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RESEARCH ARTICLE

Measuring indicators of health system performance for palliative and end-of-life care using health administrative data: a scoping review [version 1; peer review: 2 approved with reservations]

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Abstract

Background: A plethora of performance measurement indicators for palliative and end-of-life care currently exist in the literature. This often leads to confusion, inconsistency and redundancy in efforts by health systems to understand what should be measured and how. The objective of this study was to conduct a scoping review to provide an inventory of performance measurement indicators that can be measured using population-level health administrative data, and to summarize key concepts for measurement proposed in the literature.

Methods: A scoping review using MEDLINE and EMBASE, as well as grey literature was conducted. Articles were included if they described performance or quality indicators of palliative and end-of-life care at the population-level using routinely-collected administrative data. Details on the indicator such as name, description, numerator, and denominator were charted.

Results: A total of 339 indicators were extracted. These indicators were classified into nine health care sectors and one cross-sector category. Extracted indicators emphasized key measurement themes such as health utilization and cost and excessive, unnecessary, and aggressive care particularly close to the end-of-life. Many indicators

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were often measured using the same constructs, but with different specifications, such as varying time periods used to ascribe for *end-of-life* care, and varying patient populations.

Conclusions: Future work is needed to achieve consensus 'best' definitions of these indicators as well as a universal performance measurement framework, similar to other ongoing efforts in population health. Efforts to monitor palliative and end-of-life care can use this inventory of indicators to select appropriate indicators to measure health system performance.

Keywords

palliative care, terminal care, end-of-life care, quality indicators, performance measurement, evaluation

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Introduction

Growing health care costs in an environment of tight financial constraints and an aging population are challenging many health care systems globally. Recent health care reform initiatives have underscored the importance of providing quality care to patients at all phases of the disease trajectory, including palliative care (PC) both specialist and generalist, and end-of-life care (EOLC), to improve patient and health system outcomes^{1,2}. The Worldwide Palliative Care Alliance and the World Health Organization recommend provision of PC for all persons with chronic and life limiting/threatening conditions early in the illness trajectory³. However, universal access to quality, integrated and timely PC for patients remains intermittent at best, with PC largely being provided close to the end-of-life (EOL)⁴. Moreover, concerns about high costs associated with health care at the EOL are prevalent in the literature; studies attribute these costs to intensive, aggressive, and sometimes unnecessary utilization of institutionalized care, such as inpatient hospital services in the last few months of life⁵.

Monitoring health system performance is one important component of evaluating achievement of quality care for improved patient and health system outcomes. This can be done through *health system performance indicators*, which summarize directional quantitative information on the quality of health, often evaluated through measurement of structure (inputs) or characteristics of the health care system, process (outputs) or services required to provide health care, and outcomes or measures of ultimate impact of the health care provided⁶. Health system performance indicators allow comparisons across jurisdictions, organizations, and/or administrative databases to track progress over time in efforts to improve health care quality⁷. Quantitative information for indicators can utilize health administrative data or data that is routinely collected in the process of delivering health care programs and services, often used due to its extensive reach (many databases are population-based), low cost, and low respondent burden⁸. Administrative data can also enable contextualization of health system performance indicators due to availability of data on patient sociodemographic and clinical characteristics.

In recent years, jurisdictions in Canada, the United States, and the United Kingdom have focused on defining standards and monitoring health care quality as efforts to expand PC programs intensify^{9–14}, and as a result a plethora of health system performance indicators for PC and EOLC using health administrative data have been proposed^{13,15–18}. These indicators have been suggested based on differing objectives (e.g. quality improvement, performance measurement) and/or for different patient populations (e.g. cancer, intensive care units, long-term care (nursing home) patients)^{13,19–24}. Given the diversity of indicators in the literature, a scoping and cataloguing exercise becomes important in order to consolidate and summarize common measurement concepts (themes) and indicators that can be recommended for use in the performance measurement of PC and EOLC. Such a catalogue can serve as a reference guide for use by policy and decision makers, thereby reducing potential redundant efforts on collecting indicators, and enabling movement to the next

step of decision making on what to measure and how best to measure it given each jurisdiction's individual data systems. Furthermore, categorizing indicators by health care sector or setting of health care delivery can be a helpful demarcation that enables measurement of health system performance to align with funding and accountability structures²⁵. Consideration of health care setting or health sector (e.g., acute care hospitals, long-term care (LTC), home care) becomes important given each sector's potentially differing care quality aims, target populations, health care processes, and definitions of outcomes. Such organization does not preclude inclusion of indicators of transitional care or coordination of care between health care settings, but rather enables tailoring of indicator definitions that are more reflective of the relevant sector or health setting's contribution to system-level performance.

As such, the primary objective of this study was to create a catalogue or inventory of health system performance measurement concepts and indicators for PC and EOLC utilizing routinely-collected population-level health administrative databases and as categorized by health sector by conducting a scoping literature review.

