliative care delivery with frequent comanagement by a wide variety of teams</td>
<td></td>
</tr>
<tr>
<td>Measure impact at the level of the individual patient and family, including the degree to which care received is aligned with the changing priorities and concerns of patients and families. Preserve narrative while developing simple metrics reflective of the individual patient’s priorities. Use brief patient surveys and minimize data collection burden. Capture and measure against changing priorities for health outcomes and experience. Focus on limited set of data elements that are needed for decision support, and longitudinal tracking of treatments and associated outcomes. Focus on patient experience, develop core set of metrics for all conditions and create additional disease-specific metrics. Use proxies to provide information on behalf of patient when needed. Create flexible dashboards that can be adapted to and are interoperable across different settings. Provide for multiple users and inputs to the system.</td>
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FIG. 1. A patient-centered, registry-based learning health system.
follows: “complementary systems for reporting on and improving palliative care services in the United States. The Registry is a broad-reaching, annual, aggregate data reporting platform profiling palliative care teams and their programmatic activities. It does not include patient-level outcomes. In contrast, QDACT focuses on real-time data entry at the point of care and clinician feedback on clinical quality outcomes and national quality standards, while the PCQN also enables real-time clinical data entry, benchmarking, peer comparison, and quality improvement networks.”29 None of the existing U.S.-based palliative care registries yet allow for direct input of data by patients and family caregivers. Drawing on the experiences of representatives of these registries to understand what has worked well and what they would change, add, or remove from their respective systems will help ensure that the next generation of learning health system builds on the best features of the current ones.

**Get set! Tailor the general model to the palliative care context**

As the codesign team moves closer to creating its learning health system model, key tasks include considering unique aspects of palliative care practice that should guide the process, as well as beginning to imagine the future that the learning health system will bring about.

- **Consider context:** Table 1 highlights some factors that should be considered in adapting the learning health system model to fit the palliative care context.
- **Imagine the future:** Based on successful, real-world demonstrations of registry-based learning health systems in the United States and in Sweden, we can begin to develop a vision of the future, imagining the benefits of such a system in palliative care, such as the following:
  - **Focus on the individual patient and family experience** as the fundamental outcome of interest around which all care delivery is organized.30
  - **A system designed to be sensitive to changes in patient needs and priorities as the disease progresses,** affecting symptoms, function, caregiver burden, and nature of the person’s hopes and concerns
  - **Digital collection and use** of both clinical and patient- or caregiver-reported information both to guide treatment plans and as a basis for improvement, research, and health policy
  - **Access** to the system for all healthcare teams involved in the comanagement of palliative care patients to facilitate care coordination and information sharing
  - **Shared power and responsibility** among all stakeholders for designing, governing, and evaluating services, improvement, and research
  - **Measurable improvements** in individual and population experience of illness and care through (1) improving the alignment of care with each individual’s priorities and preferences; (2) application of evidence-based practices; and (3) conduct of rigorous trials (including N of 1 trials) of new approaches to add to the knowledge base
  - **Dissemination and translation of ideas and findings** through publication of articles in peer-reviewed journals; networks as described above; and outreach to patients, families, clinicians, researchers, policy makers, and payers
- **Adapt the model:** Craft an idealized design31 that illustrates and specifies how the four subsystems that comprise the whole of a learning health system fit for the future of palliative care.
  - **Individual person-centered networks** that work together across settings to co-create daily care that is responsive to changing priorities and the evolving trajectory of illness
  - **Facilitated social networks** linking patients, families, and caregivers32 that encourage them to engage directly in their own healthcare/social care and are supported by information and tools to track and support daily care, functioning, and well-being
  - **A collaborative national network** of interdisciplinary palliative care teams that compare their services and outcomes, and learn from a system that provides longitudinal and peer-comparative data and timely information on effective practices and evidence-based interventions
  - **Research collaboratories** that draw on data generated by the other networks to build new knowledge that improves patient experience, outcomes, effectiveness, and value

**Table 2. Key Factors in Building a Registry-Based Learning Health System for Palliative Care**

| Codesign: Ensure multistakeholder engagement in entire process: codesign, complement, coevaluate, and co-redesign |
| Feed Forward: Build automated data “feed forward systems” that are continuously available to support daily care decisions, to track changes in health status, and to revise and plan next steps in care |
| Dashboards: Create customized patient and clinician facing dashboards that display graphs of patient-level data (such as depression, distress levels, symptom burden, and caregiver burden) over time, guiding and aligning both the diverse concerns and the inputs necessary to deliver whole-person care in real time; enable tracking of associations between interventions and outcomes of importance to the patient/family; and encourage prompt attention by clinicians to goals and priorities as they change over time, facilitating planning and decision making. |
| Feedback: Use registry data to generate reports for both patients and clinicians, as well as comparative data for population health management, program improvement, research, public reporting, and maintenance of certification. |
| Network Facilitation and Curation: Support growth of curated, patient-facing and clinician-facing networks to promote social and peer support, learning for people living with serious illness, and the work of interdisciplinary teams, respectively. Both networks can provide feedback to improve the functioning of the learning health system registry. |
| **Rapid Cycle Testing and Scaling:** Start with small iterative pilot tests of learning health system components in different contexts before scaling up. |
Go! Begin building a registry-based learning health system for palliative care using rapid cycle tests of change

A wise approach is to start with proof-of-concept, rapid cycle alpha testing in a small number of pilot locations representing a range of contexts. After making needed refinements and improvements, integration of information technology with broad dissemination can follow. Some key factors for launching a palliative care learning health system that has the potential to be successful and sustainable are outlined in Table 2.

Challenges in the Upscaling of a Palliative Care Learning Health System

Upscaling a learning health system for palliative care will require intelligent navigation of several domains: cultural change management; careful measurement of performance to demonstrate benefits; establishment of policies that favor culture change and reward measured performance; and alignment of payment systems to promote the above.

Change management

Transformative cultural change is challenging because it involves unlearning and reimagining roles and identity, as well as relationships and power. It requires changes in the attitudes (e.g., I’m on my own in the care of my patients); beliefs (e.g., data reporting is only about billing and coding); and behaviors (e.g., change aversion and change fatigue) that form cultural patterns. Acceptance of a palliative care learning health system will ultimately depend on people seeing, learning, and believing—based on local evidence and firsthand experience—that this approach in fact produces better results that have meaning and value to them and the people they care for. Using a codesign approach for planning and implementing the system is likely to facilitate the necessary culture change.

Performance

Developing a balanced set of measures is an important part of piloting and scaling a learning health system. The value compass framework may be helpful in developing a “starter-set” of performance measures. Using the metaphor of a navigational compass, the value compass has four cardinal points of direction: North—Functional Status and Well-being; South—Costs and Utilization; East—Patient and Family Care Experience; and West—Clinical Status. Although all compass points are important, different stakeholders will be more interested in certain points. Maintaining a balanced set of measures supports ongoing coproduction of services that meet multiple needs. Figure 2 illustrates a value compass for palliative care with illustrative measures.

Policies

The environmental context favorable to developing and sustaining a learning health system in the palliative care community is, in part, shaped by health policy. Supportive health policies favor active engagement of patients and families in shared decision-making processes that honor their values and preferences, including advance care planning. They favor family-/caregiver-assisted self-management and in-home supports over use of hospitals and nursing homes.

