

# Measuring the Quality of Palliative Care at End of Life: An Overview of Data Sources

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**ABSTRACT:** Palliative care, and more specifically end-of-life (EOL) care, serves to address the physical, practical, psychosocial, and spiritual needs of dying patients and their families. The quality of this care is critical to reduce the burden of illness and moderate escalating health-care costs. Accordingly, assessing the quality of EOL care is a priority of many governments. This article is an overview of the three main types of data sources that can be used to indicate the quality of EOL care: population-based administrative data, clinical data, and patient-reported outcomes. Existing administrative data are relatively inexpensive to use and provide a whole picture of the health-care system. Clinical data are useful for benchmarking care provided against best practices. Patient-reported outcome measures capture quality as defined by the patient and directly represent impact of care. Understanding the capabilities of these data types is the basis for developing feasible quality assessments to inform program and policy development.

**KEYWORDS:** end-of-life care, palliative care, quality indicator, evaluation

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## Introduction

Approximately 1% of the global population dies annually, of which the vast majority are elderly.<sup>1,2</sup> Moreover, in most developed countries, the number of deaths is expected to double in the next 40 years, due to the proportion of elderly increasing to 25% of the population by 2030.<sup>3</sup> Over 90% of deaths are from advanced serious illness and chronic disease, such as cancer, heart, and lung disease, and progressive cerebrovascular disease,<sup>1,4</sup> which are often preceded by periods of disability, high symptom burden, and dependency.<sup>5</sup> During this dying trajectory, patients and their families can greatly benefit from palliative care.<sup>6</sup> Palliative care, as defined by the World Health Organization, is an “approach to care that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”<sup>7</sup> Palliative care is becoming increasingly recognized as a population health issue that needs to be considered in a wider context of primary and specialized care and integrated within the entire spectrum of health-care services.<sup>8-11</sup> This approach includes the ongoing monitoring of populations at risk to identify palliative care needs and introducing public policies to eliminate gaps in services. Inherent in a population-based approach is the idea that palliative care should be offered earlier in the progressive disease trajectory alongside curative

treatment, to maintain the quality of life of individuals in the years before death.<sup>12</sup>

Palliative care often implies a team approach to address the holistic needs of individuals with incurable diseases and their families, to help maintain their comfort and dignity. The professional compositions of these *teams* typically vary, depending on the particular needs of the patient. Health providers involved in care may include nurse specialists, palliative care physicians, primary care physicians, and other allied health professionals (eg, psychosocial spiritual counselors, bereavement counselors, and social workers, among others).<sup>13,14</sup> While not all people at this stage need or desire the same types of professional palliative care services or even access to specialist providers,<sup>15,16</sup> requests for interventions to alleviate both symptom distress and family caregiver burden are common in the last year of life.<sup>17,18</sup> In fact, for many, palliative care tends to be underutilized, unavailable, or applied far too late in the illness trajectory.<sup>19</sup>

Although the terms palliative care and end-of-life (EOL) care are sometimes used interchangeably, EOL care distinctly involves more exclusive and often more intense palliative care over the period of time, such as the last weeks of life, where a rapid state of decline is evident.<sup>20</sup> Palliative care and EOL care can be provided at home in the community or at institutional settings such as hospitals, residential hospices, or nursing homes, with most patients receiving care from two or more different settings in their last months of life.<sup>21,22</sup> In addition



to improving patient satisfaction and other outcomes, access to timely palliative care has been shown to reduce hospital admissions and the use of other health services at the end of life.<sup>7,21,23,24</sup> A recent study across Canada found that more palliative home care nursing costs was almost always associated with lower total health-care costs.<sup>25</sup>

To curb escalating health-care costs and to address prevailing gaps in care for the dying, many governments have prioritized the implementation and improvement of palliative care services.<sup>15,26–28</sup> This is particularly the case for EOL care, as this represents the greatest demand for specialized services. As such, service planners want to measure the quality of palliative care and EOL care regularly.<sup>29–31</sup> There are three main types of data sources that can indicate quality: population-based administrative data, clinical data including care activities and patient records, and patient-reported outcomes (PROs). These data have the potential to drive evidence-based interventions at international, national, or local levels, depending on the intended scope. The objective of this article is to provide an overview of these different data sources for measuring the quality of palliative care performance across multiple care settings, examining the strengths, limitations, and applicability of each approach. Special attention is given to the quality of EOL care because closing gaps in palliative care at this juncture is the most crucial. Overall, this introduction to the capabilities of key data sources has relevance to service providers, policy makers, and researchers toward developing feasible quality assessments to inform improvement of services for the dying.