Methods

This scoping literature review of health system performance indicators for PC and EOLC followed the Arksey and O'Malley (2005) methodological framework for scoping reviews²⁶. Scoping reviews are a "type of knowledge synthesis, (that) follow a systematic approach to map evidence on a topic and identify main concepts, theories, sources and knowledge gaps"²⁷. The primary objective of this scoping review was to collect and map health system performance indicators for PC and EOLC using routinely collected population-based health administrative data and to organize indicators by health care sector. Since this required consulting a broad array of literature to uniformly collect indicators, rather than appraisal of published indicators, this objective aligned well with the rationale for the use of scoping review methodology in comparison to systematic review methodology, and hence a scoping review methodology was chosen to complete research objectives²⁸. A scoping review protocol was not published *a priori* for this study. Subsequent sections describe specific steps taken for this scoping review in accordance with the Arksey and O'Malley (2005) methodological framework.

Identifying relevant studies for inclusion

We collected both peer-reviewed and grey literature published in English for this scoping review. For peer-reviewed literature, we conducted a search of MEDLINE and EMBASE databases between years of 2010 to July 2018. A University of Toronto librarian and comparable literature reviews were consulted in the development of the search strategy, which included a combination of the United States National Library of Medicine Medical Subject Headings (MeSH)²⁹ and keywords (see *Extended data: S1 Appendix Search Strategy*³⁰). For grey literature, we utilized Google search engine using a combination of keywords such as "palliative care", "end-of-life-care", "performance indicators", and/or "quality indicators", as well as

incorporated reference documents made available to us through our knowledge user partners based on their previously conducted literature searches. No jurisdictional restrictions were placed for the grey literature search; however Canadian references were generally better known by study authors and knowledge users, and formed the bulk of included references.

Inclusion/exclusion criteria for study selection

Inclusion and exclusion criteria were developed in accordance with the study objectives and points of inquiry for the review, notably: a) focused on core concepts of quality or performance measurement in palliative and/or end-of-life care, b) measurement conducted using population-level, routinely-collected data, and c) studies with a health system focus. The full set of generated articles was reviewed based on developed inclusion and exclusion criteria (see *Extended data: S2 Table Study Inclusion and Exclusion Criteria*³⁰).

Reviewers (SB and AG) independently screened all articles using titles and abstracts, with any conflicts resolved through discussion and inclusion and exclusion criteria accordingly updated. This generated a total of 285 articles for full text review (Figure 1). Full text review was also independently conducted by SB and AG, with a total of 54 peer-reviewed studies and 42 grey literature documents being identified for indicator extraction. Additionally, forward reference searching of reference lists was conducted to include any additional relevant articles, as well as any other relevant studies known to the all study authors. Studies outside of the study time period of 2010 to July 2018 were included. This resulted in a total of 32 additional articles included into the study for data extraction.

Charting and summarizing the data

A data extraction tool was developed to effectively chart details on presented and potential indicators (such as indicator definition, numerator and denominator if available). Indicators were

extracted if they a) measured health system performance for PC and EOLC, and b) used population-level data using health administrative datasets. Once the full set of indicators were charted, SB, AG and PT removed duplicates and conducted health sector classification. We chose to focus on categorizing our collected indicators by health sectors specifically for the Canadian province of Ontario, with a population of over 14.5 million residents³¹ with universal health coverage for costs associated with acute care, hospitalizations, physician visits, emergency room visits, long-term care, home care, complex continuing care, and medications for those meeting select age-based and need-based criteria³². Health administrative data is also collected comprehensively and at the population-level for the majority of health sectors with public health coverage, thereby increasing potential for performance measurement with indicators based on routinely-collected administrative data. For the purposes of our study, indicators were classified based on the following Ontario health sectors based on how data from health administrative databases is currently obtained and organized in Ontario administrative databases: hospital care (including emergency department (ED)); home care or care services provided in the home and community;³³ LTC (i.e., nursing homes), hospice care, physician services or care services captured through physician billing codes; medications covered through the public health insurance system;³⁴ complex continuing care (CCC) or technology-based care provided to patients with chronic and complex health conditions;³⁵ cancer care or care specifically targeted for cancer prevention and treatment; and other. A category entitled “Cross Sectors” was created to capture indicators transcending more than one health sector (e.g. place of death at various care locations). Further thematic analysis was conducted collectively by the study authors in discussion to group indicators measuring similar constructs by common themes, leading to the creation of measurement themes for indicator classification under each health sector category.

Figure 1. Article and indicator extraction process.

Consultation exercise

Following this initial categorization, a working group with subject matter experts (both researchers and clinicians) was organized to review the final list of indicators. Indicators were cross-checked to ensure a) all relevant concepts related to PC and EOLC had been captured, and b) all indicators were conceivably measurable using (Ontario/Canadian) health administrative data based on the knowledge and expertise of the subject matter experts present.

Results

Studies reviewed

A total of 1111 indicators were extracted from 128 articles. 722 indicators were excluded (due to reasons of duplication and irrelevancy), resulting in a total of 339 indicators included for summarization (Figure 1). Studies and grey literature ranged from publication dates of 1992 to 2018, with only 5 included studies published prior to 2003, and the majority (n=82) being published after 2008 (Table 1).

