

Retrospective studies of end-of-life resource utilization and costs in cancer care using health administrative data: A systematic review

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Julia M Langton¹, Bianca Blanch¹, Anna K Drew², Marion Haas³,
Jane M Ingham^{4,5} and Sallie-Anne Pearson¹

Abstract

Background: There has been an increase in observational studies using health administrative data to examine the nature, quality, and costs of care at life's end, particularly in cancer care.

Aim: To synthesize retrospective observational studies on resource utilization and/or costs at the end of life in cancer patients. We also examine the methods and outcomes of studies assessing the quality of end-of-life care.

Design: A systematic review according to PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) and AMSTAR (A Measurement Tool to Assess Systematic Reviews) methodology.

Data sources: We searched MEDLINE, Embase, CINAHL, and York Centre for Research and Dissemination (1990–2011). Independent reviewers screened abstracts of 14,424 articles, and 835 full-text manuscripts were further reviewed. Inclusion criteria were English-language; at least one resource utilization or cost outcome in adult cancer decedents with solid tumors; outcomes derived from health administrative data; and an exclusive end-of-life focus.

Results: We reviewed 78 studies examining end-of-life care in over 3.7 million cancer decedents; 33 were published since 2008. We observed exponential increases in service use and costs as death approached; hospital services being the main cost driver. Palliative services were relatively underutilized and associated with lower expenditures than hospital-based care. The 15 studies using quality indicators demonstrated that up to 38% of patients receive chemotherapy or life-sustaining treatments in the last month of life and up to 66% do not receive hospice/palliative services.

Conclusion: Observational studies using health administrative data have the potential to drive evidence-based palliative care practice and policy. Further development of quality care markers will enhance benchmarking activities across health care jurisdictions, providers, and patient populations.

Keywords

Systematic review, end-of-life, cancer, palliative care, resource utilization, costs, patterns of care

What is already known about the topic?

- Relative to the evidence base supporting clinical decision making at the time of a cancer diagnosis, there is limited understanding about what constitutes quality end-of-life care.
- Observational studies have been important drivers of evidence-based palliative care practice and policy and in identifying research priorities.

¹Faculty of Pharmacy, The University of Sydney, Sydney, NSW, Australia

²Prince of Wales Clinical School, Faculty of Medicine, The University of New South Wales, Sydney, NSW, Australia

³Centre for Health Economics Research and Evaluation, The University of Technology Sydney, Sydney, NSW, Australia

⁴Cunningham Centre for Palliative Care, Sacred Heart Health Service, NSW, Australia

⁵St Vincents' Hospital Clinical School, Faculty of Medicine, The University of New South Wales, NSW, Australia

Corresponding author:

Sallie-Anne Pearson, Faculty of Pharmacy, The University of Sydney, A15 - Pharmacy and Bank Building, Sydney, NSW 2006, Australia.
Email: sallie.pearson@sydney.edu.au

- There has been increasing interest in using observational research to understand the nature, quality, and costs of end-of-life cancer care.

What this paper adds?

- There has been an increase in observational studies assessing the nature and extent of resource utilization and associated costs at the end-of-life in adult cancer patients; 76 of the 78 included studies were published since 2000.
- Data from over 3.7 million cancer decedents from jurisdictions around the world revealed consistent patterns of care, with resource use and costs increasing exponentially but palliative services being relatively underutilized at the end-of-life.
- A number of researchers (15 studies) moved beyond quantification of end-of-life care toward use of validated indicators to assess the quality and appropriateness of end-of-life cancer care.

Implications for practice, theory, or policy

- We found a distinct lack of harmonization of research methods with hundreds of different outcomes being used to measure the quality of end-of-life care, none of which could provide direct insight into the “consumer” or “patient and/or carer” perception of end-of-life care.
- The conclusions of our review highlight that patient-centered data is crucial if we are to move toward optimizing end-of-life care globally.

Introduction

There has been an unprecedented increase in the number of cancer cases around the globe, and improved treatments have resulted in higher rates of survival than ever before.^{1,2} In this context, the importance of understanding treatment patterns, outcomes, and health system impact of cancer cannot be underestimated. The burden of cancer on health systems is growing and becoming a major item of expenditure in developed countries.³ Previous research suggests that the year following diagnosis and last year of life are the most resource- and cost-intensive periods in cancer treatment delivery.⁴ The end-of-life period is of particular interest, given the high volume of care and speculation about the quality of care provided, something that has wide-reaching clinical and economic consequences.^{3,5,6} To date, there has not been a comprehensive analysis of observational studies focusing on resource utilization and costs in cancer patients at life's end.

Observational research using health administrative data provides a unique opportunity to examine end-of-life patterns of care in large populations of cancer patients. Data sources are improving continually, with timely access to accurate person-level linked health data allowing researchers and health policy agencies to understand the impact of patient-, disease-, and health system-related factors on resource utilization and costs.⁷ The use of existing data (such as billing claims linked with cancer registry data) facilitates the creation of decedent cohorts that provide a comprehensive picture of cancer treatment. These data sets are more cost-effective and broader in scope than primary data collections, generally undertaken in small numbers of highly selected settings and patients.⁸ A more challenging issue, however, is how these large data sets can or should be used to explore the quality and appropriateness of cancer care. Defining quality and appropriateness of care is

complex across all areas of medicine, and end-of-life cancer care is no exception.^{9,10} Quality end-of-life cancer care is generally defined as reducing or withdrawing ineffective treatment (e.g. diagnostic or curative therapies) and increasing utilization of evidence-based palliative therapy while also reflecting patient preferences.^{11,12}

The aim of this systematic review is to assess the nature and extent of resource utilization and associated costs toward the end-of-life in adult cancer patients. Furthermore, we will examine the methods used and outcomes of studies assessing the quality and appropriateness of end-of-life care. Our review was limited to retrospective observational studies using health administrative data published over a 20-year period that focused exclusively on an end-of-life period.

Methods

Study identification

We searched MEDLINE, PreMEDLINE, Embase, CINAHL, and York Centre for Reviews and Dissemination databases (York CRD includes Database of Abstracts of Reviews of Effects, Health Technology Assessment, and National Health Service Economic Evaluation databases). We restricted the search to journal articles published between 1990 and 2011 (up to week 51) to coincide with the growing availability of administrative data sets. We combined keywords and subject headings to identify resource utilization or costs (*health resources, patient care, health expenditures*) in cancer patients (*neoplasms, cancer care facilities*) at the end of life (*palliative care, terminal care*) (Appendix 1). We excluded government reports, editorials, opinion pieces, conference abstracts,

or review papers identified in our search. During the study identification process, we noted several important systematic reviews focused on palliative care, and in particular quality indicators of care.^{13–16} Our review builds on this previous work and provides a synthesis of the literature specific to cancer care research using administrative health data sets.

Studies eligible for review

We included English-language journal articles reporting at least one resource utilization or cost outcome in cancer patients at the end-of-life that satisfied the following criteria:

- Study population: included adult decedents with solid tumors. Studies not specifying the minimum age of the cohort were included if authors stated the focus was adult cancer patients.
- Data sources: resource utilization and/or cost estimates were derived from administrative database(s). That is, data collected by third-party payers such as governments (e.g. Medicare, USA) and health insurance companies primarily for payment purposes.
- End-of-life focus: the study focused exclusively on an end-of-life or palliative period as stated by the authors. Studies examining end-of-life care and other stages of care (e.g. diagnosis, post-surgery) were out of scope.

Study identification occurred in the following three stages: (1) Screening titles and abstracts of studies identified in the literature search; (2) Screening full-text articles considered potentially relevant. Pairs of independent reviewers (A.K.D, B.B., or J.M.L.) used a tool based on our eligibility criteria (i.e. study population, data sources, and end-of-life focus); a third reviewer (S.P.) arbitrated when consensus was not reached (10% of articles); (3) Screening back-references to detect potential papers not identified through our search strategy. We screened back-references of all included articles, review articles, and manuscripts excluded from the review as they did not focus solely end-of-life care (i.e. articles that compared resource utilization and/or costs across all phases of cancer care or from diagnosis through to terminal care; a full list of these articles is available upon request from study authors).