FIG. 2. A palliative care value compass with illustrative measures that are meaningful to patients, clinicians, researchers, and payers.
They require use of interoperable information technology so that all stakeholders can access the same data in real time. Also, they prioritize quality measures aligned with patient/family priorities. Health policies that reward better health status and quality-of-life results driven by the patient’s priorities and preferences and those that reward care systems for making measured improvements on a small, but balanced set of patient-centered performance metrics will support a thriving palliative care learning health system. Health research policies that favor active engagement of patients and families in all aspects of palliative care research will ensure that funding for codesigned trials and studies is available. Recent legislation such as The Medicare Access and CHIP Reauthorization Act [MACRA] incenting performance on patient-reported outcomes and goals, participation in improvement activities, and prevention of costly emergencies and crises is already starting to support physicians’ active participation in state-of-the-art collaborative improvement networks that foster both practice-based improvement and transparent public reporting.\(^{35}\)

**Payment and resource allocation**

Supportive financing is critical to the successful implementation and sustainability of learning health systems. It is easy to imagine how well-designed and field-tested models such as value-based bundled payments, shared savings, graded assumption of downside risk, and evolving capitation could accelerate a major shift to support and help finance a national person-centered learning health system for palliative care. Such innovation requires a start-up investment that could come from novel, value-based, patient-focused alternative payment programs as well as the proliferation of broad and effective accountable care organizations.\(^{36}\)

In addition to the need for supportive payment and quality measurement structures at the national level, investment of local resources will be needed to integrate learning health system registries into the delivery of palliative care services at the individual organization level. Palliative care program leaders must be prepared to “manage up,” finding ways to show how investment in the human and IT resources necessary to run a high functioning palliative care program that is part of a national learning health system pays dividends for the entire organization.

**Conclusion: Onward and Upward**

Palliative care provides persons with serious illness and their families goal and value-aligned, whole-person care focused on cocreating the best quality of life possible. Its core values include individualized, patient-centered interdisciplinary and collaborative care that preserves and is guided by the patient. For the palliative care field to achieve its mission of maximizing the quality of life of every person with serious illness, we must be certain that all care is driven by patient and family priorities; however, unless we are capturing those priorities and measuring our interventions and their impact against patient and family goals, we cannot truly know the value of our services. A learning health system offers the opportunity for the field of palliative care to pause and consider—with an expanded group of stakeholders, especially patients and families living with serious illness—what is most important and how to achieve it. To create a successful system, it will be important to learn from previous efforts, and to maintain a balanced approach that is not overweighted toward cost reduction or metrics that may not matter to individual patients and frontline clinicians. The potential for a palliative care learning health system that, by design, brings together enriched information environments to support coproduction of healthcare, facilitated peer networks to support patients and families, collaborative clinician networks to support palliative care program improvement, and collaboratories to support research and the application of research to benefit individual patients is immense. The time to start is now.

**Author Disclosure Statement**

No competing financial interests exist.

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Accountability for the Quality of Care Provided to People with Serious Illness

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Abstract

Background: Care for patients with serious illness is an emerging practice area that has gained attention as value-based purchasing has increased. While the number of programs is growing, their impact on care quality and outcomes is unknown.

Objective: With support from the Gordon and Betty Moore Foundation, the National Committee for Quality Assurance (NCQA) is assessing the feasibility of creating an accountability program focused on serious illness care.

Methods: This article describes the process of developing an accountability program, findings from our initial work, and our plans to develop measures for a serious illness care accountability program. We focused on three questions:

1. What patient populations should be targeted for measurement?
2. What entities have accountability for ensuring high-quality care for serious illness?
3. What structures, processes, and outcomes should be evaluated in an accountability program for serious illness care?

Results: Our environmental scan showed that the evidence base for specific patient populations or care models is not sufficiently mature to justify traditional structure and process measures. In visits to serious illness care programs, we observed different staffing models, care models, care settings, and payment structures. We found a gap between recommended inclusion criteria and services when compared to inclusion criteria and services offered by existing programs.

Conclusions: To address the challenges, NCQA intends to develop outcome measures driven by patient and family priorities. Structure and process measures will focus on building organizations’ capacity to measure outcomes, including patient engagement and outcomes, linked to patient goals.

Keywords: accountability programs; quality of care; measure development; serious illness; value-based purchasing

Purpose of the Article

The number of Americans with serious illness is rising, along with overall costs of care. Patients with serious illness too often receive expensive care that is misaligned with their goals, values, and preferences. The current shift away from traditional fee-for-service payment to value-based purchasing presents opportunities to improve care and goal alignment, but it also comes with the risk that pressures to lower costs will reduce quality. Ideally, value-based purchasing will direct resources toward high-quality care that aligns with patients’ goals, values, and preferences.

Serious illness care programs have arisen to meet the care needs of seriously ill patients and their families. These programs are heterogeneous, with diverse definitions of serious illness and serious illness care and...
an array of care models, program staffing, settings, and organizational sponsors. But a dearth of performance measures and accountability programs addressing the quality of such care means that consumers lack the means to identify health plans, serious illness care programs, or providers delivering high-quality person- and family-centered care.

With support from the Gordon and Betty Moore Foundation, the National Committee for Quality Assurance (NCQA) is developing serious illness care performance measures and evaluating the potential for serious illness care accountability programs.

This article describes NCQA’s process for developing an accountability program, findings from an environmental scan, and plans to develop measures suitable for a serious illness care accountability program.

Developing a Serious Illness Care Accountability Program

One goal of this project is to evaluate the feasibility of developing accountability programs for serious illness care at the provider, program, Accountable Care Organization (ACO), and plan levels of accountability. To evaluate the potential for accountability programs, we will draw on NCQA’s established processes for program and measure development. Initial efforts will address three crucial questions that guide development:

1. What patient populations should be targeted for measurement?
2. What entities have accountability for ensuring high-quality patient care for serious illness?
3. What structures, processes, and outcomes should be evaluated in an accountability program for serious illness care?

Accountability programs

Accountability program development includes a feasibility review, product design, and implementation infrastructure design (Fig. 1). The feasibility review defines the product concept and then evaluates current gaps and the market for potential customers. Product design includes cyclical development and refinement of the product concept and requirements (including measure development), testing and public comment, and internal reviews. Infrastructure design includes data collection tools, program application, supporting materials, and the product release plan. Throughout this process, NCQA engages multistakeholder panels to obtain input and seeks public comment on proposed program components.

Measures for accountability

Measure development (Fig. 2) is critical in accountability program design. To develop a measure, NCQA measure developers define measure concepts that address important quality gaps (identified through an environmental scan and key informant interviews), draft measure specifications, and test draft measures. A broad set of external stakeholders, such as patients and family caregivers, providers, purchasers, plans, and researchers, inform the measure development process.

Approach

To understand the evidence for serious illness care practices, we conducted an environmental scan focused on guidelines, existing measures, and recommendations made by national organizations. We also conducted site visits with 14 serious illness care programs that agreed to serve in a learning collaborative to support and inform program and measure development. During site visits, we learned about programs’ target patient populations and inclusion criteria, care models, sponsorship, and financing structures, which helped us answer the key questions.

Environmental scan

The environmental scan targeted existing guidelines, recommendations, and measures, which we mapped against National Consensus Project for Quality Palliative Care (NCP) Guideline domains. We mapped recommendations from the Institute of Medicine Committee on Approaching Death: Addressing Key End-of-Life Issues, the Coalition to Transform Advanced Care, and the National Quality Care at the provider, program, Accountable Care Organization (ACO), and plan levels of accountability. To evaluate the potential for accountability programs, we will draw on NCQA’s established processes for program and measure development. Initial efforts will address three crucial questions that guide development:

1. What patient populations should be targeted for measurement?
2. What entities have accountability for ensuring high-quality patient care for serious illness?
3. What structures, processes, and outcomes should be evaluated in an accountability program for serious illness care?

Accountability programs

Accountability program development includes a feasibility review, product design, and implementation infrastructure design (Fig. 1). The feasibility review defines the product concept and then evaluates current gaps and the market for potential customers. Product design includes cyclical development and refinement of the product concept and requirements (including measure development), testing and public comment, and internal reviews. Infrastructure design includes data collection tools, program application, supporting materials, and the product release plan. Throughout this process, NCQA engages multistakeholder panels to obtain input and seeks public comment on proposed program components.