The 42 grey literature documents included publications from Canadian provinces (e.g., Ontario, Alberta, Saskatchewan) (n=31), where routinely collected administrative data is readily

available, and from the United States (n=6), United Kingdom (n=4), and Australia (n=1). They included documents generated by PC delivery organizations, such as local home care agencies, and also jurisdictional collaborative efforts to improve care.

Categorization of indicators

Ten health care sectors were utilized to categorize indicators, with sector categories of Cross Sector, Cancer and Home Care having the greatest number of indicators (Table 2). Table 3 presents a summary of indicators and key measurement themes by health care sector, and a collective list of all indicators collected can be found in *Extended data: S1 Table Detailed List and Information on Collected Indicators*³⁰. These findings are discussed next.

Cross sector

Within this review, a total of 58 collected indicators were categorized as transcending sectors or cross sector^{9,13–18,20–24,36–106} and four measurement themes were identified. Indicators classified under the cross sector category tended to focus on how well palliative and EOL patients were being cared for through examination of aggressiveness of care, place of care/death, availability of palliative care services and overall cost; this measurement was to better understand how the overall health care system was performing in the care of palliative and EOL patients, rather than on the performance on any specific health care sector by itself (e.g. the enrollment of patients in a palliative care program and how early this enrollment occurred).

Cancer care

A total of 57 indicators were extracted for measuring performance in the delivery of cancer care^{13,17,20,21,37,39,48,50,51,54,56,60,63,64,67,70,72–74,77–80,91,94,98,103,106–119}. These indicators centered

Table 1. Included articles by year of publication.

<i>Year of publication</i>	<i>Number of publications</i>
No date	3
<2003	5
2003	4
2004	1
2005	5
2006	4
2007	6
2008	14
2009	7
2010	10
2011	11
2012	10
2013	17
2014	15
2015	7
2016	3
2017	4
2018	2
Total	128

Table 2. Extracted indicators by health care sector.

<i>Health care Sector</i>	<i>Number of Indicators</i>
Cross Sector	58
Cancer Care	57
Home Care	48
Long-Term Care	40
Hospital	39
Hospice	36
Physician Care	29
Medications	26
Complex Continuing Care	3
Other	3
Total	339

Table 3. Summary of indicators by health care sector.

Indicator theme	Description	References
Cross Sectors (n=58)		
Place of death and Place of care	Possible locations of death include home, hospital, LTC, unknown. Time spent within a specific location of care, and whether the patient received the appropriate care when they died in a specific care setting.	9,13-18,20,22-24,36-85,107,108,120-122
Palliative care service utilization, and receipt of services	Length of stay and utilization of a palliative care program, or enrollment in a program within a specific time period, such as 3 or 6 months before death. Total number of individuals formally identified as <i>palliative</i> , and <i>palliative</i> upon pre-admission to hospital. Identify proportion of population who receive PC outside of acute care.	13-18,21,38,39,43,51,61,62,65,72,76,81,83,84,86-100
Costs	Costs measured by health sector utilization, and percentage of total budget spent on EOLC in last year of life. Costs were also compared between patients who did or did not receive PC, and per episode of care.	9,43,52,67,93,99,101-105
Aggressiveness of care and burdensome transitions	Composite indicator consisting of: death in acute care hospital, chemotherapy use in the last 14 days, greater than 1 ED visit in the last 6 months and 30 days of life, greater than 1 hospital admission in the last 6 months and 30 days, any Intensive Care Unit (ICU) admission in last 6 months and 30 days of life. Also measured as a rate of aggressive care in the last 3, 30 and 90 days per decedent in potential sectors of: acute care admission, ED visit, Complex Continuing Care (CCC)/rehab, LTC, ICU, or hospice.	45,48-50,70,71,81,106
Cancer Care (n=57)		
Outpatient visits to a cancer centre	Number of visits (chemotherapy, physician appointments), and patients seen at a PC clinic, referrals to PC clinic with Palliative Performance Scale (PPS) rating of 60 and PPS 10 - 30, and median time between diagnosis and referral to a PC clinic.	39,68,103,109,123-125
Symptom and Functional Status Assessment	Assessment of complex advanced symptoms including screening rates, whether the symptoms were addressed with treatment, and referral to additional services. Screening rates for cancer patients were also compared across functional status scores, and time until death.	13,21,41,44,53,61,67,76,78,84,86,90,103,107,120,126-129
Treatment	The delivery of chemotherapy and radiation within a specific time period before death (i.e., last 6 months, 5 months, 2 months, 30 days, 2 weeks or 14 days). Also, treatment was compared across functional status, to reflect aggressive treatment at the EOL, and the use of palliative radiation and palliative chemotherapy.	13,17,20,21,37,39,48,50,51,54,56,60,63,64,67,70,72-74,77-80,91,94,98,103,106-119
Home care (n=48)		
Utilization and length of stay	Utilization measured as the number of visits or hours of home care specified for different time periods (i.e., last 6 months of life), involvement of different health professions (i.e., nursing, personal support worker (PSW), physician, social work, respite care, medication delivery) and disease groups (i.e., cancer, congestive heart failure). Variation in home care support captured by measuring the change in hours of support, and mean hours of home care leading up to death.	13,16-18,39,42,43,52,58,65,67,68,70,72,80,87,92,99,103,110,123,128,130-136