### What is Quality EOL Care?

As with definitions of quality palliative care, those of quality EOL care reflect the multidimensional domains of care described by WHO,<sup>32–34</sup> that is, adequate pain and symptom management, psychosocial support, avoidance of inappropriate medical interventions, and maintenance of quality of life for the patient and family, as well as their satisfaction with care. However, research has found that what is most important to patients and their families at EOL is a slightly more abstract concept, especially when pain and symptom management and practical needs are being reasonably met and not at the forefront of concern.<sup>35,36</sup> Access and availability of EOL services to meet core supportive care domains is critical, beyond this, patient and family concerns focus toward factors such as determination of care, the nature of the care provided including provider disposition, trust, and care continuity, achieving life closure, death preparation, and the circumstances of death.<sup>36–39</sup> Patient and family perceptions of these elements impact satisfaction with care and influence whether the EOL experience is considered of high quality. The difficulty is in translating all these aspects of quality into measurable variables. Despite the challenges of quantifying quality palliative and/or EOL care, doing so is important

to understand how to best improve or provide better care in a given system.

As a starting point to measure the quality of palliative and EOL care in health-care systems, extensive work has been done to identify key indicators for examining these services on a large scale.<sup>40–42</sup> Specifically, a quality indicator in health care is a quantifiable and comparable feature of care or a care event that is deemed critical.<sup>30,31,40</sup> Systematic reviews of indicator sets identified 20 unique indicator frameworks in total for measuring the quality of palliative care, which consist of 370 measures.<sup>40–42</sup> Some of the frameworks are focused on patients with advanced cancer,<sup>43,44</sup> some on the vulnerable elderly,<sup>45,46</sup> and some on defining clinical indicators.<sup>47–50</sup> Two examples of indicator sets are those proposed by the National Quality Forum in the United States and the United Kingdom's Department of Health, each with 14 and 34 recommended indicators, respectively.<sup>51,52</sup> As is the case with many of the frameworks, there is partial overlap in the quality indicators included, yet differences in the domains of care covered.<sup>40</sup> The National Quality Forum framework is more symptom management centric, whereas the Department of Health set is more setting specific and contains a greater focus on care processes. Other relevant palliative care quality measurement projects exist in Australia, Belgium, and the Netherlands, among others.<sup>53–55</sup> The majority of these quality indicator frameworks were developed through a combination of literature review and expert consensus, with indicator selection largely driven by what data are available or can be practically collected. In general, the framework measures rely on data from nationally/regionally held administrative data systems or repositories, local clinical record, and reporting systems and, to some extent, perceptions of care obtained from the patient and/or their family.<sup>31</sup> Outcomes from the patient/family perspective are less easily captured and therefore often unavailable as an existing data resource.

In terms of identifying specific measures, the wide variation in definitions of quality and quality indicators presents several challenges. For instance, in the US, many palliative care programs are not routinely measuring quality, those who are often using locally developed, nonvalidated indicators. For those who wish to assess quality, there are no nationally used sets of measures with benchmarking that apply across populations and settings. To address this and help develop standards for quality measurement in palliative care, the Measuring What Matters (MWM) framework developed a list of 10 top ranking quality indicators for palliative care that are clinically relevant and cross-cutting.<sup>56</sup> For the most part, these indicators relate to activities within specified times upon admission to hospice care or hospital, namely: (1) comprehensive assessment completed, (2) physical symptoms screened, (3) pain managed, (4) dyspnea screened and managed, (5) discussion of emotional/psychological needs, (6) discussion of spiritual/religious concerns, (7) documentation of surrogate, (8) documentation of treatment preferences, and (9) care consistent

**Table 1.** Summary of data types.

DATA TYPE	DEFINITION	DATA SOURCE EXAMPLES	TYPICAL VARIABLES [EXAMPLE MEASURE]
Administrative data	Population-based regional or nationally compiled healthcare usage and event data from multiple settings “healthcare usage”	Vital statistics Healthcare billing database Hospital discharge abstract data repository	Frequency of emergency room visits Days in hospital Site of death Palliative care billing codes used Home care/hospice provided Physician home visits Pharmaceutical administration Formal healthcare costs [% of deaths in hospital]
Clinical data	Site or program-based provider recorded occurrences and activities directly or indirectly involving patient care “documented processes and vital signs”	Activity checklists Patient charts Medical reports	Anticancer treatments near death Comprehensive needs assessment completed Advance directives reported Time to referral for required resource Surrogate documented [Comprehensive assessment within 24 hrs of admission]
Patient reported data	Perceptions of care collected from patients and their families “user perceptions”	Survey, focus group, or interview data	Overall satisfaction with care Pain and other symptoms managed Meeting of physical, psychosocial, spiritual, and information needs Provider rapport Smooth transitions between care settings Management of death Involvement in care planning [Perceived extent to which patient was given the opportunity to discuss advance care planning with his/her healthcare providers]

with documented preferences. The tenth indicator is a measure of the patient and family EOL care experience, though no tool is endorsed.