Data extraction

Articles meeting our eligibility criteria underwent comprehensive data extraction by two independent reviewers (J.M.L. and B.B.); a third rater (S.P.) reviewed 30% of articles. We extracted the following data from included studies:

1. Study characteristics: first author, year of publication, journal, study year(s), funding source, objectives, and setting.
2. Cohort characteristics: number of cohorts (details of any comparison groups), cohort size(s), inclusion/exclusion criteria, data source used to identify cancer patients, and cancer type(s).
3. End-of-life period: if different periods were used across outcome measures (e.g. last 12 months of life for hospice and last 2 weeks of life for chemotherapy), we recorded the longest period and noted other periods as sub-analyses.
4. Resource utilization: study periods, data set names, and aspects of resource utilization and/or costs examined. Resource utilization was classified into the following categories: diagnostic/tests/laboratory; physician visits; hospital admissions; emergency department visits; intensive care unit (ICU) use; medications (including chemotherapy); surgery; palliative care services (e.g. hospice, community care), and other.
5. Cost data sets and perspective: payer (e.g. government), provider (hospital), or patient.
6. Main outcome measures and study conclusions: relating to resource utilization/costs at the end-of-life in cancer patients based on administrative health data. Some studies reported outcome measures outside this scope (not reported in our review).
7. Comprehensiveness of reporting: we assessed studies according to 10 key items from the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines:¹⁷ background/rationale, objectives, setting, participants, variables, data sources, study size, descriptive data, main results, and study funding (items 2, 3, 5, 6–8, 10, 14, 16, 22).

Analysis and reporting

Our review is consistent with the AMSTAR (A Measurement Tool to Assess Systematic Reviews)¹⁸ and PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)²⁵ reporting criteria. Due to heterogeneity in study methodology and outcomes, we could not use traditional meta-analytic approaches to combine individual study results. Instead, we describe key study features and provide a qualitative analysis of common themes across included studies.

We also calculated the recency of studies, defined as the time between the last year of the study period and publication year. Each manuscript is reported separately.

Finally, we also analyzed separately studies using indicators of end-of-life care: we report rates across these indicators.

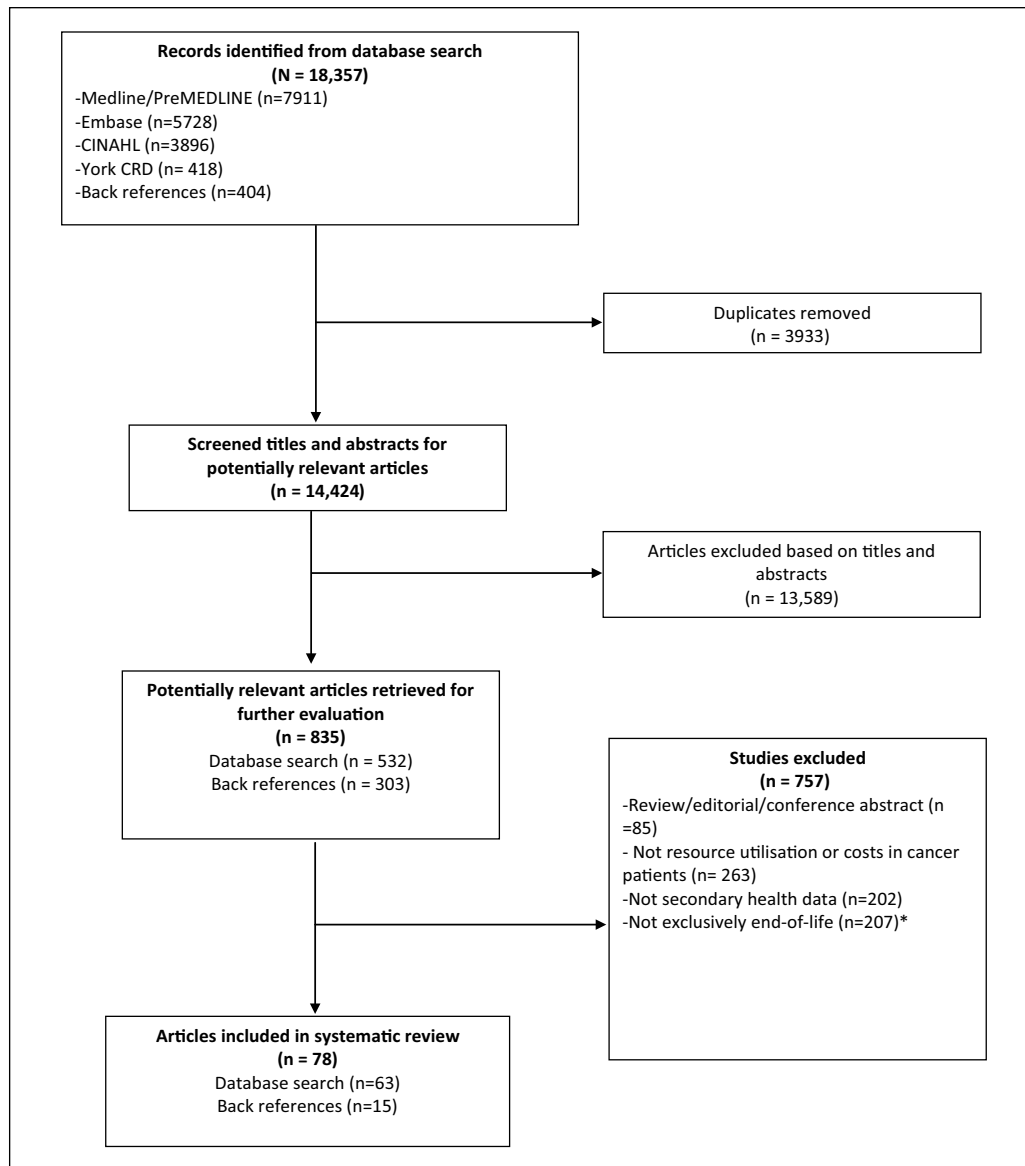


Figure 1. Process of study inclusion in the systematic review.

CRD: Centre for Reviews and Dissemination.

*In total, 39 studies examined end-of-life care in addition to other stages of care (e.g. from diagnosis, post-surgery); the remaining 168 studies did not examine end-of-life care.

Results

Studies identified

We screened the titles and abstracts of 14,424 articles and reviewed 835 full-text manuscripts, 78 of which were included in the review; 15 of the 78 were identified through back-reference searches (Figure 1).

Study characteristics

In total, 71 studies examined resource utilisation alone or in combination with costs,^{18–22,26–91} and 7 studies explored costs only.^{92–98} Only 2 studies were published prior to

2000, and the volume of publications grew steadily, with the largest number being published in the period 2008–2011. The median time between publication year and the last year of the study period was 5 years (range 1–10 years). The majority of studies were from the North American setting (55 studies) and funded by government grants (60 studies) (Table 1).

Classification of the end-of-life period

Our systematic review focused on studies with a defined “end-of-life” or “palliative period.” The most common periods were the last 6 or 12 months of life (49 studies); 10 of these studies included a sub-analysis of shorter

Table 1. Characteristics of included studies.

	All studies (%) (n = 78)
Study focus	
Resource utilization	52 (66.7)
Costs	7 (9.0)
Resource utilization and costs	19 (24.4)
Publication year	
<2000	2 (2.6)
2000–2003	19 (24.4)
2004–2007	24 (30.8)
2008–2011	33 (42.3)
Study setting	
Asia	8 (10.3)
Australia	5 (6.4)
North America	55 (70.5)
Europe	10 (12.8)
Recency (lag between last observation year and publication year)	
1–2 years	2 (2.6)
3–5 years	40 (51.3)
>5 years	35 (44.9)
Not reported	1 (1.3)
Study funding	
Public grants	60 (76.9)
Industry	3 (3.8)
Other ^a	3 (3.8)
Not reported	12 (15.4)

^aOther: charitable organization, health insurance fund, consumer advocacy group.

time-periods such as the last month or last 2 weeks of life. The end-of-life period used across studies ranged from 3 days to 3 years (Table 2).

Cohort characteristics

Cancer diagnoses. Study populations consisted of decedents, mostly with any cancer diagnosis (54 studies), categorized according to International Classification of Disease (ICD) codes. Cancer diagnoses were identified primarily in cancer registries (32 studies), administrative health claims (17), death certificates (10), health insurance databases (4), or a combination of sources (15 studies). Most studies (50) included only decedents whose cause of death was cancer; two studies included both decedents who died from cancer or with cancer (but from a non-cancer cause of death). A total of 26 studies did not specify cause of death (Table 2).

Age, sex, and other comorbidities. Studies tended to focus on adult populations aged 65 years and over. The majority of studies included both sexes (73 studies), 4 focused on sex-specific cancers, and 4 had cohorts primarily or exclusively of men (veterans' populations). A total of 32 studies reported measures or indices of comorbid conditions for their cohort(s).

Table 2. Methodological features of included studies.