Indicator theme	Description	References
Referral and initiation of homecare	Wait times between referral to home care and initiation of services; identifying patients who are approaching EOL and flagged for home palliative care; and how early homecare began in the patient's care trajectory. Place of death and care, and hospital readmission rate compared to home care received at the EOL.	14,16,17,39,41,52,57,67,68,70,71,92,103,105,126,132,134
Patient outcomes and quality of care	Multidisciplinary care as reflected by the range of providers making home visits, and patient outcomes that reflect good clinical practice, such as pain and pressure ulcers. Characteristics of home care were also evaluated, including whether there was 24/7 home PC coverage, prognosis and goals of care documentation, and proportion of patients discharged home from hospital with and without home care.	18,39,51,61,67,86,91,92,105,132,137,138
Costs	Cost of home PC visits	99,139
Long-Term Care (LTC) (n=40)		
Referral and length of stay	Referral to LTC, length of stay, and comparison of cancer and non-cancer patients who were in LTC.	65,67,87,123,139,140
Burdensome transitions at EOL	Number or percent of LTC clients with at least one burdensome transition within a specific time period. Burdensome transitions defined as 2 or more hospital admissions for any reason or 1 hospital admission for pneumonia, urinary tract infection (UTI), dehydration or sepsis in last 90 days of life ¹⁴¹ ; or, admissions or the number of hospitalizations and transfers from LTC within a specific time period (i.e., last 180, 90 or 30 days).	24,40,98,141,142
Symptom management within LTC.	Percentage of deaths with uncontrolled symptoms (including Stage IV pressure ulcers, anxiety, dyspnea, pain etc.)	24,51,58,67,83,141–143
Costs.	Total monthly costs for nursing home residents in the last 6 months of life	24
Hospice (n=36)		
Patients' enrollment and access	Enrollment to hospice across different time periods from death (i.e., last 3/7 days), as well as length of stay in hospice. Hospice care for disease groups, such as cancer and non-cancer were also compared. The number of referrals made to residential hospice, location of where patients were admitted to hospice from (LTC, Home care etc.), were also measured. Wait times of less than 3 days between referral and enrollment in hospice care, and number of referrals to hospice who died while waiting for admission were measures of access to care.	15–17,20,43,45,48,49,51,54,60,64,66,67,69,74,77,78,86,99,106,109,111,118,144
Utilization	Hospice care use, bed utilization, and health care provider visits close to death	16,20,55,106,144,145
Quality of care	Measures of quality of care including screening, assessment and treatment (pain, dyspnea, bowel regimen) and patient/caregiver experience	145
Hospice quality	Rating of hospice and willingness to recommend	145
Costs	Funding provided to hospice	43

Indicator theme	Description	References
Hospital (n=39)		
Emergency Department (ED) Use	ED utilization was measured as individual visits, or an average number of visits within a specific time period. ED use without a hospitalization, and unscheduled ED visits were also captured.	12,13,15-17,19-21,39,41-43,48-50,54,56,61,63-65, 67-70,72-74,78-80,91,92,94,98,99,103, 110-112,118,119,121,123,133-135,140,146
Costs	Costs associated with an ED visit, inpatient admission, and episodes of care using a diagnostic test, or a specific type of hospital admission (such as Alternate Level of Care or Palliative Care Unit) were captured.	13,18,67,68,99,102,104,109
Hospital Utilization	Inpatient utilization was measured as number of days for length of stay, or the number of admissions during a specific time period (i.e., last year, 6 months, 3 months, 1 month, 30 days of life). The admitting unit of the admission was also specified, such as rehabilitation, intermediate bed, general bed, or Alternate Location of Care (ALC) bed. Hospitalization rates were also measured, including whether the hospital admission had an admitting diagnosis of palliative care and difference in rates based on those receiving care from a GP vs. not	9,12,13,16,17,21,38-40,43,45,47-50,54,56,60,63,64,67, 68,70,72-75,77-79,82,85,87,91,98,99,102,103,105,106, 108,112,118,123,130,131,134,135,139,140,144, 147-151
Intensive Care Unit (ICU) Use	ICU admissions were captured as the number of days spent in ICU, or the number of visits within a specific time frame (i.e., last 6 months, 90 days, 30 days). The rate of deaths associated with an ICU admission was also assessed.	13,15,17,19-21,39,44,45,47-50,54,59-61,63,64,69,70, 72-74,76-79,81,91,98,103,106,110,112,114,118,131, 133,148,152
Hospital Readmission and Discharge	Hospital readmission rate or the number of readmissions within a specific study period (i.e., last year, 6 months, 90 days, 30 days). Patient discharge disposition, and whether there was home care or an ED visit prior to the admission, was also measured.	9,18,36,43,51,57,58,67,74,86,92,102,103,140,147
Alternate level of care (ALC)	Number of days spent in an ALC bed, and percentage of acute care/post-acute ALC patients waiting for their most appropriate destination.	9,18,57,58,67,92,103,105
In-hospital treatment and procedures	Rate of resuscitation for patients coded as palliative and other medical procedures	73,79,81,98,118,140-142
Physician Care (n=29)		
Multidisciplinary and continuity of care	Multidisciplinary care was reflected by the number of different providers (i.e., social work, general practice (GP)). Physician care was further scrutinized, including the percentage of physician visits seen that were GPs and non-GPs. The Modified Continuity Index (MMCI) was used to reflect continuity and collaborative care.	18,21,38,57,65,87,91,98,103,144,148
Home Visits	The number of patients who received home visits at different periods before death (i.e., last 2 weeks). Number of palliative physician home visits, proportion of patients with physician house calls in last 2 weeks of life, and number of patients with at least one physician house call.	13,16,18,39,57,61,65,67,68,70,71,80,91,99,103, 110,118,123,131,135,140,151
Outpatient Care	Number of visits made to different outpatient health care providers, such as GPs and specialists, including medical oncologists. The percentage of palliative care delivered from primary care and from an outpatient palliative care clinic were also compared.	16,18,38,39,65,68,83,89,91,94,98,99,118,130,131, 133,139,144