Another example from the study by Raijmakers et al includes using a similar review and consensus process in Europe, where a short list of seven indicators was created.<sup>57</sup> These indicators were as follows: (1) record of a bereavement home visit within a week of death, (2) access to a dedicated family room for meetings, (3) limited patients receiving chemotherapy in last two weeks of life, (4) evidence of pain control, (5) pain score, (6) gastrointestinal symptom score, and (7) provider patient/family communication quality score. The MWM and Raijmakers et al’s frameworks provided pointed initial lines of inquiry for gathering evidence to inform program and policy development and delivery of services. Although what needs to be measured to ascertain the quality of palliative and EOL care is sufficiently clear, how to obtain these data is not.<sup>58,59</sup>

The following section provides an overview of the three main different data approaches that can be used to measure the quality of EOL care. Each approach has strengths and weaknesses, with certain data types and variables being more appropriate to given care settings or populations than others.<sup>30</sup> Definitions and examples of the data source types are summarized in Table 1.

### Overview of Data Approaches

**Administrative data.** Administrative datasets are population-based, regional or nationally compiled health-care

usage and event data from multiple settings, rather than from a specific setting such as a hospital palliative care unit. Examples of administrative datasets in the US are the Centers for Medicare & Medicaid Services’ claims data<sup>60</sup> and the Surveillance, Epidemiology and End Results (SEER) Cancer Registry.<sup>61</sup> National palliative care standards and surveillance data systems have been developed in the US, England, and Australia, among other countries based on administrative data sources.<sup>29,62–65</sup> These data systems focus on patient characteristics and service activities. Typical EOL care-related outcomes contained in administrative data are: frequency of emergency room visits, days in hospital, site of death, palliative care billing codes used, home care/hospice provided, formal health-care costs, physician home visits, and pharmaceutical orders.

Administrative datasets provide a potential wealth of information for researchers. Earle et al published one of the first guidelines for using administrative data to measure the quality of EOL care, along with the stated benefits and weaknesses of this approach.<sup>66</sup> The most compelling features of administrative datasets are that they contain existing data, are accessible in electronic format, and often cover large samples or populations. For these reasons, using these data is relatively inexpensive and less time consuming than primary data collection. The use of unique identifiers is often standard in administrative datasets allowing for the combining of databases, making it possible to link individuals across health-care sectors and settings. These datasets also have the advantages



of being longitudinal, allowing for comparison over time and being inclusive in containing data on all deaths and funded health care received.

The practicality and versatility of administrative data makes them useful for studying the palliative care system as a whole, such as identifying and providing insights into decedents with terminal disease who never received formal EOL care, to inform strategies toward improving equitable access. Furthermore, knowing the types of health-care services patients' access before death can illuminate care patterns that produce the most favorable outcomes.<sup>67</sup> Importantly, fiscal outcomes can be examined to determine the costs of health care and the cost effectiveness of new interventions.<sup>23</sup> However, because informal care is rarely captured in administrative data, analysis of total care costs may be fractional in outpatient settings.

There are a number of other limitations to using administrative data. Fitting these existing data to new research questions requires consideration of the constraints of the methods used to populate the dataset. A major issue is that these data are not intended for measurement of quality in the individual care provided or the direct outcomes that result. As a result, these data were indirect measures of quality outcomes. Outcomes defined as quality related, such as home death, may not actually represent a positive experience for all patients. Similarly, the breath of information available from administrative sources is limited; derived outcomes lack context and may be prone to confounding variables, for example, community size or a patient's acuity of illness. Definition and coding of variables may change over time, impeding longitudinal comparisons. These data are sensitive to health system changes and other temporal trends. There may be inconsistencies in how data were collected and coded at the source sites, affecting data completeness and accuracy. There may be long delays between the time that the data are originally collected, compiled, cleaned, and released for research. Finally, access for researchers to these data sources may be limited due to privacy concerns. Countries have strict health information privacy acts in place to govern data transfer to protect the anonymity of patients in these datasets. Shared data need to be carefully de-identified, which may result in the censure of certain variables, even if access is provided.