	All studies (%) (n = 78)
Minimum age for inclusion (years)	
Any age	6 (7.7)
16–20	21 (26.9)
65–70	30 (38.5)
Other	3 (3.8)
Not reported	18 (23.1)
End-of-life period	
≤1 month	9 (11.5)
3 months	1 (1.3)
5 months	1 (1.3)
6 months	20 (25.6)
9 months	2 (2.6)
12 months	29 (37.2)
>12 months	3 (3.8)
Variable ^a	11 (14.1)
Not reported	2 (2.6)
Cancer types	
Any	54 (69.2)
1	12 (15.4)
2	4 (5.1)
3–4	8 (10.3)
Resource utilization/costs	
Single aspect of resource use	30 (38.5)
Multiple aspects of resource use	41 (52.6)
Costs only	7 (9.0)
Comparison group	
None	46 (59.0)
Cancer	15 (19.2)
Non-cancer	17 (21.8)

^aEnd-of-life period was variable, for example, time from an event such as hospice enrollment, until death.

Comparison groups. In total, 17 studies compared outcomes in a cancer cohort to a patient cohort with non-cancer medical conditions or causes of death (e.g. heart disease, chronic obstructive pulmonary disorder). Another 15 (focusing exclusively on cancer patients) compared patients receiving different patterns of cancer care or based on factors such as place of death, race, health insurance status, or country of residence (e.g. United States vs Canada).

Cohort sizes. The sum of cancer cohorts included in our study exceeds 3.7 million cancer decedents. There was large variability in the size of the cancer cohorts (median 9427; range 89–388,511) and non-cancer cohorts (median 7037; range 325–180,190).

Comprehensiveness of reporting

All studies reported background/rationale, objectives, and key results. All reported setting (country) but a number of US studies (9) did not report the states from which data were collected. All studies reported eligibility criteria; however,

Table 3. Aspects of resource use examined across included studies.

Aspect of resource utilization examined	n	References
Diagnostics/tests	1	26
Physician visits	23	26–48
Hospital admissions	38	20,21,26–32,34–37,41–46,48–66
Intensive care unit visit	22	20,21,26–29,46,50–52,55,57,64–72
Emergency department visit	21	21,26,28,34,38,41,42,46,49,50,52,54,57,61,64–69,73,74
Chemotherapy	17	20,21,26,30,31,38,42,46,51,52,57,65–69,91
Non-cancer prescription drugs ^a	12	27–32,46,64,75–78
Palliative services (including hospice)	32	18–20,22,28,29,33–36,43–47,52,57,58,64–66,70,77,79–87
Surgery	1	51
Other ^b	26	22,26,28–32,34–39,41,43–45,47,51,55,57,65,77,88–90

^aIncludes five studies examining only opioids.^{29,46,64,75,77}

^bOther included palliative radiotherapy, skilled nursing, home-care services, and specific life-sustaining treatments such as cardiopulmonary resuscitation or mechanical ventilation.

the details ranged from very brief (e.g. died in 1996) to highly specific criteria including the stage of cancer, health insurance status, and place of residence (Appendix 2). The majority of studies described cohort sizes and data sources, 2 did not report the size of the cancer cohort, 3 did not name the data source for identifying cancer diagnosis, and 3 did not report the data source for resource use/costs. All studies provided some data on the age of the study population (e.g. percentage of cohort within each age group) but reporting was heterogeneous; 42 did not report any descriptive statistics (mean/standard deviation or median/range), and 18 did not state the minimum age for inclusion. Most studies reported sex (73 studies), and 32 studies reported the comorbidity profile of the study cohorts. A total of 12 studies did not report the funding source.

Outcomes and summary of study findings

The following section summarizes the methods, main outcomes, and study findings by study focus.

Resource utilization (n = 71 studies)

In all, 71 studies reported outcome measures relating to resource utilization, 30 of which examined only one aspect of resource use. The most common outcomes involved hospital use: hospital admissions (38 studies), ICU use (22 studies), and emergency department attendances (21 studies). Palliative services (32 studies) and physician visits (23 studies) were also frequently reported. A number of studies examined medication use: 17 examined chemotherapy and 12 examined other prescription drugs (5 of which focused exclusively on opioids) (Table 3 and Appendix 2).

Study periods. The median study period was 5 years (range 1–16 years).

Data sets. In total, 66 studies used administrative health data maintained by government agencies including claims data and veterans' health administration databases. The most common databases were from the United States—Medicare (Centers for Medicare & Medicaid Services, 11 studies) and Surveillance, Epidemiology, and End Results (SEER)-Medicare (15 studies)—and provincial Canadian databases (20 studies).

Outcome measures. Studies focusing on one aspect of resource use (30 studies) tended to detail a range of different metrics (e.g. *hospital admissions*—number of admissions; length of stay; *opioids*—number of prescriptions or patients receiving opioids). The exception was studies examining the uptake of palliative care programs such as hospice that usually reported enrollment rates alone. A total of 41 studies examined multiple aspects of resource use, and these studies reported numerous outcome measures ranging from two aspects of resource use to a comprehensive analysis including inpatient, outpatient, and community care.

Indicators of care. In total, 15 studies examined resource utilization in terms of “quality” indicators of end-of-life care, all of which were published since 2003 (Table 4). With the exception of 3 studies from Taiwan, all were from the North American setting (5 Canada; 7 United States). These studies used large cancer cohorts (median 22,818; range 2040–260,090) and only one study compared cancer with a non-cancer condition—heart failure.⁶⁴ Many studies selected indicators similar to those used in the seminal study by Earle and colleagues,⁵² but few studies reported the same combination of indicators. Importantly, the majority of indicators were focused on the care delivered during the last month of life or less. Indicators were generally termed “aggressive” (12 studies) or palliative care markers (11 studies); 8 studies reported a combination of indicator types. The variability in definitions of “aggressive” and

Table 4. Summary of included studies using indicators of “aggressive” or palliative care: rates represent the lowest to highest proportion of study populations receiving end-of-life care markers.

Indicator of end-of-life care	Rates (%) ^a	References
Marker of “aggressive” care		
Chemotherapy		
Last 14 days ^b	1–19	21,38,46,52,67–69
Last 30 days	10–38	20,57,65
New regimen last 30 days	1–6	46,52
Toxicity	46	46
None last 6 months of life	63	42
Emergency department visits		
Last 14 days	27–37	38,67,68
>1 visit last 30 days	7–19	21,46,52,57,65,69
≥1 visit last 30 days	39	64
No visit last 6 months	58	42
Hospital admissions		
Last 7 days	16	46
Last 30 days	45–64	20,64
>1 admission last 30 days	8–33	21,46,57,65
>14 days of last 30 days in hospital	11–58	52,57,65
Only 1 hospitalization last 6 months	47	42
≤20% last 6 months spent in hospital	72	42
Intensive care unit admissions		
Last 14 days	5–6	67,68
Last 30 days	3–19	8,20,21,46,57,69
Life-sustaining treatments		
CPR last 30 days	7–12	57,65
Intubation last 30 days	17–27	57,65
Mechanical ventilation last 30 days	19–33	57,65
Marker of palliative care		
Hospice enrollment		
≤3 days before death (late enrollment)	11–36	46,52,57,64,65,84
≤7 days before death (late enrollment)	19–23	83,19
Last 30 days	36	20
No enrollment last 30 days	66	46
Enrollment duration ≥2 months (appropriate enrollment)	6–29	83,19
Last year of life	15–19	57,65
“Prior to death”	51–57	20,64
>180 days before death (inappropriate enrollment)	6–8	83
Opioids		
Outpatient prescription short- or long-acting last 30 days	25	46
Outpatient prescription short- or long-acting last 60 days	46	64
Other		
Physician house call last 14 days	25–28	38
Community follow-up last 6 months	16	42
GP follow-up last 6 months	18	42
Home care last 6 months	21–78	38,42

CPR: cardiopulmonary resuscitation; GP: general practitioner.

^aBased on average rates of use in cancer cohort (if reported).

^bTime periods were used interchangeably for the purposes of synthesis across studies: 30 days = 4 weeks and 1 month; 14 days = 2 weeks.

“palliative” care across the studies is demonstrated by use of 25 different indicators for the five most commonly examined services (chemotherapy, emergency department visits, hospital admission, ICU use, and hospice). Commonly used “aggressive” or “intensive” indicators included

intensive care or emergency department visits, inpatient hospital admissions, chemotherapy, and life-sustaining treatments close to death. Palliative indicators focused commonly on hospice care, pain relief (opioids), and primary and community care at the end-of-life. Not

surprisingly, no study used indicators directly reflecting “consumer” or “patient and/or carer” perceptions of care.

Main findings. Despite the heterogeneity in cohorts and outcome measures, a number of findings were common across studies. First, regardless of the outcome, resource utilization increased sharply as death approached, particularly in the last 3 months of life. Second, resource use reduced with increasing age. Finally, palliative services such as hospice care were often reported as underutilized but when used were usually associated with reduced resource utilization (in particular, reductions in “aggressive” therapies and hospitalizations).