Indicator theme	Description	References
Medications (n=26)		
Cost	Drug costs for the patient, and costs incurred by the government, per prescription.	9,18,40,46
Symptom Management	Determined if symptoms were managed by the most appropriate medications (and for such specific disease types), such as short- or long-acting opiate within 60 days before death. Medications evaluated included opioids, narcotics, antipsychotics and anxiolytics. Also, overmedication and number of prescriptions, as well as aggressive treatment was also included, such as the prescribing of antibiotics at the EOL.	21,40,44,46,61,69,74,84,87,98,107,115,118,126,139,144,153-156
Access to medications	Palliative drug benefits	46,51,68,87
Complex Continuing Care (n=3)		
Palliative care delivered within Complex Continuing Care (CCC)	Pain management, and the delivery and cost of palliative care services within CCC and rehabilitation hospitals were measured.	58,68,133
Other (n=3)		
Emergency services	Ambulance utilization	56,87
Lab/Medical Equipment	Medical and lab equipment expenses; diagnostic testing at EOL	98,144

around three key measurement themes which were tied to the overall provision of quality care to cancer patients, including the regular assessment and management of symptoms, wait times for specific cancer care services, and aggressive care near the end-of-life.

Home care

A total of 48 indicators were categorized under the home care sector^{13,16–18,39,42,43,52,58,65,67,68,70,72,80,87,92,99,103,110,123,128,130–136} with four key measurement themes. Most indicators described patient utilization/cost of, or access to PC and/or home care services. Indicators on patient outcomes and quality of care emphasized specific clinical characteristics (e.g. pain, cognitive function), and involvement of specific health care providers (multidisciplinary care, social workers).

Long-term care

A total of 40 indicators were extracted for the LTC or nursing home sector^{43,48,54,60,61,67,70,74,76,87,91,100,106,137–144} classified under four key measurement themes. Indicators focused on the quality of care being provided through adequate symptom management and burdensome transitions at the EOL; indicators also focused on length of stay and costs of these patients at the end-of-life.

Hospice

A total of 36 indicators were categorized under the hospice sector^{25–29,31,34,45–47,51,52,54,57,58,60,63,64,67,69,72,75,76,80,81,90,96,101,116,122,128,141,142} and five key measurement themes were identified. Overall, indicators heavily emphasized access to timely, adequate and good quality hospice care, with a large number of indicators measuring access to hospice care across as measured based on different time periods prior to death, by disease groups, etc.

Hospital

A total of 39 indicators were extracted for the hospital sector^{19,22,23,25–29,31–35,41–54,56–60,63,64,66–86,89–91,95–108,110–113,116–119,120–122,123,127–133,135–143,145,148} under seven key measurement themes including ED use, intensive care unit use, and cost. Hospital-specific indicators largely focused on utilization, costs related to utilization, and the appropriateness of hospital care at the EOL.

Physician care

A total of 29 indicators were extracted for the physician care sector^{23,26,29,32,35,40,41,42,60,66,68,70,71–74,76,77,79,80,83,87,89,91,92,95,96,97,99,100,103,106,108,111,116,119,120,130,132,133,135,137,138,141,142,145,148} under three key measurement themes. Indicators largely emphasized understanding the intersection between generalist and specialized PC provided by different physicians (general physicians, PC specialists, oncologists etc.) in outpatient settings.

Medications

A total of 26 indicators were extracted on medication use^{9,18,21,40,44,46,61,69,74,84,87,98,107,115,118,126,139,144,153–156} under three measurement themes. Indicators were largely focused on the most appropriate medications for symptom management, including overmedication and aggressive treatment at the end-of-life.

Complex continuing care (CCC)

A total of three indicators were measured within the CCC sector that typically focuses on rehabilitation and/or PC. They focused on pain management¹⁰⁸, access to PC⁵⁸, and cost⁶⁸. This sector was the most underdeveloped in the literature compared to other sectors with respect to performance measurement likely due to its uniqueness to the Ontario context.