Measures for accountability

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**FIG. 1.** NCQA accountability product development process. NCQA, National Committee for Quality Assurance.
Forum,8 and the Center to Advance Palliative Care.9 We also mapped the PEACE,10,11 Assessing Care of Vulnerable Elders,12 and the Australian Palliative Care Outcomes Collaboration13 measure sets.

We weighed the relevance of the Center for Medicare and Medicaid Services (CMS) reporting requirements for organizations providing community-based serious illness care, including hospices, home health agencies, and ACOs, and NCQA standards addressing home-based care delivery (Accreditation of Case Management for Long-Term Services and Supports [LTSS] and LTSS Distinction for Health Plans) and oncology (Oncology Medical Home Recognition). Last, we identified systematic literature reviews and results of recent studies on community-based serious illness care to evaluate the evidence base for measurement.

Learning collaborative site visits

Involving serious illness care programs in measure development will help the team evaluate measure feasibility, reliability, and validity across different program models. To emphasize the voice of patients and caregivers in this project, we contracted with two paid patient advisors to serve as team members and recruited two patients and one family caregiver to serve on the stakeholder panel. We also required each learning collaborative site to convene a patient and family advisory panel with at least six members who either live with serious illness or are family caregivers of patients with serious illness (66 individuals, total); these panels will provide local input on serious illness care measures and quality improvement efforts.

The learning collaborative comprises 11 serious illness care programs in 9 states: Alabama, California, Illinois, New Jersey, New York, North Carolina, Pennsylvania (2), Utah (2), and Virginia. Organizational homes for the programs include hospice (1), Veterans’ Administration Medical Center (1), academic medical center (1), stand-alone hospice agency (1), medical groups (2), and health systems (5). Ten programs are within larger nonprofit organizations. While most have a broad population focus, two programs provide specialty care (oncology and pulmonology) and two provide primary care.

In recruiting learning collaborative sites, we sought diversity in organizational type, population served, and care models. All programs that we considered had been identified as exemplary9,14 or had program elements or structures not otherwise represented among the other sites under consideration for inclusion. Programs were required to provide ambulatory or home-based serious illness care to 100 or more patients per month to be considered. We conducted in-person site visits (with the exception of two that were telephonic) lasting between four and six hours to evaluate whether programs met project inclusion criteria. Between 3 and 10 staff members participated from each program or parent organization. Site visits addressed serious illness decision making, care planning and documentation, disease and symptom management, emotional/psychological/social/spiritual care, and caregiver support. For each topic, program staff described their approach to care delivery, ongoing quality measurement and improvement activities, training, and health information technology. We also asked about current participation in demonstration or accountability programs.

Findings

What patient population should be targeted for serious illness care measurement?

The environmental scan suggested that no single narrative or operational definition of serious illness was used consistently across serious illness care programs.1,4 Serious illness was defined by one or more of the following elements: life expectancy, limited treatment options, decline in functional status, decline in quality of life, specific chronic conditions, multiple chronic conditions, high symptom burden, and/or high utilization.

The NCP Clinical Practice Guidelines for Quality Palliative Care, 4th edition project15 has adopted Kelley’s definition of serious illness: “a health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life or excessively strains their caregiver.”1,4

Inclusion criteria for enrolling in a serious illness program were diverse across programs we visited, but all used one or
What entity should be accountable for serious illness care?

Accountability programs and measures apply to precisely defined entities in healthcare delivery. Entities involved in serious illness care include health plans, ACOs, medical groups, home health agencies, hospices, and specialty organizations operating under medical provider licenses. When developing accountability programs and specifying performance measures, it is critical to match program requirements to actions within the measured entity’s control. Measures for clinicians, groups, and programs can focus on assessment, care planning, care coordination, and care delivery. A medical practice delivering serious illness care may be required to send a comprehensive care plan to a hospital when admitting a patient, but would generally lack the ability to influence a hospital’s actions. Performance measurement at the program or provider level is ill-suited to achieve systemic change across silos.

In contrast, measurement at the plan or ACO level can work across silos and address care coordination, care outcomes, and utilization. Clinician and group measures can also be adapted for use at the plan or ACO level to improve care for all seriously ill patients within the population, not just those who are fortunate enough to enroll in a serious illness care program.

It is important to consider how the number of patients included in a measure differs by type of organization. If the number is too low, it becomes difficult to measure performance reliably. Program-level measurement risks this challenge, but even measures that may not reliably distinguish between different programs have the potential to inform health plans or other payers considering creation of a serious illness care benefit or contracting with serious illness care programs.

What structures and processes should organizations be accountable for when delivering serious illness care?

Serious illness care models are designed to address care and support needs of seriously ill patients and their families. Models range from the well-defined and established (e.g., hospice and in-patient palliative care) to emerging care models (e.g., out-patient palliative care clinics and home-based primary care for home-bound elderly). While studies demonstrating positive utilization outcomes and cost savings associated with palliative care are promising, the evidence base for quality-of-life outcomes, improved symptom management, and the specific program elements is weak.

A recent meta-analysis of patient and family outcomes associated with palliative care found associations between palliative care and improvements in advanced care planning, patient and caregiver satisfaction, and lower healthcare utilization, but associations with caregiver and symptom burden outcomes were mixed. In a systematic review of randomized trials of early outpatient and home-based palliative care by Davis et al., study findings were inconsistent. Some showed improved quality of life and reduced cost of care; others showed no improvement in quality of life and no difference in cost of care compared with usual care. The authors attributed differences to methodological challenges, in part, including heterogeneous care models and patient populations.

More recent studies have shown financial benefits from community-based serious illness care. Lustbader et al. found that home-based palliative care provided to patients in an ACO was associated with cost savings, reduced hospitalization, and increased hospice use. Another study compared the impact of three community-based oncology care programs that used different models to reduce cost and improve quality of life. All three models were associated with decreased costs of care in the last 30, 90, and 180 days of life. One model, which used lay navigators, was associated with decreased hospitalization and emergency department visits and increased hospice use.

There are no evidence-based guidelines for community-based palliative care. The NCP’s consensus-based guidelines for palliative care were developed for hospice and hospital-based palliative care programs. The NCP is updating the guidelines to address components of care—beyond those focused on hospital-based care—that are necessary for home-based serious illness care, such as patient-safety guidelines for providers in a patient’s home. Recent expert consensus recommends that patients with serious illness have access to a broad range of program elements, from 24/7 telephone support to home-based care from a palliative physician.

Our site visits showed that even among the group of programs identified as high performing, most programs do not offer the recommended comprehensive scope of services. We observed program elements that spanned from low-touch telephonic case management to high-touch, home-based palliative and primary care (Fig. 3). Some programs provided 24/7 telephone support, using nurses who were not trained in palliative care, to address the needs of high-utilizing patients. Some programs emphasized primary palliative care. In one program, nurses conducted home visits for assessment, but not care delivery. On the other end of the spectrum, some programs provided in-home medical, nursing, and/or social
work care addressing palliative, behavioral health, and primary care needs.

Staffing models also differed among programs. Some expansive programs had interdisciplinary teams that included one or more physicians, an advanced practice registered nurse (APRN), registered nurse and/or licensed practical nurse, social worker, pharmacist, and chaplain. Other programs had smaller teams, such as an APRN/social work home-visit team supported by consultant physicians and a pharmacist, or a physician/nurse/social worker model.

All programs used an assessment and care plan, but specific elements addressed differed. Similarly, although each program engaged in advanced care planning and conversations about serious illness, most of them either did not follow a structured protocol (e.g., Vital Talk, Serious Illness Conversations, or Respecting Choices) and relied instead on clinician training and experience or combined elements of different structured protocols.

When creating accountability programs or measures that require a program to offer specific care or services or to use specific staffing models or deliver care in specific settings, a link between the required structures or processes and beneficial patient outcomes is critical. The strongest link is a robust evidence base, ideally in the form of evidence-based practice guidelines. Consensus guidelines can be used to make the link, but they are weaker than evidence-based guidelines. Expert opinion can be used to support inclusion of specific care elements, structures, or processes in an accountability program, but it provides the weakest link between the care element and beneficial outcomes. Diversity of care models, services, and staffing points to a lack of consensus about what a serious illness program should offer.