The uptake of services varied on the basis of sex,^{20,21,53,72,79,85,86,88,90} marital status,^{22,82} ethnicity,^{18–20} comorbidity burden,^{54,71,88} insurance status,^{69,82,83,87} and geographical location.^{21,22} In particular, those in rural locations received fewer palliative services and were more likely to visit the emergency department or be admitted to hospital close to death.^{20,21,61} In the US setting, minority populations such as Asian Americans were less likely to access hospice care compared with white Americans.^{18,19} Being married was associated with greater use of palliative services such as hospice.^{22,82} Furthermore, women were reported as more likely to enroll in palliative care services^{20,79,85,86} and less likely to receive “aggressive” services compared with men,^{21,72,88} with some exceptions.^{53,90} Fee-for-service (FFS) coverage was associated with poorer quality and more “aggressive” care than Managed Care Organization (MCO), Health Maintenance Organization (HMO), or Veterans insurance.^{69,82,83,87} A consistent finding was that patients with FFS coverage accessed hospice care less frequently or closer to death compared with managed care enrollees.^{82,83,87} Higher comorbidity burden was consistently associated with greater resource use.^{54,71,88} Finally, cancer type was associated with resource use^{30,72,75,89,90} but there were no consistent patterns.

In relation to quality indicator studies (Table 4), not only was the nature of markers heterogeneous but so were the rates of use. One of the most common indicators of “aggressive” care was chemotherapy delivery close to death; between 1% and 19% of cancer decedents received chemotherapy in the last 14 days of life and between 10% and 38% received chemotherapy in the last 30 days of life. Similarly, hospice enrollment was highly variable across studies, with between 15% and 57% of decedents enrolling in hospice prior to death and 11%–36% of hospice users being enrolled close to death (i.e. within 7 or 3 days of death). This variability most likely reflects cohort differences and/or cross-jurisdictional differences in end-of-life service delivery.

Costs of end-of-life care (*n* = 26 studies)

All 26 studies reported costs from a payer perspective (Appendix 2). Most studies (15) were from the United

States, with the remaining studies from Europe (6), Asia (2), Canada (2), and Australia (1). All studies reported the costs associated with resource utilization, but seven did not present resource utilization data.

Study periods. The median study period was 2.8 years (range 1.1–11).

Data sets. Studies used government or health insurance databases, most commonly Medicare claims and health-care financing files.

Outcome measures. Common outcome measures were overall expenditures and expenditure by service type or month before death.

Main findings. Costs increased sharply as death approached. Furthermore, in studies examining expenditures by service type, hospital admissions accounted for a greater proportion of costs than other services.^{31,35,36,78} The reduction in costs by age were driven by reduced utilization of hospital services (including ICU)^{29,70,94} or a focus on palliative care services as opposed to “aggressive” treatments in elderly populations.^{59,63} Additionally, there was an association between comorbidity burden and higher expenditures at the end-of-life.⁹⁵

Discussion

The increasing availability of routinely collected health data has enhanced opportunities to conduct whole-population observational studies across the full spectrum of cancer care. Our systematic review details all studies published over a 20-year period that made use of linked health administrative data to characterize and quantify health resource use and health system costs incurred for the care of cancer patients approaching life’s end. The studies in our review are heterogeneous in nature; however, their key messages are remarkably similar. Furthermore, the practice patterns detailed in this work have important clinical, policy, and fiscal implications. In particular, the outcomes generated by these studies provide opportunities for “benchmarking” current care practices, particularly across similar institutions or jurisdictions, and facilitate opportunities for subsequent studies to explore questions relating to quality care.

The studies in this review highlight the prolific use and extensive range of therapeutic options available to cancer patients during the end-of-life period and the health system impact of this care. Not surprisingly, emergency department visits, hospital visits, and, in particular, ICU admissions were the key drivers of resource use and expenditures. In contrast, we observed that palliative care and hospice services remain underutilized, and when used, these services were associated with reductions in

health expenditure and “aggressive” end-of-life treatment compared to hospital-based pathways.

Many factors were important determinants of the patterns of end-of-life care, suggesting there may be common barriers to effective palliative treatments for end-of-life care across the several jurisdictions covered in this review. For instance, there were notable disparities in access to palliative care in minority populations, patients living in rural settings, and patients with FFS insurance coverage.^{18–22} Furthermore, elderly decedents received fewer healthcare services (palliative and “aggressive” treatments) across the board compared with younger decedents. The reasons for these systematic findings warrant further investigation and raise fundamental questions about what constitutes appropriate or quality care in the end-of-life setting for different patient populations.⁹⁹

Consistent with concerns about unnecessary medical interventions at the end-of-life and the importance of quality care, a number of studies in our review moved beyond simple quantification and used indicators or markers of the quality of care. The indicators were highly explicit and focused almost exclusively on care received in the last month of life. Moreover, no study reported any “patient-reported outcomes of care”—likely because these data are not routinely collected in health administrative data sets. While the data from these studies highlight that in many settings a substantial proportion of patients encounter interventions such as curative chemotherapy or life-sustaining treatments close to death, interpretation of these findings is challenging. Indeed, health professionals and consumers alike have identified problematic aspects of several commonly used end-of-life indicators identified in this review, including chemotherapy, hospital and palliative care services.¹⁰⁰ Specifically, patient preferences and availability of local resources have been deemed crucial in determining whether indicators reflect quality care.^{100–102} For instance, chemotherapy close to death may reflect patient, family, or community preferences as opposed to inappropriate decisions made by treating clinicians (particularly in younger cancer patients). Similarly, extensive use of hospital services might signal best available care in a community with limited hospice or home-care palliative services.^{100,101} Clearly, there is need for continued development of quality end-of-life indicators if they are to drive evidence-based clinical care and policy making.¹⁰³

The next frontier in this research domain is further refinement and validation of markers of the quality of care. Importantly, validated markers could enhance the assessment of quality of care within and across healthcare jurisdictions, providers, and specific patient populations, and over time. At a minimum, this process could take place at the health jurisdiction level but it is highly desirable for minimum data sets, indicator development, and application to be harmonized across jurisdictions. There would be considerable merit in engaging a range of key stakeholders

including clinicians, policy makers, and patients across international boundaries in an effort to standardize benchmarking initiatives.^{8,99} One example of this is the global atlas of palliative care at the end-of-life co-produced by the Worldwide Palliative Care Alliance and World Health Organization, which is the first report on the need and availability of palliative care globally.¹⁰ This atlas provides a baseline against which to measure improvements in the access and quality of end-of-life care and demonstrates significant disparities in access to care internationally, with the majority of adults in need of palliative care living in low- and middle-income countries. This publication is an extremely valuable tool and demonstrates that jurisdiction-specific projects focusing on patient outcomes and indicator development are also necessary to drive quality improvement.^{14,16,104}

From a methodological perspective, our results highlight the inherent challenges of using routinely collected health data for observational research. For instance, the significant lag between study end dates and year of publication and the restriction of cohorts to those eligible for subsidized healthcare within a sole jurisdiction are common barriers to rapid and generalizable research reflective of current practice. The last decade has seen significant improvements in access to comprehensive linked secondary health data for research and this will continue to improve. Implementing more streamlined data access and approval mechanisms will result in more timely publication of quality, whole-of-population evidence that has greater potential to underpin contemporary clinical and policy decision making.

Study limitations

We noted a high level of variability in reporting and terminology, a significant challenge for both identifying and synthesizing this body of work. We call for improved consistency in terminology which is likely to result in more specific flags to identify studies of this kind. It is unrealistic for researchers, clinicians, and policy makers to review more than 14,000 abstracts to identify fewer than 100 studies in this field, with no guarantee of capturing all relevant literature.¹⁰⁵ Our approach for identifying potential studies included scanning hundreds of back-references. Despite our comprehensive methods, it is difficult to ascertain how many studies we did not include in this review. Additionally, limiting our search strategy to English-language articles and excluding grey literature may have resulted in underrepresentation of research from regions outside North America, including Scandinavian countries that hold incredibly rich linked administrative health data sources. Moreover, the absence of consistent reporting on basic cohort characteristics such as age and study eligibility criteria, including cause of death, is highly problematic. Routine publishing on features of study populations and

the nuances of various health systems is paramount for the benefits of using indicators for benchmarking across healthcare settings to be realized. This is likely to improve with the increased scrutiny by high-quality journals that publish observational studies.¹⁰⁶

One of the unique features of this body of research is the use of the retrospective decedent design.^{8,107,108} The strength of this approach is efficiency in identifying relevant patients to examine resource use and costs within a specified end-of-life period. However, there have been strong arguments that designs of this nature “should be laid to rest” as they do not reflect an accurate portrait of all patients living with advanced disease.¹⁰⁹ Notably, these studies do not include patients who survived or benefited from “aggressive” treatments. It has been argued that population-based cohort designs following patients with advanced life-limiting disease prospectively, after a sentinel event such as the diagnosis of metastatic cancer, offer a more accurate representation of disease trajectories.¹⁰⁹ Importantly, the two studies in our review incorporating both retrospective and prospective designs identified similar patterns of resource use⁴⁶ and associated costs.⁹⁸ Nevertheless, key stakeholders need to be mindful of the strengths and limitations of each design in terms of contribution of research to the evidence base informing practice and policy.