Other

Three indicators did not fit the sectors above. They were ambulance use by EOL patients^{56,87}, medical lab services and equipment expenses¹⁴⁴, and diagnostic testing at the end-of-life¹³³. These indicators were classified together under the “Other” sector category.

Discussion

The purpose of our scoping review was to collect, organize, and share a distilled inventory of sector-specific health system performance measurement indicators for PC and EOLC. Our scoping review revealed 339 indicators, organized across nine distinct and one cross-cutting health care sector categories. Indicators within each sector category were subgrouped by key measurement themes. Collectively, these indicators represent the field’s thinking on how best to measure high health system performance in the delivery of both PC and EOLC.

One of the most commonly occurring measurement themes across sectors focused on health system utilization (e.g., hospital length of stay, ICU admissions, chemotherapy or home care received). Indicators of utilization were collected both for comparison across palliative/end-of-life and non-palliative/non-end-of-life populations (to represent access), to examine cost of delivered care, and also to understand how well the system was performing in the delivery of care (e.g. on wait times). However, emphasis on utilization through measurement of process indicators, such as in the hospital sector, highlighted that measurement themes such as patient experience and effectiveness of palliative care were not captured. Measurement of such themes through indicators can serve as an indication of the achievement of positive patient and health system outcomes.

Another frequent measurement theme across sector categories was the aggressiveness of care at the EOL for palliative and EOL populations. This theme included indicators of inappropriate treatment, medications, and transitions at the end-of-life that would be avoided in a well-performing health system focused on quality patient care. As health system resources become finite, this measurement theme will likely gain prominence in not only helping to improve patient outcomes, but also in reducing costs from unnecessary and aggressive health services.

Despite the wealth of indicators collected, the measurement of patient-centered or patient-reported outcomes was infrequent at the population-level using health administrative databases. Measurement of themes related to unmet care and self-management support needs, advance care planning, goals

of care, consideration of patient preferences, and patient and caregiver burden were limited. However, absence of indicators from the review does not mean that measurement is not occurring, but rather, that it may not be occurring in population-level health administrative databases. Given the importance of these indicators, measurement through primary data collection may be required to obtain a comprehensive picture of health system performance.

Additionally, the literature review revealed that although there were a large number of indicators, many of these indicators measured similar constructs, but with different specifications. This includes variations in identifying the time period of measurement and the patient population. There were also differences in how debated concepts in the literature were operationalized such as what constitutes markers of quality care (example, how to define a burdensome transition). S1 Table (*Extended data*³⁰) includes each of these collected indicator iterations across various data sources in more detail. The multiple variations of indicators – with little justification of why they were chosen – posed challenges in summarizing the data, and in recommending how these indicators should be measured. This difficulty was compounded by the absence of information on how indicators were operationally defined, including lack of information on the numerators and denominators in many of the extracted studies. As such, subsequent iterations of similar indicator themes resulted in issues of comparability across jurisdictions. While noting differences in data availability, efforts are needed to systematically define a set of standardized indicators for use across jurisdictions. There have been efforts by some stakeholders to implement accepted performance measurement frameworks^{98,151}. Subsequent efforts can then be aimed at improving the construction and measurement of these indicators, and also in continuing efforts to evaluate system performance.

Limitations specific to the methods and results of this scoping review exist. Indicators were collected based on their ability to be extracted from a population-based data source, dependent on the judgement of study authors and subject matter experts which may have introduced some bias (e.g. large focus on Canadian grey literature). As one of the reasons for this scoping review was to better understand which health system performance indicators currently exist for local efforts of policy planning, a bias towards indicators that can be readily collected in the Canadian and/or Ontario context may exist. Moreover, quality appraisal of indicators was not conducted. Next, the conflation of the terms, *palliative*, *end-of-life*, and *terminal* care was difficult to operationalize when searching and organizing indicators. For the purposes of this review, all terms were included as a part of the search strategy to ensure indicators reflected all references to care related to advanced disease. When reviewing administrative data sources and medical-based records, health service encounters can be coded either as *palliative* or *end-of-life* depending on the care setting and health service provider^{157,158}. Authors however recognize that *palliative care* reflects a philosophy of care and service that can be provided at any time during the advanced disease trajectory, whereas *end-of-life care* is not always palliative, and is provided during the final period of a patient's life. Lastly, this research study answers the

question on the types and varieties of indicators available for measurement of performance in PC and EOLC using administrative data. However, it does not answer the question on what these indicators *should* be based on quality and policy criteria. Next steps would include conducting a consultation with relevant stakeholders to create a universally accepted performance measurement framework of what health system performance measurement for PC and EOLC should look like, using the list of indicators provided in this study as a reference guide. This would include patient-reported outcome measures that have not been included in this study. While some jurisdictions may not be ready to measure many of these indicators, findings from this study can provide insight on what can be potentially measured.