Discussion

To successfully develop measures for serious illness accountability programs, NCQA must have a strategy for defining the target population, determining the right levels of accountability, and navigating an environment with a developing evidence base and a gap between expert recommendations and services offered.

As we continue with the project, we will consider the evidence linking improved outcomes to structures and processes when applied to a precisely defined population of seriously ill patients. We will also evaluate the degree to which the definition should promote access to serious illness care to a broad patient population, when most organizations currently lack the financial and workforce resources needed to meet aspirational standards.

We have concluded that it is necessary to target both provider groups/programs and plans/ACOs for accountability and measurement, to fill gaps in clinical care performance measurement and in meeting the needs of people with serious illness at the population level.

The lack of evidence for specific elements of community-based serious illness care and the heterogeneity among care models make it premature to prescribe specific care or services, staffing models, or site of care in an accountability program. Given the immaturity of the evidence, we will focus on process measures that build the infrastructure needed for outcome measures addressing symptoms, functioning, engagement, and experience with care. We are working toward measurement approaches that consider patients’ priorities for outcomes and goals.

Accountability program and measure development will emphasize outcomes that are important to patients and families, data needed to measure those outcomes, and standards and processes needed to capture the data needed for outcome measures, as well as any measures that are critical to patient protection that may not be adequately addressed in outcome measures. This approach avoids the pitfalls of prematurely aligning measures with emerging care models and instead allows organizations to use innovation to find the best path to high-quality serious illness care.

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Author Disclosure Statement

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Linking Quality and Spending to Measure Value for People with Serious Illness

Andrew M. Ryan, PhD1,2 and Phillip E. Rodgers, MD, FAAHPM2,3

Abstract

Background: Healthcare payment is rapidly evolving to reward value by measuring and paying for quality and spending performance. Rewarding value for the care of seriously ill patients presents unique challenges.

Objective: To evaluate the state of current efforts to measure and reward value for the care of seriously ill patients.

Design: We performed a PubMed search of articles related to (1) measures of spending for people with serious illness and (2) linking spending and quality measures and rewarding performance for the care of people with serious illness. We limited our search to U.S.-based studies published in English between January 1, 1960, and March 31, 2017. We supplemented this search by identifying public programs and other known initiatives that linked quality and spending for the seriously ill and extracted key program elements.

Results: Our search related to linking spending and quality measures and rewarding performance for the care of people with serious illness yielded 277 articles. We identified three current public programs that currently link measures of quality and spending—or are likely to within the next few years—the Oncology Care Model; the Comprehensive End-Stage Renal Disease Model; and Home Health Value-Based Purchasing. Models that link quality and spending consist of four core components: (1) measuring quality, (2) measuring spending, (3) the payment adjustment model, and (4) the linking/incentive model. We found that current efforts to reward value for seriously ill patients are targeted for specific patient populations, do not broadly encourage the use of palliative care, and have not closely aligned quality and spending measures related to palliative care.

Conclusions: We develop recommendations for policymakers and stakeholders about how measures of spending and quality can be balanced in value-based payment programs.

Keywords: healthcare payment for serious illness; measuring value of care; rewarding performance; serious illness; spending performance

Introduction

Value-based payments are accelerating rapidly: the Centers for Medicare and Medicaid Services (CMS) seeks to tie 90% of traditional Medicare payment to measures of quality or value by 2018.1 While not the primary target of recent policies, the value of spending on the seriously ill, patients with life-limiting illness,2 is receiving increasing attention. High spending during the last year of life is one of the main drivers of spending differences between the United States and peer nations.3 Reducing this spending and improving quality of life for seriously ill patients has been recognized as a major opportunity for improvement in U.S. healthcare. However, linking spending and quality – and rewarding value for patients with serious illness under value-based payment models – presents numerous challenges. First, there

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have been limited attempts to develop measures of spending for the seriously ill. Second, quality measures are essential in this context to avoid the appearance of rationing care for the sick and vulnerable at the expense of their well-being and quality of life. Third, where spending and quality measures have been developed, it is unclear how they should be combined. While previous research has catalogued potential approaches to combine quality and spending measures, these methods have not been applied to the seriously ill.

In this article, we review the literature about measuring quality and spending for the seriously ill, linking spending and quality measures, and jointly rewarding spending reductions and quality improvement. We focus our analysis on accountability efforts related to care for the seriously ill that combine quality and spending indicators. We close with recommendations for policymakers and stakeholders about how measures of spending and quality can be balanced in value-based payment programs.

Methods

Our literature review sought to identify literature related to two areas: (1) measures of spending for people with serious illness, and (2) linking spending and quality measures and rewarding performance for the care of people with serious illness. We limited our search to U.S.-based studies published in English between January 1, 1960, and March 31, 2017. We supplemented this search by identifying public programs and other known initiatives that linked quality and spending for the seriously ill. Our search strategy is described in Table 1. We also reviewed articles known to be relevant by the authors, which were not identified in the search.

Models to link quality and spending feature four core components: (1) measuring quality, (2) measuring spending, (3) linking/incentive mechanisms, and (4) payment adjustment mechanisms (Fig. 1). We organized our results according to these components. Measuring quality for the seriously-ill was not the focus of our review. Results from this section are not comprehensive, and instead discuss general principles for measurement.

Results

Measuring quality for the seriously ill

Serious illness care may be oriented toward increasing patients’ comfort, satisfaction with care, quality-of-life quality, and quality of death, rather than solely on prolonging life. As a result, a patient-centered perspective for quality measurement is essential. This orientation often requires novel data, including patient registries and surveys of patients and caregivers. Understanding potentially ineffective treatment, such as the use of chemotherapy within the last 14 days of life, is particularly salient among the seriously ill. Ultimately, quality

<table>
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<tr>
<th>Search domain</th>
<th>Search query</th>
<th>Total articles identified</th>
<th>Relevant articles identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Measures of spending for people with serious illness</td>
<td>(“seriously-ill” [Title/Abstract] OR “Serious illness” [Title/Abstract] OR “End of life” [Title/Abstract] OR “Terminal care” [Title/Abstract] OR “Palliative care” [Title/Abstract] OR “hospice” [Title/Abstract]) AND (“1960/01/01” [PDAT]: “2017/03/31” [PDAT]) AND (“Spending” [Title/Abstract]) OR “Cost” [Title/Abstract] OR “Payment” [Title/Abstract] OR “Efficiency” [Title/Abstract] OR “inefficiency” [Title/Abstract])</td>
<td>2141</td>
<td>18 articles that were relevant for specifying measures of resource use or spending for patients with serious illness; 15 articles evaluating the impact of hospice, palliative care, and advance directives on spending (or the cost effectiveness of these programs); 14 articles related to linking spending and quality measures for patients with serious illness.</td>
</tr>
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</table>
FIG. 1. Components of models to link quality, spending, and payment.