Concluding remarks

The studies in this review add value to a very complex area of medical care. Further progress will be made with increasing use of comprehensive linked data sets, particularly in relation to understanding disease and health system drivers of end-of-life treatment pathways and further development and validation of markers used to evaluate service delivery and quality care. Analyses of population-level health service delivery data clearly contribute greatly to our understanding of service utilization, patterns of care, and health costs across jurisdictions. However, there remain many unknowns that should be addressed using a range of study designs and data sources. Importantly, there is a need for research that explores the effectiveness of care delivery in relation to patient preferences, how various approaches to care impact on quality of life, and indicators that could be developed using health administrative data sets to truly reflect stakeholders’ perceptions of the quality of care.^{110–114} Thus, the challenge remains to explore and identify data for collection in health administrative data sets that will complement existing patterns and costs of care data and shed light on the patient perspective—one that is pivotal to implementing system-level improvements for the care of those living with cancer and other terminal illnesses.¹⁰⁶

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Declaration of conflicting interests

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Appendix I

Complete search strategy for Ovid MEDLINE

Ovid MEDLINE search strategy (1990 to 27 October 2011):

1. "Costs and cost analysis"/
2. Cost of illness/
3. Health care costs/
4. Health expenditures/
5. Drug costs/
6. Employer health costs/
7. Cost control/
8. Hospital costs/
9. Hospital charges/
10. Health resources/
11. Resource utilisation.mp.
12. Resource utilization.mp.
13. Home care services/
14. Emergency medical services/
15. Emergency service, hospital/
16. Patient care/
17. Critical care/
18. Episode of care/
19. Hospitalization/
20. Length of stay/
21. Patient admission/
22. Long-term care/
23. Nursing care/
24. Home nursing/
25. Respite care/
26. Primary care nursing/
27. Palliative care/
28. Terminal care/
29. Cancer care facilities/
30. Hospices/
31. Or/1-30
32. (ec or sn or ut).fs.
33. 31 and 32
34. Exp neoplasms/
35. 33 and 34
36. Limit 35 to yr = "1990-2011"
37. (letter or editorial).mp.
38. 36 not 37
39. Exp animals/not humans.sh.
40. 38 not 39
41. Limit 40 to English language
42. Remove duplicates from 41
43. Limit 42 to "all adult"

This search strategy formed the basis of search strategies for Pre MEDLINE, Embase, CINAHL, and York CRD; these search strategies are available from the authors upon request.

Appendix 2

Summary tables of all included studies

Resource utilization studies (n = 52)

Table 5. Studies reporting a single aspect of resource use (n = 24).

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Aabom (2005), ⁴⁹ Denmark	Examine the impact of terminal diagnosis on hospital admissions and place of death (3 months)	Died between 1996 and 1998; cancer primary cause of death (N = 3445)	Hospital admission rates with and without terminal diagnosis Risk of hospital admission Predictors of receiving a terminal diagnosis	Hospital admission rates increase at the end-of-life Terminal diagnosis associated with lower rates of admission but longer length of stay ≥70 years; female, hematological cancer less likely to receive a terminal diagnosis 84% cohort ≥1 ED visit in the last 6 months of life One-third visit in the last 2 weeks of life—72% of which resulted in hospital admission Abdominal pain, lung cancer, and pneumonia—the three most common reasons for visits during last 6 months of life
Barbera (2010), ⁷³ Ontario	Examine use of ED and reasons for ED visits at the end-of-life (6 months)	Died of cancer between 2002 and 2005. Excluded if cancer diagnosis at death; death within 30 days of surgery; health insurance invalid in last 6 months of life; died outside Ontario (N = 91,561)	ED visits ED visits last 2 weeks of life	
Berger (2003), ⁷⁵ United States	Examine opioid prescribing in metastatic cancer (12 months)	Died between 1 January 1998 and 31 December 1999; diagnosed with metastatic cancer. Excluded if multiple tumor sites; not continuously enrolled in fund for last 12 months of life; enrolled in Medicare/supplement plan (N = 2132)	Opioid use (by month) Patients receiving opioids Prescriptions and number of “days of therapy”	Opioid use increased for all cancers Cancer patients with bone metastases more likely to receive opioids compared with other cancer patients
Burge (2003), ⁷⁴ Nova Scotia	Explore the association between family physician continuity of care and use of ED services (6 months)	Died between 1992 and 1997, of cancer; pathology report confirming cancer diagnosis; ≥3 ambulatory visits for last 6 months of life (N = 8702)	ED visits (compared in those with low, moderate, and high family physician continuity of care) Family physician home visits Predictors of family physician visits	Greater family physician continuity of care associated with less ED use
Burge (2005), ⁴⁰ Nova Scotia	Examine the association between income, residence, and family physician home visits (6 months)	Died between 1992 and 1997; cause of death: lung, colorectal, breast, or prostate cancer (N = 7212)		Middle- or high-income neighborhoods received more family physician visits

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Table 5. (Continued)

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Burge (2008), ⁷⁹ Nova Scotia	Examine the association between age and palliative care program registration (6 months)	Died between 1 January 1998 and 31 December 2003 of cancer; living in district health authority in Nova Scotia (N = 7511)	Palliative care program enrollment (by age) Predictors of palliative care enrollment CPR use Predictors of CPR use	Men and patients aged >65 years less likely to be enrolled in palliative care program CPR less likely for older patients and females; more likely in patients with higher comorbidity burden and non-oncology primary physician No differences in use of chemotherapy by cancer type Chemotherapy use decreases with increasing age Approximately 25% received chemotherapy
Chen (2009), ⁸⁸ Taiwan	Determine prevalence of CPR (1 month)	Died between 2001 and 2006 of cancer. Excluded if no NHI claim for inpatient or outpatient care in last month of life (N = 204,850)	Chemotherapy treatment (frequency, duration) in 30-day period prior to death	
Emanuel (2003), ⁹¹ United States	Examine use of chemotherapy (6 months)	Died in 1996; fully entitled FFS Medicare beneficiaries; cancer, the cause of death. Excluded if enrolled in ESRD program (N = 8875)		
Huang (2002), ⁵³ Ontario	Describe hospital use (6 months)	Died between 1986 and 1998 of cancer in Ontario; histologically confirmed cancer diagnosis (N = 203,713)	Hospital days (rates, trends, last 180 days) Patients hospitalized on any given day at the end-of-life Factors affecting time in hospital (patient, disease, and health system)	92% cancer patients hospitalized at the end-of-life Exponential increase in last month of life Patients <50 years of age, female, hematological cancer (vs solid tumor) spent more time in hospital Total time in hospital decreased during the study period
Johnston (2001), ⁸⁹ Nova Scotia	Examine patient and health system variations in the delivery of palliative radiotherapy (9 months)	Died between 1994 and 1998 of cancer in Nova Scotia; cancer diagnosis before death (N = 9978)	Palliative radiotherapy consult Palliative radiotherapy following a consult Patient and health system factors associated with palliative radiotherapy	Patients >80 years of age less likely to receive palliative radiotherapy 37% had a consult and 24% received palliative radiotherapy Patients with head and neck cancer more likely than those with gastroenterological or hematological cancers to receive palliative radiotherapy
Keating (2008), ⁸¹ United States	Examine the association between healthcare services and hospice use (hospice use at end-of-life period not further defined)	Died on or before 31 December 2001; first primary diagnosis of breast cancer between 1992 and 1999; enrolled in Medicare Parts A&B FFS; advanced breast cancer (stage III/IV). Excluded if cancer diagnosis at death; month of diagnosis unknown; not continuously enrolled in Medicare until death (N = 4455)	Hospice use from diagnosis to death Late enrollment in hospice (within 14 days of death) Association between resource use (physician, hospital, outpatient services) and hospice use	37% cohort enrolled in hospice before death; 41% of hospice users enrolled within 14 days of death Hospitalizations, physician visits, and cancer specialist visits associated with increased hospice use

Table 5. (Continued)