Overall, this study reviews – by health care sector – population-level health system performance indicators for PC and EOLC that can be measured through administrative databases. Although a large number of indicators have been reported for each sector, these indicators are often variations on the same theme, reflecting a lack of consensus on key debated concepts within the PC and EOLC literature. Future work is needed to achieve consensus 'best' definitions of these indicators as well as a universal performance measurement framework, similar to other ongoing efforts in population health¹²¹. Our scoping review will reduce duplication of the extensive amount of work that is required when a jurisdiction wishes to make a concerted effort to improve care in palliative and EOL populations through adoption of a performance measurement framework; one of the first steps in such efforts is typically to collect performance indicators from literature. This review can instantaneously inform indicator selection and development for other local, national and international efforts currently underway to improve PC and EOLC. Such performance measurement through indicators can help identify gaps in the access and quality of care and evaluate the impact of PC interventions that aim to bridge these gaps.

Data availability

Underlying data

All data underlying the results are available as part of the article and no additional source data are required.

Extended data

Dataverse: Supplementary files for Measuring indicators of health system performance for palliative and end-of-life care using health administrative data: a scoping review, <https://doi.org/10.7910/DVN/R3S0RT>³⁰.

This project contains the following extended data:

- S1 Appendix: Search Strategy
- S1 Table: Detailed List and Information on Collected Indicators
- S2 Table: Study Inclusion and Exclusion Criteria

Reporting guidelines

Dataverse: PRISMA-ScR checklist for 'Measuring indicators of health system performance for palliative and end-of-life

care using health administrative data: a scoping review', <https://doi.org/10.7910/DVN/R3S0RT³⁰>.

Data are available under the terms of the [Creative Commons Zero "No rights reserved" data waiver](#) (CC0 1.0 Public domain dedication).

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This study provides a useful and welcomed overview of EOLC quality indicators that have been developed or used in published studies.

Overall the presentation is clear, but we have a number of comments and suggestions the authors may wish to address.

1. Rationale for the Canadian perspective versus the conclusions about comparability across jurisdictions: the emphasis on Canada is strongly integrated in the article, both in the choices for the classifications of health sectors used to classify the indicators and in the analysis criterion for “conceivably measurable using (Ontario/Canadian) health administrative data”. That seems to be somewhat in conflict with the conclusions and plea the authors seem to make about comparability across jurisdictions.
2. We endorse the call for cross-national comparability. However, we would welcome a bit more reflection about the plea for more comparability across jurisdictions. There are likely several reasons for variations, including data availability but also different discourses around quality care. It is not so unsurprising then that experts within one jurisdiction face-validate indicators in a different manner than those in another. What would be needed to develop these? What rigorous efforts, using what methods, would the authors suggest for such a process? Our own experiences in cross-national comparisons learn us that issues around measurement equivalence, but also conceptual equivalence are a huge challenge.
3. Aims: the aim includes measurement concepts AND indicators, whereas the results talk about indicators. This creates confusion about the concept of ‘measurement concept’ and how it differs from the indicators. Either it needs some operationalization, or, alternatively, you could remove it from the aim.

4. Methods: literature search: the search strategy and inclusion/exclusion criteria were well done, are provided in an online format and were described precisely. It is easy to access the files through the citation to the data repository. However we have three comments: First, why is the search limited to July 2018? As this is a quickly expanding field this seems like an important limitation. What is the risk of missing important recent development efforts? Second, no validation strategy for the search string was followed and this could be mentioned as a limitation. Third, inclusion criteria for study selection are OK but there is no mention for the criteria for indicator selection. Authors remove 722 indicators for irrelevancy, but based on what criteria? Reasons for removal would also be useful in the flowchart.
5. Results: Quality assessment: the authors did not do a formal quality assessment for the studies being reviewed. Knowing the heterogeneity of included studies/literature, we can understand the practical difficulties in using existing quality assessment tools. However, as a reader we would benefit from at least some reflection or discussion about the methodological quality and rigor in indicator selection (eg convenience selection vs. formal validation efforts? What methods are used?). It would also be very helpful to have an overview of the level of scientific evidence underlying an indicator. It is likely that for most indicators the evidence-level is expert opinion and that only a limited number are based on evidence of causal impact on quality of life or related concepts. As such an overview would probably present demand a huge undertaking it is perhaps something that the authors may wish to stipulate as an attention point for future research?
6. Discussion: There is quite a strong emphasis on indicators being sector-specific. Not sure if this is accurate as the idea is not to use these indicators within a certain sector. We believe that for many of the indicators there is a system-wide responsibility to assess and improve quality. For instance, referral to home care is the responsibility of not only the actors within home care but also those outside that sector. Careful not to suggest an even stronger echeloning of health care.
7. Discussion: The authors focus on the fact that the measurement of patient-centered or patient-reported outcomes was infrequent at the population-level using health administrative database. This is an important point but we think it may be important to provide readers with more discussion about why this is so (not routinely collected?) and what would be needed to move forward to allow for inclusion of such indicators.
8. Discussion: strengths and limitations: would be good to have a separate paragraph discussing these. Also, some of the limitation mentioned in the points above may need to be included.
9. A minor point about the classifications: it seems that you approached the classification of indicators both deductively (i.e. using Ontario's health sector classification) and inductively (i.e. based on the types of indicators you found. The inductive approach is a result from your review (and should also be presented as such) and we would welcome more insight about how you came to the classification.
10. Specific sentences:
 - "One of the most commonly occurring measurement themes across sectors focused on

health system utilization (...)" --> health system utilization could be used as a term to describe most of the other indicators as well. Consider a more specific term.