Table 2. Examples of Models to Link Quality, Spending, and Payment for National Programs

<table>
<thead>
<tr>
<th>Program</th>
<th>Payment adjustment model</th>
<th>Linking/incentive model</th>
<th>Measuring quality</th>
<th>Measuring spending</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehensive ERSD Care Model</td>
<td>One- or two-sided shared savings/risk model, bonus or loss</td>
<td>Spending and quality hurdle + quality adjustment model</td>
<td>Clinical measures (75%)</td>
<td>Total Medicare Part A and Part B spending (including dialysis facilities)</td>
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<td></td>
<td></td>
<td></td>
<td>• 6 process measures</td>
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<td>• 2 outcome measures</td>
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<td></td>
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<td></td>
<td>Reporting measures (25%)</td>
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</tr>
<tr>
<td>Oncology Care Model</td>
<td>± Adjustment to fee-for-service payments ($160 bonus for monthly enhanced oncology services; performance-based payment)</td>
<td>Spending and quality hurdle + quality adjustment model</td>
<td>12 measures related to</td>
<td>Part A and Part B spending (and some Part D) for six-month episodes (beginning with chemotherapy initiation)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Communication and Care Coordination</td>
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<td>• Person and Caregiver-Centered Experience and Outcomes</td>
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<td>• Clinical Quality of Care</td>
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<td></td>
<td>• Patient Safety</td>
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<tr>
<td>Home Health Value-Based Purchasing</td>
<td>± Adjustment to Home Health Prospective Payment System</td>
<td>Unconditional model</td>
<td>19 performance measures (90%)</td>
<td>None</td>
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<tr>
<td></td>
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<td>• 6 process measures (OASIS)</td>
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<td>• 8 outcome measures</td>
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<td>• 5 consumer experience</td>
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<td>• (HHCAHPS)</td>
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<td>3 reporting measures (10%)</td>
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<td>• Influenza</td>
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<td>• Herpes zoster</td>
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<td></td>
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<td>• Advanced care planning</td>
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measures should be chosen based on their reliability, validity, clinical relevance, and feasibility to collect. These measures will also depend on the context of measurement and specific programmatic needs (Table 2).

Measuring spending for people with serious illness

Articles that evaluated spending and resource use among patients with serious illness used one of two approaches: a retrospective approach, which calculated spending during a specific period of time before death; and a prospective approach, which calculated spending after a specific event. Retrospective approaches to spending evaluated spending patterns of seriously ill patients during a variety of “look-back” periods, including the last 365 days and 180, 90, 30, 15, 14, 17, 7, and 2 days of life. Many of these studies also evaluated utilization [e.g., physician visits, hospitalizations, emergency department visits, and intensive care unit (ICU) consultations]. Prospective approaches to evaluate spending tend to begin after a specific event. This event was often an initiation of in-home or hospital-based palliative care or hospice enrollment. Other studies evaluated spending for terminal episodes in the ICU. Some prospective approaches were not initiated by specific events: one trial of palliative care began evaluating spending for terminally ill patients with an estimated prognosis of a year or less to live. Under prospective approaches, episodes tend to conclude at the time of a patient’s death, rather than a fixed period from the initiation of the episode.

Linking/incentive models

Four linking/incentive models have been used by sponsors to explicitly link spending and quality indicators to provider reimbursement: unconditional; conditional; quality hurdle; and cost hurdle models. Unconditional models evaluate quality and spending indicators independently, assign weights to each, and calculate a weighted sum that determines a payment adjustment. This approach has been proposed in Medicare’s Hospital Value-Based Purchasing program and the Hospice Value-Based Payment program. The downside of unconditional model is that payment incentives can accrue to low-quality providers that also have low spending. Conditional models evaluate quality and spending indicators jointly, and determine payment incentives based on quality for a given level of spending, or vice versa. This approach currently used the Physician Value-Based Payment Modifier. The downside of this approach is that it typically requires spending and quality performance to be classified into discrete “cells” of quality and spending performance, leading to threshold effects. Hurdle models incentivize or penalize providers who meet a minimum performance standard. A quality hurdle model requires a minimum quality standard to be met before savings can be accrued. A spending hurdle model does the same, for spending. Medicare’s Shared Savings accountable care organization (ACO) program has elements of both quality and spending hurdles: savings can accrue only to ACOs that surpass the minimum savings rate and meet a minimum quality standard. Above the hurdle, ACOs’ rate of shared savings then depends on the level of quality performance. Under two-sided risk models, financial losses become less severe for ACOs with higher quality performance.

Examples of programs and payment adjustment models linking quality and spending for the seriously ill

A number of articles discussed conceptual issues associated with the move toward alternative payment models for patients with serious illness. These articles tended to focus on palliative care related to oncology. Others emphasized the move toward alternative payment models among commercial insurers. Research anticipating the potential impact of payment reform found that reductions in chemotherapy reimbursement from the Medicare Modernization Act led to less intensive oncology care at the end of life. Another study found that the Physician Group Practice Demonstration, a precursor to ACO programs, was not associated with changes in cancer spending. A recent study of oncology care models sponsored by the Center for Medicare and Medicaid Innovation (CMMI) found that the oncology medical home and patient navigation models led to reduced spending in the last 30, 90, and 180 days of life. CMMI has also funded Four Seasons Hospice and Palliative Care to expand palliative care delivery outside the hospital and offset hospital spending by providing more effective community-based patient and caregiver support services.

Additional work has showed that palliative care embedded within an ACO was associated with greater savings. The Trinity Pioneer ACO of Iowa focused on palliative care services as a way to generate savings, mainly by increasing the number of palliative care consultations. Some evidence suggests that delivery systems have reduced treatment costs through the use of palliative care, which is relevant for ACO models. This has been accomplished by the Palliative Care Benchmarking Project by defining “high-risk” patients for palliative care based on admission for one of 26 Diagnosis Related Groups (DRGs) and using rates of palliative care consultations among eligible patients as a quality measure. The use of ACOs to advance palliative care is similar to managed care efforts to coordinate palliative care around a capitated payment model that was developed almost two decades ago.

Table 2 shows how three national programs for seriously ill patients have linked measures of quality and spending to adjust payment to providers. The Comprehensive End-Stage Renal Disease (ERSD) Care Model is an ACO program. While its approach to assigning beneficiaries and evaluating spending and quality is similar to the other CMS ACO models, the ERSD model is unique in its exclusive focus on a seriously ill population. The program uses a hurdle model to adjust the shared savings or losses incurred by ACOs based on their quality performance. The program has been implemented recently but not yet evaluated. CMS has also developed the Oncology Care Model, an episode-based payment model. Under this model, hospitals are at risk for all hospital and physician spending, and some prescription drug spending, in the six months following the start of chemotherapy. Participating providers receive a maintenance fee for each patient treated under the model and are eligible for shared savings or shared losses based on their quality and spending performance (determined by the hurdle
model). This payment model, however, is not focused exclusively on seriously ill patients with life-limiting illness, and also includes patients who may be cured by therapy.

Home Health Value-Based Purchasing is another payment model that focuses, in part, on the seriously ill population. This program, modeled on the Hospital Value-Based Purchasing, adjusts payment for hospice providers based on a series of quality and spending measures. Payment adjustments are will be made to the Home Health Prospective Payment System using the unconditional model. Payment adjustments are expected begin at ±3% of hospice payment in 2018, increasing to 8% by 2022.

Discussion

Within or apart: Creating separate models of incorporating seriously ill patients within extant models

Any programs that financially reward quality and spending performance for serious illness care would be implemented alongside alternative payment models that have already been implemented. Should initiatives for serious illness care be incorporated into extant programs, or should they become their own programs? The benefits of incorporating the seriously ill into extant programs are that they can draw on the structures and processes that have been developed to manage population health. The drawbacks are that these structures, particularly their quality and spending measures, may not be appropriate for serious illness care. For instance, hospice providers are rarely included in ACOs.

The advantage of separate accountability programs for serious illness care is to enable a greater focus on the needs of the patients and caregivers receiving it. Such programs could conceivably have more clinical homogeneity and clearer expectations about spending and quality across the disease course. This could help align the specifications of spending and quality measures. However, even within common disease areas such as cancer, there can be extensive clinical heterogeneity for different types of disease (e.g., breast cancer, prostate cancer, esophageal cancer, and lung cancer). The disadvantages of separate programs for the seriously ill are that numerous programs could create administrative complexity for providers and payers, and confusion for patients and caregivers. Given the rise of multimorbidity in the United States, different patients could conceivably be eligible for numerous programs, creating potential problems related to coordination and accountability across programs. In addition, the number of patients qualifying for these separate programs would likely be small, leading to unreliability in performance measures for spending and quality. One option could involve combining multiple payers in an initiative, as had been done in the Oncology Care Model.