**Clinical data.** Clinical data consist of measures of care processes or patient physiological functioning, based on best practices. These data can represent care site or program-based provider recorded occurrences and actions taken, either directly or indirectly involving patient care. Nearly all the MWM's indicators, that were previously mentioned, fall into this category of data, obtained through medical record abstraction.<sup>56</sup> Examples of clinical data outcomes are: anticancer treatments near death, comprehensive assessment completed, advance directives reported, time to referral for a required resource, and surrogate documented. A number of EOL clinical indicators have been proposed, for example, Lorenz et al described 21 evidence-based clinical and process measures representing the quality

of EOL for the elderly, covering elements of symptom control, comprehensive assessment, advance care planning, documentation of care preferences, caregiver stress assessment, and bereavement support assessment.<sup>68</sup>

Process measures are important to assessing technical aspects of EOL care. A number of quality guidelines for EOL clinical practice such as the NICE quality standards and the National Consensus Project Clinical Practice Guidelines have been proposed that can serve as benchmarks.<sup>69,70</sup> Collecting these data can provide timely, prospective information that is easy to quantify, compare, and interpret for study sites. Unlike administrative data, clinical data can be used to improve the care of the patients captured in the data. The fact that the data are entered or charted at the time of the event eliminates recall bias, a limitation of retrospective data collection.

Although process data are valued by planners and providers, there are barriers to recording this information.<sup>31</sup> Excessive clinical data collection can be burdensome for providers, as well as for EOL patients, and can delay care of immediate needs. Process recording often relies on the completion of a checkbox to affirm that an activity was completed, which may incentivize a focus on documentation rather on the thoroughness and appropriateness of the care procedure. Indeed, these counting exercises of stipulated care activities if badly timed and against the better judgment of experienced providers can be detrimental to the care experiences of both the patient and the health professional. Interpretation of recording criteria may vary, leading to inconsistency in data. Moreover, only EOL patients who access the program where measurement occurs are included in the data, which for small volume programs may overestimate the actual impact in the community. Finally, patient perspective variables such as care preferences can be difficult to measure prospectively as these can change over time.<sup>35,71</sup>

**PRO data.** PRO data are perceptions of care collected from patients and their families. This can include qualitative and quantitative data collected in survey, focus group, or interview format. Data administration can occur at care sites or as a broader population-based observational study and can be either ongoing or at intervals. Example variables include the perceived meeting of physical, psychosocial, spiritual, and information needs, the management of pain and other symptoms, whether care preferences were met, involvement in care planning, continuity of care, and overall satisfaction with care. The major advantage of PRO measures of quality is that they are true indicators of the impact of the care provided. These measures can be extensively comprehensive and capture what constitutes quality care to the individual. The feedback provided through PROs is invaluable at the local level in providing these providers with direct insights into the quality of their services. Open-text PROs may elicit specific suggestions on how providers and organizations can improve the care experience. The major drawback to patient reported data is that they are resource intensive to collect and analyze.



Also language translation of instrumentation and responses is required to include perceptions of care, representing the cross section of languages spoken in the community.

A further challenge is that no consensus has emerged as to a specific measure for collecting quality PROs.<sup>56,72</sup> A systematic review by Lendon et al of instruments to measure patient and family perceptions of EOL care found 51 different surveys, many of which were designed to measure satisfaction with domains of care on a scale, rather than the subjective care experience.<sup>72</sup> Although requiring less time to complete, satisfaction scales are prone to restricted ranges in scores, ceiling effects, and acquiescence bias.<sup>73–75</sup> Alternatively, instruments that capture patients' care experiences and the contexts of these perceptions have more potential for identifying gaps in care that can help inform service improvement.<sup>75</sup> Another barrier to PRO data is collecting questionnaire data from patients who are actively dying, many of whom have cognitive and physical impairments, can result in poor response rates and selection bias.<sup>76,77</sup> Several research studies have used questionnaires for bereaved caregivers,<sup>72,78</sup> which have been found to be an adequate substitute for collecting these data directly from the patient.<sup>74,76,79,80</sup> Bereaved family caregiver-reported outcomes are becoming more the standard of quality EOL assessments<sup>72,81,82</sup> and have the advantage of covering the full EOL care trajectory care provided including that immediately before death, which can be most vital, as well as bereavement care.<sup>79</sup>