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Lavergne (2011), ⁹⁰ Nova Scotia	Determine factors affecting access to palliative radiotherapy (9 months)	Died between 2002 and 2005 in Nova Scotia; cancer cause of death (N = 13,494)	Palliative radiotherapy consultations Palliative radiotherapy Association between patient, clinical, and geographic factors and previous resource use with palliative radiotherapy	Younger patients, males, and those with lung, breast, melanoma, or colorectal cancers had higher rates of palliative radiotherapy
McCarthy (2003), ⁸² United States	Determine factors associated with time of hospice enrollment and length of stay (12 months)	Died between 1 January 1988 and 31 December 1998; first primary diagnosis of lung or colorectal cancer (1973–1996); resided in SEER area; Medicare beneficiaries. Excluded if cancer diagnosis after entering hospice or in situ disease (N = 119,377)	Rates of hospice enrollment Length of stay in hospice Factors associated with length of stay (age, time since diagnosis, stage at diagnosis)	Hospice use increased over the 10-year study period More likely for those with distant metastases, married, urban resident, higher income, and those in managed care (vs FFS). Consistent across lung and colorectal cancers
McCarthy (2003), ⁸³ United States	Examine the impact of insurance type on hospice enrollment and stays (12 months)	Died between 1 January 1988 and 31 December 1998 with cancer; diagnosed between 1 January 1973 and 31 December 1996; resided in SEER area; Medicare beneficiaries (N = 260,090)	Hospice enrollment Length of stay Indicators of quality of care (appropriate vs inappropriate enrollment) (Comparison by health insurance status: managed care vs FFS)	Medicare beneficiaries with managed care insurance access hospice earlier and stay longer than patients with FFS insurance
Moorin (2006), ⁶⁰ Australia ^b	Compare hospital utilization across five causes of death (3 years)	Died during 1997–2000 in Western Australia; cases stratified by five underlying causes of death (three cancer: lung, colorectal, prostate; two non-cancer: cardiovascular disease; ischemic heart disease) (N = 4250)	Hospital use by cause of death Impact of socio-economic status, geographic location, and private patient status on hospital use	91% study sample ≥ 1 hospital admission last 3 years of life Geographic location, socio-economic status, and private patient status impact on extent of hospital utilization—effects varied by cause of death
Ngo-Metzger (2003), ¹⁸ United States	Examine ethnic differences in hospice enrollment (6 months)	Died between 1 January 1988 and 31 December 1998. Medicare beneficiaries; diagnosed first primary lung, breast, colorectal, gastric, or liver cancer (1 January 1973–31 December 1996) in a SEER area. Excluded if diagnosed with in situ disease or after entering hospice; birthplace or race/ethnicity unknown (N = 184,081)	Hospice enrollment by cancer type, race, and place of birth	Hospice use lower in Asian Americans and foreign-born patients

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Table 5. (Continued)

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Ngo-Metzger (2008), ¹⁹ United States	Examine ethnic differences in hospice use and length of stay (12 months)	Died between 1 January 1988 and 31 December 1998; Medicare beneficiaries; diagnosed first primary lung, breast, colorectal, gastric, or liver cancer (1 January 1973–31 December 1996) in a SEER area. Excluded if diagnosed with in situ disease or after entering hospice; birthplace or race/ethnicity unknown (N = 184,081)	Hospice enrollment Late enrollment: proportion of patients enrolled within 7 days of death Length of hospice stay Optimal enrollment: proportion of patients enrolled for 2 months or longer	Asian Islanders less likely to enroll in hospice than white Americans 20% of the study population enrolled in hospice. Of these, 20% enrolled within 7 days of death and 6% stayed >2 months
Schneider (2007), ⁶² Germany	Examine trends in hospital stays in advanced cancer patients ("palliative phase"; focus last 2 years)	Died in 2004 from lung, colon, prostate, or female breast cancer (N = 355)	Hospital admissions Duration of hospital stays	Majority of hospital admissions occurred in last year of life Similar frequency of admissions across all cancers; lung and colorectal cancers had longer length of stay
Sharma (2009), ⁷¹ United States	Assess the impact of continuity of care and ICU use in advanced lung cancer patients (<12 months)	Died within 1 year of diagnosis of stage IIIB or IV lung cancer (1 January 1992–31 December 2002); enrolled in Medicare Parts A&B 1 year before death; hospital admission in last 6 months of life; resident in SEER area. Excluded if enrolled in HMO any time from diagnosis to death (N = 21,183)	ICU use during last hospital admission before death (compared outpatient to inpatient; provider continuity vs no continuity) Factors associated with ICU use in the final hospitalization Hospice use (home or inpatient hospice service) Predictors of hospice use (patient, disease, healthcare system, other resource use) Trends in hospice use over the study period	Continuity of care in the last year of life associated with reduced ICU use during terminal hospital admission Use of ICU increased over the study period 1993–2002 Greater comorbidity burden associated with higher rates of ICU use Hospice use was low (1/6) Small increase in rates over the study period Females, >65 years of age, current/previously married; ≤ 1 comorbid condition, more likely to use hospice Hospice use influenced by cancer type but not primary physician specialty
Tang (2010), ⁸⁵ Taiwan	Examine patient, disease, and healthcare system determinants of hospice use (12 months)	Died between 2001 and 2006 from cancer. Excluded if no NHI claims for inpatient or outpatient services in last year of life (N = 204,850)	Hospice enrollment in the last 3 days of life (poor quality care indicator) Predictors of hospice enrollment	Hospice enrollment in last 3 days of life ranged from 17% to 19% from 2001 to 2006 Late enrollment more likely if received "aggressive care" such as chemotherapy, ICU, multiple ED visits or hospital admissions, CPR, in the last month of life
Tang (2011), ⁸⁴ Taiwan	Examine impact of healthcare services received in last 12 months of life on late hospice enrollment (3 days)	Died between 2001 and 2006 of cancer. Excluded if no costs incurred in last month of life; did not use hospice in last year of life; missing data on date of hospice enrollment (N = 31,529)	Hospice enrollment in the last 3 days of life (poor quality care indicator) Predictors of hospice enrollment	Hospice enrollment in last 3 days of life ranged from 17% to 19% from 2001 to 2006 Late enrollment more likely if received "aggressive care" such as chemotherapy, ICU, multiple ED visits or hospital admissions, CPR, in the last month of life

Table 5. (Continued)

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Virnig (1999), ⁸⁷ United States ^b	Compare patterns of hospice use by health insurance status (before death)	Died in 1992; hospice patients and Medicare beneficiaries residing in South Florida. Excluded if hospice admission date was 1 January 1992 (N = 3929)	Hospice enrollment Length of hospice stay (compared cancer and non-cancer patients; and by health insurance status: FFS vs HMO)	Rates of hospice use higher in HMO versus FFS populations in both cancer and non-cancer patients Length of stay longer in those with HMO insurance compared with standard FFS Overall length of stay longer in those with cancer diagnosis Hospice use and length of stay similar across cancer types Rates higher in patients <80 years of age and females
Virnig (2002), ⁸⁶ United States	Compare patterns of hospice use across different cancer types (before death)	Died in 1996 of cancer; hospice use for cancer (N = 388,511)	Hospice use before death Length of hospice stay	Hospice use and length of stay similar across cancer types Rates higher in patients <80 years of age and females
Wu (2010), ⁷² Taiwan	Determine prevalence of ICU care (1 month)	Died between 2001 and 2006 of cancer. Excluded if no NHI claims for inpatient or outpatient care in the last month of life (N = 204,850)	ICU use Predictors of ICU use (patient, disease, healthcare system, healthcare resources)	<10% cancer patients use ICU in final month of life Use influenced patient and healthcare system factors, more likely in: males, older (>65 vs <65 years of age), higher comorbidity burden ICU use: more likely for hematological and esophageal cancers than distant metastases and pancreatic; less if medical oncologist is primary physician

CPR: cardiopulmonary resuscitation; ED: emergency department/emergency room; ESRD: end-stage renal disease; FFS: fee for service; HMO: Health Maintenance Organization; ICU: intensive care unit;

NHI: National Health Insurance; SEER: Surveillance Epidemiology and End Results (National Cancer Institute).

Studies shaded in gray used indicators/markers of care to examine resource utilization.

^aTime period for outcome measures are the same as the end-of-life period unless otherwise stated.

^bStudy compares cancer patients with non-cancer medical conditions/causes of death.

Table 6. Studies reporting multiple aspects of resource use (n = 28).