Defining eligible patients and accountable clinicians

Eligibility among seriously ill patients for accountability programs may be based on some or all of the following patient characteristics: serious illness diagnosis (e.g., advanced cancer, heart failure, and neurodegenerative illness); functional and nutritional decline; patterns of healthcare utilization; or receipt of certain types of care (e.g., hospice care and palliative care). Patient consent is essential, and while obtaining consent would introduce programmatic complexity, it would mitigate concerns that serious illness care may be saving money at patients’ expense.

Given the diverse care needs of seriously ill patients, having individual hospitals or physician practices be accountable for care creates significant challenges with respect to both proactively identifying patients who can benefit from palliative care services and influencing the continuum of care. Larger care systems, such as integrated delivery systems, Medicare Advantage plans, or ACOs may be better structured to be accountable for the care of seriously ill patients. However, larger organizations may not have the clinical delivery capacity to meet the palliative care needs of their populations, especially in rural communities or highly competitive markets. Bridging these gaps requires flexible payment models that are oriented toward care coordination and clinical consultation among diverse practices, rather than a one-size-fit all approach.

Defining the period of accountability

After patients meet clinical criteria for a given care model, a prospective episode can then be initiated. There is some precedence for this approach for the seriously ill: a prognosis of one year or less left could be an inclusion criterion for an alternative payment model. The end of the episode could be the death of the patient the desire of the patient to end the episode, or the patient’s loss of eligibility. This is the approach taken in Medicare’s ERSD Comprehensive Care Model. The Oncology Care Model initiates at the beginning of chemotherapy and extends for six months. Initiation of hospice or palliative care is another trigger to begin an episode. The drawback with this approach is that it is potentially at odds with the larger goals of palliative care, which are not so much to reduce spending after the start of hospice care or palliative care, but to encourage more hospice and palliative care. A retrospective episode, on the other hand, evaluates quality and spending in over a specified period preceding death. Because interventions focused on the seriously ill have the potential to affect both patients’ time to death and spending at the end of life, the use of prospective and retrospective episodes may result in different inferences about the impact of an intervention. As a result, the choice of a prospective or retrospective episode should be guided by the goals and expectations of the program or intervention.

Determining the types of care for which clinicians are accountable

Payers have different options for determining the types of care that would be included in episodes of serious illness. Episodes could be defined broadly, and accountable providers would thus be responsible for all healthcare used by patients, even that which is not necessarily related to the serious illness. Alternatively, an episode could be defined narrowly and accountable providers held responsible only for care related to the given serious illness. Broad episodes make sense for hospice and palliative care when a key goal is to avoid aggressive treatment that does not improve either disease progression or quality of life. Narrow bundles may be more appropriate for hospice and palliative care providers caring for patients who are continuing to receive potentially valuable disease-oriented care like chemotherapy. Research
suggests that episode spending tends to be highly consistent, regardless of broad or narrow definitions. 42

Setting targets for spending

Alternative payment models are evolving toward partial risk approaches that include upside and downside risk with quality adjustment. 43 This involves setting a target for spending and comparing the spending of the accountable provider with the target. Under a one-sided “shared savings” model, if spending if below the target, the accountable provider shares some of the savings that are generated. Under a two-sided model, an accountable provider risks losing revenue for spending above the target. Medicare is moving away from one-sided models toward two-sided risk: under the MACRA legislation, two-sided target. Medicare is moving away from one-sided models to-ward two-sided risk: under the MACRA legislation, two-sided risk is required for providers to meet the criteria for “advanced” alternative payment models.

Spending on medical care is likely to vary considerably in an episode of serious illness, with spending increasing toward the end of life. 9,46–48 Spending targets should account for these trajectories, adjusting for time periods when patients are closer to the end of life. Practically speaking, this means that spending expectations should be higher for a patient with an episode of serious illness that last four months, compared to an episode lasting 24 months.

Finally, setting spending targets for patients with very high spending will be a challenge. Medicare’s bundled payment and ACO programs have explicit rules to limit providers’ risk for high spending patients, capping the spending for which accountable providers are responsible at the 95th percentile or two standard deviations from the mean. Payers could take a similar approach for episode payments among the seriously ill. Yet because so much of health spending is concentrated among the highest cost patients, many of whom have serious illness, excluding these patients from accountability programs misses an important opportunity for savings. Efforts to prospectively identify patients at risk for very high spending, segmenting this population, and providing upside risk alone for the spending, may be one approach to balance incentives for efficiency, while avoiding excess risk for providers.

Avoiding unintended consequences of rewarding quality and spending for seriously ill

Due to the vulnerability of seriously ill patients, programs that link quality and spending must anticipate and safeguard against unintended consequences. One potential unintended consequence is that providers would seek to avoid caring for seriously ill patients who appear to be particularly costly. Published data show that some hospices restrict enrollment for high cost patients, 49 while others limit admission for patients with shorter, and less profitable, expected lengths of stay. 50 Relatedly, because many costs associated serious illness care accrue close to death, providers have an incentive to decline patients with very short life expectancies. These concerns could be remediated through robust risk adjustment, use of alternative risk models for particularly costly patients, and monitoring the life expectancy of patients who are enrolled in palliative care programs. Another unintended consequence is that providers could attempt to reduce spending at the expense of quality. Ensuring robust quality standards, potential extensive performance measures, and the use of quality hurdle payment models, could alleviate this concern.

Conclusion

In this article, we identified and evaluated key programs and program features for accountability efforts related to care for the seriously ill that combine quality and spending indicators. Future research should evaluate the measurement properties for quality and spending indicators focused on the seriously ill, hopefully culminating in new measures that are endorsed by the National Quality Forum. In addition, research should evaluate the impact of programs focused on improving value for seriously-ill populations, such as the ERS ACO program, the Oncology Care Model, and the Home Health Value-Based Payment program.

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Accountability for Community-Based Programs for the Seriously Ill

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Abstract

Innovation is needed to improve care of the seriously ill, and there are important opportunities as we transition from a volume- to value-based payment system. Not all seriously ill are dying; some recover, while others are persistently functionally impaired. While we innovate in service delivery and payment models for the seriously ill, it is important that we concurrently develop accountability that ensures a focus on high-quality care rather than narrowly focusing on cost containment. The Gordon and Betty Moore Foundation convened a meeting of 45 experts to arrive at guiding principles for measurement, create a starter measurement set, specify a proposed definition of the denominator and its refinement, and identify research priorities for future implementation of the accountability system. A series of articles written by experts provided the basis for debate and guidance in formulating a path forward to develop an accountability system for community-based programs for the seriously ill, outlined in this article. As we innovate in existing population-based payment programs such as Medicare Advantage and develop new alternative payment models, it is important and urgent that we develop the foundation for accountability along with actionable measures so that the healthcare system ensures high-quality person- and family-centered care for persons who are seriously ill.

Keywords: accountability system; community-based palliative care programs; value-based payment system

Industrialized nations are faced with the challenge of a growing population of frail, older persons. In the United States, about two-thirds of Medicare beneficiaries have multiple chronic conditions, and one-third have functional limitations.1,2 At the same time, there are concerns about the growing proportion of U.S. gross domestic product devoted to healthcare, which is projected to hit 20% by 2025.3 In part, the volume-based incentives and absence of price controls in the healthcare system that resulted in this level of spending have also resulted in concerns over the quality of care provided to these persons. Providing value-based care—rather than volume based—to people with serious illness while constraining the growth of healthcare costs is a critical policy challenge that presents significant opportunities for innovation in care delivery.

The National Academy of Medicine (NAM) has noted that by helping to clarify and honor patient values, goals, and preferences, quality could be enhanced by avoiding preventable and unnecessary medical interventions that will not help achieve patient goals and are unlikely to benefit or may even harm the patient.4 Patients generally prefer to receive home- and community-based palliative care when feasible.
which studies show decreases costs. In addition, people with serious illness are typically receiving their care from multiple physicians in various settings of care, resulting in care fragmentation. Enhanced care coordination can reduce this fragmentation while improving the experience of care and decreasing avoidable complications.