- !" As health system resources become finite (...)" > Have they ever been infinite?
- 1. Discretionary: a visual summary of the themes would make the results more comprehensible. Similarly, the 'description' column of table 3 is a bit unclear, it might be clearer to give some examples of specific indicators.
- 2. Small language issues: adequately use end-of-life (adjective) versus end of life (noun); same for consistent use of population level vs population-level.

Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Partly

Are all the source data underlying the results available to ensure full reproducibility?

Partly

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Palliative care, Public health

We confirm that we have read this submission and believe that we have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however we have significant reservations, as outlined above.

Reviewer Report 06 April 2021

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Catherine J Evans

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Thank you, this is an interesting and comprehensive scoping review on health system quality/performance indicators for palliative care and end of life care. The scope of the review is impressive in aiming to encompass all settings and conditions, and inclusion and searching of grey literature. As the authors conclude, the findings are important to inform quality indicator selection for commissioners and policy makers and acknowledge important limitations that the review identifies the types and variety of indicators available, but not what indicators should form criteria for quality and policy makers.

Creation of a universally accepted performance framework for palliative and end of life care is identified as a priority research area, developed in consultation with key stakeholders. Patients and families would be key stakeholders, with country context specific consideration for low, middle, and high income countries.

The review identifies 339 indicators. The exploration of these by respective setting to identify common categories is important to distinguish key quality indicators by respective settings, convergence and gaps. The themes identified by respective settings are helpful to consider key indicators for respective settings.

As the authors discuss, the main area of convergence across settings is measurement of health service use towards the end of life as a quality indicator and identification of gaps of patient level indicators such as patient experience, and outcome data such as symptom distress. The authors call for use of outcome measures in routine care to address this. Helpful for the authors to refer to examples of this approach at a national level, such as the:

- Palliative Care Outcomes Collaborative (PCOC) in Australia <https://www.uow.edu.au/ahsri/pcoc/> and publications on embedding objective measures of quality in routine care¹.
- Progression of this work in the UK in the Outcome Assessment and Complexity Collaborative suite of measures for use in palliative and end of life at King's College London <https://www.arc-si.nihr.ac.uk/research-and-implementation/our-research-areas/palliative-and-end-life-care/outcomes-health-and->, <https://www.kcl.ac.uk/cicelysaunders/attachments/Studies-OACC-Brief-Introduction-Booklet.pdf> and Hull York Medical School <https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/resolve>

I have a few main points about the robustness of the scoping review:

1. The scoping review is well defined in terms of the rationale and methods, and concepts of quality indicators and health systems. However, important to have defined the concepts of palliative care and end of life care. This is eluded to as a limitation. The paper would have been strengthened to have defined these concepts in the methods, to enable consistent application of this eligibility criteria
2. Although the search is comprehensive, the last search was in July 2018. This is a fast moving area of health care. As such, there is an expectation of a search in the last 12 months as there is no justification to not updated for nearly three years.

3. As a scoping review, it is important to identify other systematic reviews on this topic area to cite in the background to justify the review and/or refer to in the discussion. For example, Henderson *et al.* (2019)²
4. Methods:
 1. Search strategy – the abstract states searched Medline and EMBASE, but the supplementary file details Pubmed and EMBASE. Please correct to give correct reporting of the databases searchers.
 2. Search terms for palliative care – this would have been strengthened by using/drawing on Sladek's 2006 *JMLA* search filter for studies on palliative care³.
 3. Sentence on "*Studies outside of the study time period of 2010-2018...*" is confusing. It implies that publications were identified after 2018. When what reporting is the use of reference chaining to identify publications prior to 2010. This needs to be updated for clarity.
 4. Figure 1 needs to align with PRISMA reporting to include number of studies identified by respective sources e.g. data bases searched, grey literature, screening at title and abstract and number excluded, and screening at full paper and reasons for exclusion against the eligibility criteria. The PRISMA for scoping reviews checklist is included as a supplementary file, but this can't be opened. Please review to ensure full reporting on the identification and screening for eligible publications.
 5. Detail on the analysis to form the themes for the indicators is very brief. Important to understand the process, how were disagreements managed, how ensured robust process across the 339 indicators.
5. Results – tables interesting and clear. Supplementary table interesting re-reporting on nominator and denominator, and how rarely presented.
6. No quality appraisal of the included studies, or indicators. This limits consideration on the quality of the included studies, and the indicators identified and for policy makers to discern between the indicators identified. This needs to be detailed in the limitations, for conclusions to be considered from this crucial limitation of the study.

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Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Research on palliative care delivery, new models and evaluation and use of outcome measures in routine clinical care.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

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