First author (Year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Allan (2005), ³⁷ British Columbia	Compare resource use in patients with and without palliative designation (≤ 12 months)	Died between 1998 and 1999 of cancer; resident of British Columbia Regional District (N = 2734)	GP and specialist visits/year Hospital nights/year Home support and home care (hours/month)	Palliative designation: fewer nights in hospital and hours of home support but more nursing visits GP and specialist visits comparable in both groups
Barbera (2006), ⁶⁷ Ontario	Describe aggressiveness of cancer care (2 weeks)	Died in 2001 of cancer. Excluded if cancer diagnosis at death; death within 30 days of surgery; insurance invalid during last 6 months of life; died outside Ontario (N = 21,323)	ED visits ICU use Chemotherapy administration	Aggressive care common in the last 2 weeks of life; ED (27%), ICU (5%), and chemotherapy (4%) Palliative care in last 6 months of life associated with less aggressive care in last 2 weeks of life
Barbera (2008), ⁶⁸ Ontario	Evaluate indicators of aggressive care (2 weeks)	Died in 2002 of lung cancer. Excluded if cancer diagnosis at death; insurance invalid during last 6 months of life; died outside Ontario (N = 5855)	ED visits ICU use Chemotherapy administration	Aggressive care common in the last 2 weeks of life in lung cancer patients; ED (32%), ICU (6%), and chemotherapy (5%)
Barbera (2010), ³⁹ Ontario	Describe patterns of end-of-life care (6 months)	Died between 2000 and 2004 of cancer. Excluded if cancer diagnosis at death; death within 30 days of surgery; health insurance invalid during last 6 months of life; died outside Ontario (N = 112,398)	Home care House calls last 2 weeks of life	There was high use of home care (68%) and physician house calls toward the end-of-life (24%) Service use decreased with increasing age
Barbera (2010), ³⁸ Ontario	Examine patterns of end-of-life care indicators (6 months)	Died between 1 January 2003 and 31 December 2004 of gynecological cancer. Excluded if died outside Ontario; cancer diagnosis at death; death within 30 days of surgery; health insurance invalid during last 6 months of life (N = 2040)	Chemotherapy administration; ED visits last 2 weeks of life Home care in the last 6 months of life and physician house calls in last 2 weeks of life	Aggressive care common in the last 2 weeks of life in gynecological cancer patients; ED (31%–37%) and chemotherapy (1%–5%) 73% received a home-care visit and 27% a physician house call Older patients less likely to receive services toward the end-of-life
Bergman (2011), ²⁶ United States	Examine resource use at end-of-life in those enrolled versus not enrolled in hospice (6 months)	Died between 1992 and 2005 of prostate cancer. Excluded if not enrolled in Medicare Parts A&B for ≥ 12 months post diagnosis; cancer diagnosis at death (N = 14,521)	Diagnostic, treatment procedures and physician visits by hospice enrollment status Factors associated with hospice use Rates of high-intensity care: ICU, ED, chemotherapy, CPR, cystoscopy, stent/nephrostomy	Hospice-enrolled men with prostate cancer were less likely to receive high-intensity care at the end-of-life

Table 6. (Continued)

First author (Year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Burge (2005), ⁴⁸ Nova Scotia	Describe trends in family physician visits to advanced cancer patients (6 months)	Died between 1 April 1992 and 31 March 1998 from lung, colorectal, breast, or prostate cancer (N = 7212)	Family physician visits (number, location) Hospital admissions and length of stay Change in outcomes coinciding with health system restructure (hospital downsizing)	94% cohort \geq 1 family physician visit and >85% of patients \geq 1 day as a hospital inpatient Number of admissions and length of stay decreased over time but no indication of increased family physician visits Health system restructure did not increase community-based services Low rates (6%) of hospital admissions in hospice patients Approximately one-third of hospitalized patients received aggressive care at the end-of-life
Cintron (2003), ⁵¹ United States	Report rates of hospitalization after hospice entry (12 months)	Died between 1 January 1988 and 31 December 1998; Medicare beneficiaries; primary diagnosis lung or colorectal cancer; enrolled in hospice care in last year of life; continuously enrolled in FFS for last 6 months of life. Excluded if enrolled in MCO; discrepancy between hospice benefit end date and date of death (N = 23,608)	Hospital admissions after hospice entry Services received by patients admitted to hospital after hospice entry (aggressiveness of care received when in hospital including ICU and surgery)	
Duffy (2007), ⁴¹ United States ^b	Examine patterns of inpatient and outpatient service use (12 months)	Died between October 1 2001 and 30 September 2002; VHA decedents; died in VHA hospital or extended care facility. (inpatient diagnoses used to classify groups of decedents (cancer vs other causes of death)) (N = 6369)	Healthcare utilization (comparison between six disease types and adjusted for demographic covariates) Hospital days Outpatient visits	Cancer most common cause of death but not highest users of health services at the end-of-life; ESRD highest number of outpatient visits and frailty highest number of inpatient days Inpatient days increased significantly in last quarter before death across all diseases
Earle (2004), ⁵² United States	Examine rates of markers of aggressive care in patients with advanced solid tumors (1 month)	Died between 1993 and 1996 of cancer, living in a SEER region. Excluded if not eligible for Medicare Parts A&B; enrolled in HMO during study period; survival time less than 1 year after diagnosis (N = 28,777)	Chemotherapy last 14 days of life; New chemotherapy regimen <30 days before death; > 1 ED visit; > 1 hospital admission; > 14 days in hospital; 1 ICU use last month of life Hospice use	Aggressive care increased over the 4 year study period Patients receiving chemotherapy at the end-of-life more likely to receive other types of aggressive care such as ED, hospital admissions, or ICU use Hospice use inversely correlated with indicators of aggressive care

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Table 6. (Continued)

First author (Year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Gagnon (2004), ⁴² Quebec	Examine access to palliative care (6 months)	Died between 1992 and 1998 of breast cancer; underwent an invasive procedure for diagnosis or treatment in Quebec between 1992 and 1998. Excluded if the cause of death was not breast cancer (N = 2291)	Palliative care-oriented profile score created with (1) place of death and (2) resource use during last 6 months of life (high score = best possible palliative care) Influence of age on palliative care-oriented profile score	Rates of palliative care indicators were low (18%–21%). 75% had few indicators of palliative care in the last 6 months of life <50 years of age receive less palliative care than patients >70 years of age Approximately 40% visited ED and >50% hospital admission in last 6 months of life
Ganzini (2010), ⁷⁷ United States	Compare end-of-life care in veterans dying of cancer with or without schizophrenia (6 months)	Died between 1 January 2003 and 31 December 2008 of cancer; ICD9 diagnosis of schizophrenia compared to randomly selected veterans without a major mental illness (N = 256)	Opioid use Physician orders for CPR or tube feeding Hospice enrollment and duration of enrollment	Veterans with and without schizophrenia received comparable end-of-life care Of patients with schizophrenia, 73% received opiates and 55% were enrolled in hospice; 81% and 52% in patients without schizophrenia Patients with schizophrenia died younger than those without schizophrenia Cancer patients more likely to be hospitalized and receive palliative care than COPD patients No differences in physician visits
Goodridge (2008), ⁴³ Saskatchewan ^b	Compare healthcare utilization in individuals dying of lung cancer or COPD (12 months)	Died in 2004; eligible for prescription drug benefits; cause of death recorded as lung cancer or COPD in Saskatchewan health database (N = 433)	Physician visits Hospital admissions and length of stay Palliative care services	Cancer patients more likely to be hospitalized and receive palliative care than COPD patients No differences in physician visits
Grande (2002), ⁴⁴ United Kingdom	Examine differences in resource use in cancer patients referred to HAH care versus not (12 months excluding the last 30 days of life)	Died from cancer; referred to HAH between 16 June 1994 and 19 June 1995; comparison group died during same period as HAH group and resided in HAH catchment area (N = 327)	Healthcare services Predictors of HAH referral	Cancer patients referred to HAH tended to be older, die from (vs with) cancer; accessed hospital/nursing services; had contact with an oncologist; and previously used cancer services compared with non-referred
Grande (2003), ⁴⁵ United Kingdom	Examine differences in resource utilization in cancer patients who die at home versus inpatient care (12 months)	Died from cancer during a 16-month period; died at home or as inpatient. Excluded if not a resident of local area (N = 327)	Patients receiving services Intensity of resource use after first home-care service Inpatient days	Patients who died at home used more specialist and district nursing resources compared with those who died in an inpatient setting Patients who died at home began home nursing care closer to death than those who died as inpatients
Ho (2011), ²¹ Ontario	Evaluate aggressiveness of end-of-life care (1 month)	Died between 1 January 1993 and 31 December 2004 of "any" cancer in Ontario. Excluded if no valid health insurance number; died within 30 days of cancer diagnosis (N = 227,161)	Chemotherapy dose in last 14 days of life; > 1 ED visit; > 1 hospital admission; or 1 ICU use last month of life Predictors of aggressive end-of-life care Rates of each indicator over the study period (1993–2004)	Younger patients, men, and patients residing in rural locations were more likely to receive aggressive care Aggressiveness of care increased over the study period