Two validated questionnaires from the Lendon et al's review that have been most widely used are the After Death Bereaved Family Member Interview and the Views of Informal Carers—Evaluation of Services (VOICES-SF) survey.<sup>72</sup> The After Death Bereaved Family Member Interview was one of the first PRO measures in the US to capture care experiences prior to death on a national scale.<sup>83</sup> The main outcome measures are core to EOL care, including whether health-care professionals: (1) provided the desired physical comfort and emotional support to the dying person, (2) supported shared decision-making, (3) treated the dying person with respect, (4) attended to the emotional needs of the family, and (5) provided coordinated care. In England, the VOICES-SF survey was used in the National Bereavement Survey (2011–2014) to examine quality of EOL services.<sup>84,85</sup> The VOICES-SF assesses various dimensions of the caregiver's perceptions of the patient's care experiences with providers and services in multiple care settings,<sup>86</sup> unlike the After Death Interview that focuses mainly on the last setting of care before death.<sup>83</sup> VOICES also reviews different time periods, such as the last three months of life, the last two days of life, and circumstances surrounding the death.

In Canada, the CaregiverVoice survey, based on the VOICES instrument, is being used in home care, residential hospice, and hospital settings in Ontario.<sup>22</sup> This survey contains the VOICES' domains for multiple care settings encountered, modified for easier comparisons across different

settings and providers, in addition to items about transitions in care and advance care planning. A unique feature of the VOICES and CaregiverVoice surveys is the opportunity for respondents to write comments about what they felt was good and bad about the care provided in the last months of life, to help ensure that perceptions of care most important to the individual are captured. These open-ended comments are also useful in providing specific context and direction in EOL care provision as to what is working and not working. An added feature of the CaregiverVoice survey is that it was designed to be completed online, which enables both streamlining of items relevant to the particular care received and to reduce postage and data entry costs, making the collection of PROs more feasible.

**Considerations in selecting the most appropriate data source(s).** Practicality needs to be at the forefront in reflecting on the applicability of the aforementioned data sources to a quality measurement initiative, to ensure that this effort is feasible.<sup>87</sup> Factors to be taken into consideration include the availability of resources, time frame of the project, readiness of the institution/system, geographic scope, resident expertise present, previously identified gaps, and current priorities.<sup>88</sup> If primary data collection is not a viable option, then existing data from clinical or administrative systems will have to be leveraged. Frameworks have been proposed for assessing palliative and EOL care that can be used to help define measures of interest and structure the findings.<sup>88–90</sup> Many of the principles to approaching quality improvement are applicable to initiating measurement efforts, such as starting small, working incrementally, being flexible, building consensus/support, and sharing successes.<sup>91</sup>

## Conclusions

Quality measurement of palliative care and EOL services is a core priority of global efforts to strengthen these services.<sup>92</sup> In this article, we describe three main types of data sources that can be used to assess the quality of EOL care. Each approach has its strengths and limitations; performance measurement should use all three types of data, when possible. Administrative data about EOL care accessed are often reported and easy to calculate but address only services used, not the quality of those services. Many indicator frameworks also focus on physical aspects of care such as pain management and rely heavily on clinical data.<sup>40,41</sup> Clinical data can indicate compliance to best practices, but the reporting of key processes tends to emphasize quantity over quality. Clinical data are also time consuming to collect, hard to standardize, and thus challenging to compare across institutions and at a population level. Administrative data or clinical data alone may inadequately represent the scope of outcomes that are important to EOL patients and their families.<sup>56</sup> PROs consisting of patient/caregiver evaluations of care are critical to assessing EOL care,<sup>56</sup> but there remains limited information on how to standardize these types of measures.<sup>31</sup>



Nonetheless, the capabilities of administrative, clinical, and PRO data sources are evolving along with advances in data management, providing new opportunities for assessing the quality of EOL care.<sup>30</sup> The hope is that with future development, standardized measures of quality collected by provider organizations, either as clinical data or PROs, can be compiled into a national palliative care reporting systems, in effect creating administrative databases of process outcomes and PROs to provide broader health system insights into care quality, as has been done in other health-care sectors.<sup>93</sup> While priority of palliative care assessment and planning is often given to EOL care, consideration also needs to be given to the introduction of these services earlier in the care trajectory.

Beyond care for the dying, the types of data sources described are also relevant for measuring quality care in chronic disease management and other sectors of the health-care system, although the variables of relevance would differ accordingly. Further research and resources are needed to make it easier to evaluate and compare quality indicators between different settings, different patient populations, and different regions and countries. Ultimately, more development and partnerships with organizations to develop standardized measurement and benchmarking is needed, within nations and globally.

### Author Contributions

Wrote the first draft of the manuscript: DB and HS. Contributed to the writing of the manuscript: DB and HS. Agreed with manuscript results and conclusions: DB and HS. Jointly developed the structure and arguments for the paper: DB and HS. Made critical revisions and approved the final version: DB and HS. All the authors reviewed and approved the final manuscript.

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