The changing incentives in the healthcare system have led to innovation in the delivery of serious illness care, in both the private and public sectors. For example, Aspire Health is a privately held company that contracts with Medicare Advantage and other managed care plans to provide home-based palliative care to high-need, high-cost patients in 19 states. At the same time, the federal Medicare Care Choices Model (MCCM) demonstration program allows over 140 participating hospices to provide services to hospice-eligible Medicare beneficiaries without forgoing disease-directed treatment.

As we innovate, a word of caution should be noted. Not all seriously ill persons are dying. Among the costliest 5% of patients who account for 50% of all U.S. healthcare spending in a year, about half recover and have lower costs in subsequent years. Only about 10% of these patients have been, in retrospect, in their last year of life. The remaining 40% are patients with multiple chronic conditions, often accompanied with functional and cognitive impairment, that have persistently high costs year over year. As we move from volume-based incentives to value-based incentives, we need an accountability system to ensure that cost containment pressures do not lead to undertreatment or worse quality of care for this vulnerable population.

In May 2017, the Gordon and Betty Moore Foundation convened 45 participants to identify a path forward for building an accountability system for high-quality, community-based serious illness care programs. The goal of the convening was to create guiding principles, begin identifying appropriate quality measures, specify an approach to defining measure denominators that best capture the seriously ill population, and identify research needs and next steps.

There are three key components of an accountability system: (1) accreditation and certification; (2) public performance information; and (3) value-based payment. In establishing an accountability system, a key first step is defining high-quality care. The NAM proposed a set of evidence-based core competencies for high-quality serious illness care (Table 1).

### Guiding Principles for Measurement

At this time of innovation in the creation of new delivery models (e.g., Aspire Health, Aetna Compassionate Care Program, community-based palliative care programs), testing of a potential new Medicare benefit (e.g., the MCCM demonstration that allows hospices to provide palliative care services along with care for potentially extending life), and consideration of new payment programs under the Medicare Access and CHIP Reauthorization Act (MACRA), it is important that actionable quality measures guide the further development of these programs. Quality measures are needed to provide transparency and accountability to ensure the public that these programs are focused on improving the quality of life and care of this vulnerable population, not primarily focused on constraining cost.

Participants in the convening were asked to provide their input on a set of guiding principles for the further development and use of measures. In an online survey, they were asked to rank the importance of a draft set of principles. The full set of principles was refined based on the feedback received. The final set of principles is listed in Table 2. It should be noted these are a set of ideals, and it is not expected that a measure would fulfill all these criteria.

There are important tensions and trade-offs that should be acknowledged and considered in decision making about measures. Measure sets will need to balance the opposing goals of being comprehensive and parsimonious, and capturing what is most important to the patient and caregiver while not being overly burdensome. Patients are the best source of that information, but many seriously ill people, such as those with cognitive impairment and persons near death, are unable to report on their experiences of care. Although not currently a standard of practice in the Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient experience surveys and other assessments, family caregivers should be invited to serve as proxies when patients are unable to respond. In addition, it is important to consider the potential for unintended consequences from the choice of measures and how measures are defined and implemented. An example of an unintended consequence is forcing a process of care considered central to quality that the patient does not want. For example, many seriously ill patients and families welcome spiritual support from the healthcare team. Yet, not all people with serious illness want to discuss their religious beliefs with a healthcare professional or spiritual care provider. A measure focused on ensuring access to spiritual counseling should not result in unintended consequences by forcing the patient to be seen by a spiritual care counselor.

### Table 1. Core Competencies for High-Quality, Community-Based Serious Illness Care Programs

- Identification of the target population
- Team-based care
- Caregiver training
- Attention to social determinants of health
- Communication training and supports
- Goal-based care plans
- Symptom management
- Medication management
- Accessibility (including 24/7 coverage)
- Transitional care
- Measurement of value for accountability and improvement

The selection of process measures needs to be based on high-quality evidence that links that process to patient- and caregiver-reported outcomes. In addition, caution is needed when establishing cut points for process measures. Cut points should be based on empirical research and should incorporate the population distribution, expert opinion, and—most importantly—associations with patient- and caregiver-reported outcomes. For example, the use of late referrals to hospice as an accountability measure of poor quality must carefully consider the fact that about one in five hospice patients either previously refused hospice or suffered a sudden medical event that resulted in a late hospice referral.12

_The starter measure set should be refined over time based on additional research and future developments in the field (Table 4). In addition, the measure set should be refined as new guidelines and standards are developed and released. The National Coalition for Hospice and Palliative Care is updating guidelines for best practices in community-based serious illness care, which will fill the gap in current evidence-based recommendations for these programs. Similarly, the Joint Commission’s existing programs and the National Committee for Quality Assurance (NCQA) process to develop standards and an accreditation program will define the critical components of these programs. The measure set should evolve to reflect and be synergistic with existing and evolving evidence, guidelines, and standards._

**Proposed measure starter set**

Based on the guiding principles for measurement and the current gaps in measures, the convening attendees agreed on a starter set of measures. This starter set was modified based on additional expert review. The Proposed Measure Starter Set, presented in Table 3, includes well-being of patients and caregivers, experience of care, process measures of clinical care, advance care planning, safety, utilization, and costs, and access. The table indicates whether the proposed measure already exists or needs to be developed as a new measure. Several of these measures are already in use, as noted by the National Quality Forum (NQF) endorsement status. Further work is needed to examine psychometric properties in a potential new population as modifications to the definition of serious illness change the denominator of the target population.

The starter measure set should be refined over time based on additional research and future developments in the field (Table 4). In addition, the measure set should be refined as new guidelines and standards are developed and released. The National Coalition for Hospice and Palliative Care is updating guidelines for best practices in community-based serious illness care, which will fill the gap in current evidence-based recommendations for these programs. Similarly, the Joint Commission’s existing programs and the National Committee for Quality Assurance (NCQA) process to develop standards and an accreditation program will define the critical components of these programs. The measure set should evolve to reflect and be synergistic with existing and evolving evidence, guidelines, and standards.

**Measurement Challenge of Small N**

A significant issue for quality measurement of serious illness care is small numbers. Many community-based palliative care programs enroll small numbers of patients. Small numbers of patients result in small sample sizes for quality measures, resulting in low measure reliability. The Medicare Payment Advisory Commission (MedPAC) highlighted this issue in its 2017 Report to the Congress, and suggested as a solution that Center for Medicare and Medicaid Services (CMS) move to population-based measures that assess performance for a group of providers, rather than at the individual provider level.13 Depending on the proposed definition of the denominator, the small number of persons served per provider is an important constraint on the implementation of an accountability program.

Finally, in the absence of carefully focused accountability systems, seriously ill patients may be overlooked in larger models that encompass a broader population. For example, in an accountable care organization (ACO) model, the seriously
ill typically represent a small portion (5–10%) of the patient panel. The impact of care for the seriously ill portion of the population on overall quality measures can be so small that the ACO may conclude it is not worth investing significant resources into improving the quality of their care. This is compounded by the fact that very high-cost—often seriously ill—patients are considered outliers and are excluded from cost measures by CMS, including in ACO models. One solution is to apply different weights to quality measures for the seriously ill that will incentivize these models to improve the care of the seriously ill.

**Measuring goal concordance**

CAHPS surveys are used to assess patient experience for the purposes of assessing provider performance in a variety of CMS quality and payment programs. In the development of a new CAHPS enrollment survey and refinement of the existing CAHPS bereaved family member survey, “goal concordance” with care is an important domain. Additional research is needed to examine its validity, actionability, and other psychometric properties. For example, concerning is that a person may have said at an earlier time they want to die at home, but then have symptom distress that requires transfer to a hospital or general inpatient-level hospice care for appropriate treatment. Changes in circumstances result in changes in options that often cannot be anticipated in advance, which can result in a clinician being wrongly penalized for failure to provide goal concordant care based on an earlier advance care plan when the care was appropriate and necessary. Goal concordant care is not just about life sustaining care but also about what is important to the person...
and what outcomes they want to avoid. As recently noted by Teno et al., there are important challenges in measuring goal concordance of care as an accountability measure that should be taken into consideration. They include:

1. Patient and family readiness or lack of readiness for information and discussion of goals of care may result in distress if this conversation is forced to a time point when the patient and/or family are not ready. This has been termed "information toxicity." 

2. Prospective measurement of goals as they evolve over time requires time and resources with reflection on what is the right denominator.

Given the limitations of accurately assessing goal concordance in real time, the focus in the near term may need to be on measuring key aspects of the quality of communication from the consumer perspective. (e.g., Did the provider listen to you? Were you allowed to ask all your questions? Was information provided in a way you can understand?)

**Measuring value**

NQF defines value of care as a “measure of a specified stakeholder’s preference-weighted assessment of a particular combination of quality and cost of care performance.” Given the importance of patient preference in defining quality—especially in serious illness care—patient preferences should also inform assessments of value. Additional research is needed on how to most appropriately assess the patient preference-dependent component of value in serious illness care. Andrew Ryan, PhD, and Phillip Rogers, MD, as part of this special supplement outline the pros and cons of various models for linking quality and costs.

### Improving EHR and other data platforms

As Curtis et al. discuss, there are important barriers to electronic health record (EHR) functionality, including missing and inaccessible data elements, to measure the care of the seriously ill. With the implementation of the IMPACT Act, data elements and quality measures from postacute care patient assessments are being standardized across settings. These standardized elements and measures, including functional and cognitive status, can be mapped and made interoperable with EHRs. However, without a critical mass of EHR users requesting these changes, or policy changes requiring them, EHR vendors are unlikely to take the steps necessary to establish genuine interoperability. There is an opportunity to

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**Table 4. Priority Next Steps and Research Needed**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Priority</th>
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<tbody>
<tr>
<td>Measurement</td>
<td>Adapt CAHPS measure/module that examines key domains, including communication and goal concordant care vs. CAHPS survey that is administered about 2–3 months postenrollment in community-based programs for persons with serious illness. As always with CAHPS instruments, the perspective of the patient and caregiver plays a critical role in development. Improve public reporting by ensuring that information is presented to patients, caregivers, and providers that is timely, easily understood, and actionable. Develop, test, and validate a new approach to measure “goal concordant” care, and examine whether bereaved family and patient reports of discordant care are valid and actionable. Convene stakeholders to propose enhanced functions that promote data exchange and interoperability of EHRs to allow actionable measurement for quality improvement and accountability. Conduct analyses to understand the reliability and validity of proxy responses for a patient throughout the disease trajectory. Conduct analyses to understand the responsiveness of measures to interventions.</td>
</tr>
<tr>
<td>Denominator</td>
<td>Examine the specificity, sensitivity, and positive predictive value of utilization-based criteria to identify seriously ill persons at high risk for utilization and mortality against a “gold standard” needs assessment to identify persons who would benefit from enhanced community-based services. Assess the degree to which a utilization-based definition can be enhanced by inclusion of function and cognitive status measures, currently part of postacute care assessments mandated by the IMPACT Act, and what population is excluded from the denominator because of the lack of these assessments. Create a brief second-step telephone screen (after identifying patients based on claims and diagnostic criteria) to identify one’s need for enhanced services and evaluate how many persons would have to be screened to identify one who would benefit from these services. Translate these findings to a comprehensive EHR strategy that could identify the “denominator” and thus enhance access to services and ease measurement for accountability.</td>
</tr>
<tr>
<td>Registry-based cocreation learning system</td>
<td>Pilot test a cocreation learning system model using the following steps: (1) form a lead team that is part of current efforts to form a registry collaborative among the existing registries; (2) involve a range of stakeholders in the design process, including patients and families, care teams, clinicians, researchers, and registry holders, and gather input from information technology experts, health system leaders, payers, and implementation scientists; and (3) coordinate with other related efforts, including the American Academy of Hospice and Palliative Medicine and American Board of Family Medicine registries.</td>
</tr>
<tr>
<td>Value-based payment</td>
<td>Simulate various models for linking quality and spending information to identify potential unintended consequences.</td>
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</table>
convene stakeholders to align and prioritize these and other key EHR interoperability and information opportunities. Medical specialty societies and provider trade associations would be key stakeholder groups to involve. A broad approach could also help spread the costs of changes across many different groups.

The denominator: who should be offered enhanced services?

Any care model and payment system require a means of identifying who should be offered enhanced services. For the seriously ill population, the denominator should mirror the consensus definition of serious illness as closely as possible. If the population definition—or the denominator of a quality measure—is too broad, too many individuals may be included who do not need the services (i.e., low specificity), reducing the value of the program. On the contrary, if the denominator is too narrow, too many individuals who would benefit will be excluded (i.e., low sensitivity). This trade-off directly impacts the cost and resources needed to effectively screen the population, as well as the feasibility of incorporating small and community-based programs. At the same time, while high-cost patients often have high needs, these groups are not completely overlapping. Some high-needs patients will not be highest cost, and vice versa. The most important consideration is for whom community-based palliative care will have the greatest impact on quality and/or cost. An article by Kelley et al. proposes operationalization of the denominator and provides recommendation for future research to refine the denominator (Table 4).

As noted, community-based programs for the seriously ill are growing rapidly in Medicare Advantage plans and some ACOs. At the convening in Banff, the group focused on two other potential future scenarios for the wide adoption of an accountability system for community-based programs for persons with serious illness: (1) development of a cocreation patient registry and (2) adoption of an advanced alternative payment model (APM) with downside financial risk for clinicians caring for persons with defined elements of serious illness. These scenarios are not mutually exclusive, and over the long term, a more population-based approach may be most feasible and impactful.

A cocreation registry creates a partnership between the care team and the patient and caregiver for eliciting patient priorities, concerns, and preferences for care. Patients provide information about their symptoms and quality of life, and these data are made available to clinicians in real time along with other clinical data to inform decision making at the point of care. An article by Kamal et al. lays the vision for cocreation registry. We will briefly discuss APMs.

The Affordable Care Act (ACA) established the Center for Medicare and Medicaid Innovation (CMMI) at CMS to develop and test new models of care delivery and value-based payment, also known as APMs. While existing CMMI models have been developed internally, a new mechanism exists for models to be proposed by outside stakeholders and tested by CMMI. The MACRA of 2015 established the ability for organizations to propose advanced APMs for testing, requiring providers to accept some downside financial risk as well as accountability for quality. There are two advanced APMs that have been submitted by C-TAC and the American Academy of Hospice and Palliative Medicine and are currently under consideration. As part of any APM for the seriously ill, it is very important that the accountability system is developed as these models are tested. If a new APM for serious illness moves forward to implementation, CMS should fund the development of actionable new measures and modification needed for current measures to complete the set. In addition, engagement with the Learning and Diffusion Group at CMMI, which collects lessons learned from CMMI’s APM development and implementation, may help inform the final design of these models. As these two serious illness advanced APMs move through the review process, efforts should be made to harmonize their approaches as much as possible.

Conclusion

Measurement is the foundation of an accountability system for community-based serious illness care. The three components of an accountability system—value-based payment, public reporting, and accreditation and certification—will only be effective if the right set of feasible, valid, actionable, and meaningful quality measures is included. In this article, we have identified a set of guiding principles for measurement (Table 2) and a starter set of measures for use by an accountability system (Table 3) and its components. We have identified a series of research priorities (Table 4) for more fully defining the Proposed Starter Set. Beyond research, outreach and stakeholder engagement will be needed to align efforts, build momentum, and design an accountability system that is centered on the needs of seriously ill patients and their caregivers.

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