Table 6. (Continued)

First author (Year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Keating (2010), ⁶⁹ United States	Compare aggressiveness of end-of-life care in patients treated in the VHA versus Medicare FFS (1 month)	Died in 2005; male, diagnosed with stage IV lung or colorectal cancer between 2001 and 2002 (metastatic cancer patients). Excluded if enrolled in Medicare HMO last 30 days of life (N = 5826)	Dose of chemotherapy in last 14 days of life; I ICU use; > I ED visit last month of life	Veterans received less aggressive care compared with men treated through Medicare FFS Veterans less likely to receive chemotherapy and ICU use than Medicare patients
Legler (2011), ⁵⁴ United States	Examine the impact of comorbidity burden on resource use at the end-of-life (6 months)	Died in 2002 of cancer; received hospice care in 6 months before death; primary cancer diagnosis (N = 27,166)	ED, ICU, hospital admission from time of hospice enrollment until death Comparison of rates of resource use in patients with high versus low comorbidity burden	Higher likelihood of ED, hospital admissions, ICU use in patients with a higher comorbidity burden
Liu (2009), ⁵⁷ Taiwan	Compare quality of end-of-life care by physician specialty—medical oncologist versus other specialist (12 months)	Died between 1 January 2001 and 31 December 2006 of cancer. Excluded if no NHI claims for inpatient or outpatient care in last month of life (N = 204,850)	Last month of life: chemotherapy overuse; > I ED visit, > I hospital admission, > 14 days in hospital; life-sustaining treatments (CPR, ventilation, intubation) No hospice care in last year of life or late hospice referral (within last 3 days of life)	Cancer patients under care of a medical oncologist were more likely to receive chemotherapy, spend > 14 days in hospital but less likely to visit ED, ICU, or receive life-sustaining treatments No impact of primary physician type on likelihood of hospital admission or hospice referral
McNamara (2007), ⁵⁸ Australia	Examine use of specialist palliative care services (12 months)	Died between 1 July 2000 and 31 December 2002 in Western Australia; underlying cause of death cancer with or without the addition of a condition amenable to palliative care (N = 8007)	Use of specialist palliative care services Hospital admissions Likelihood of SPCS Proportion of hospital-based versus community-based SPCS access	97% of the study population had at least 1 hospital admission in last 12 months of life; length of stay ranged from 1 to 361 days Approximately 40% of the study population did not receive palliative care services
O'Brien (2007), ⁴⁷ Nova Scotia	Identify disparities in end-of-life care in nursing home and community dwelling patients (not stated)	Died between 2000 and 2003 of cancer. Excluded if died outside province or information on place of residence missing (N = 7587)	Palliative radiation (last 9 months of life) Medical oncology consult (last 12 months of life) Enrollment in palliative care	Nursing home residents less likely to receive palliative radiotherapy, medical oncology consult, and palliative services compared with non-nursing home residents Nursing home residents were more likely to be female, older (≥ 90 years), diagnosed with cancer at death, have lived in rural counties, and died out of hospital

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Table 6. (Continued)

First author (Year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Rosenwax (2006), ²² Australia ^b	Use of palliative care in people dying with cancer versus other conditions (12 months)	Died between 1 July 2000 and 31 December 2002 in Western Australia; underlying cause of death cancer or selected non-cancer condition deemed amenable to palliative care. Excluded if fetal deaths alive <1 day (N = 7399)	Use of SPCS, hospital-based and community-based Predictors of receiving SPCS (compared frequency services across 3 groups)	Cancer patients less likely to receive SPCS if single/widow, >85 years of age, or lived outside a major city Two-third of cancer patients received SPCS compared to one-tenth of non-cancer patients
Rosenwax (2011), ⁶¹ Australia ^b	Describe hospital and ED use in people who died of cancer versus other conditions (12 months)	Died between 1 August 2005 and 30 June 2006 in Western Australia; informal primary carer at time of death; did not reside in residential aged care facility; died of cancer or 1 of 9 conditions deemed amenable to palliative care (N = 746)	Hospital admission: number of admissions and length of stay ED visits	Exponential increase in hospital admissions as death approaches Similar numbers of hospital admissions in cancer and non-cancer cohorts Two-third of ED presentations in last year of life resulted in hospital admissions
Setoguchi (2008), ⁴⁶ United States	Evaluate a claims-based indicator of opiate use at the end-of-life (14 months)	Died between 1 January 1994 and 31 May 2003; aged ≥65 years; diagnosis of breast, colorectal, lung, or prostate cancer (1 January 1994–31 May 2003). One or more Medicare claim and 1 prescription within 14 months of death; continuous Medicare eligibility. Cause of death only available for subset of cohort (deaths in New Jersey, 1994–2002) (N = 32,810)	Opiate use last 30 days of life Not admitted to hospice; admitted to hospice ≤3 days of death Chemotherapy dose last 14 days of life; new chemotherapy regime <30 days of life; >1 ED visit; >1 hospital admission; 1 ICU use; last month of life Chemotherapy overuse—ED or hospital visit for chemotherapy toxicity (within 90 days of last chemotherapy regime)	Long acting opioid use was low (approx. 10%) suggesting underuse of opiates in palliative care Visit with oncologist positively associated with use of chemotherapy, opiates and hospice use Majority of patients not admitted to hospice at the end-of-life (66%)
Setoguchi (2010), ⁶⁴ United States ^b	Compare medications and healthcare services in HF and cancer patients at the end-of-life (not stated)	Died between 1997 and 2004 of cancer; diagnosed with lung, colorectal, prostate, breast (1 January 1997–31 December 2004); active in insurance program in year prior to cancer diagnosis HF cohort: identified from hospital claims and died of cardiac disease (N = 7565)	Use of hospice: date of first hospice enrollment after index date (HF hospitalization or cancer diagnosis) Opiate use last 60 days of life (patients outside hospice or nursing home) ED visit; hospitalization; ICU use last month of life	Hospice enrollment (51%) and opiate use (46%) higher in cancer patients (HF: 20% and 22%, respectively) Use of acute care services higher in HF patients (ED 60%, hospitalizations 64%, and ICU 19%) than cancer patients (ED 39%, hospitalizations 45%, and ICU 7%)

Table 6. (Continued)

First author (Year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Sheffield (2011), ²⁰ United States	Examine hospice use and aggressiveness of care at the end-of-life (≤ 4 weeks)	Died between 1992 and 2006; diagnosed pancreatic cancer 1992–2005 (first primary cancer); enrolled in Medicare Parts A&B without any HMO enrollment for 12 months before and 3 months after diagnosis. Excluded if diagnosed at autopsy (N = 22,818)	Hospice use and early enrollment (at least 4 weeks before death) Predictors of hospice care by disease stage, time trends Chemotherapy, ICU use, hospitalization last month of life	Hospice enrollment increased over the study period but reduction in early enrollment Increased aggressiveness of care (ICU and chemotherapy) over the study period Older, female, white; visit with oncologist (vs surgeon, other specialist) more likely to use hospice
Tang (2009), ⁶⁵ Taiwan	Evaluate the quality of end-of-life care (12 months)	Died between 2000 and 2006 of cancer (N = 242,530)	Chemotherapy use; > 1 ED visit; > 1 hospital admission; > 14 days in hospital; use of life-sustaining treatments (ICU, CPR, intubation, and mechanical ventilation) last month of life No hospice use in last 12 months of life; late hospice referral (≤ 3 days of life) Changes in indicators over the study period 2000–2006	Increase in hospice, chemotherapy, ED, hospital admissions and ICU over the study period; use of life-sustaining treatments decreased Care more aggressive in Taiwan compared with United States, based on benchmarks of end-of-life care
Warren (2011), ⁶⁶ United States and Ontario	Compare end-of-life care in the United States and Ontario (5 months)	Died between 1 January 1999 and 31 December 2003 of any cancer. Diagnosed with NSCLC. Excluded if > 1 cancer diagnosis; died before 65.5 years; cancer-directed surgery within 1 year of diagnosis; died within 30 days of diagnosis; not continuous enrollment in FFS Medicare Parts A&B for entire study period (United States only) (United States: N = 13,533; Ontario: N = 8100)	Inpatient hospitalizations; ED; ICU; chemotherapy; palliative care by month (rates/100 person-months) ED, ED resulting in hospital admission, hospital admissions (and length of stay), ICU use in (and length of stay) last month of life	All decedents use healthcare services extensively in last 5 months of life; particularly in the last month of life Limited hospice care in Ontario may account for different practice patterns, that is, lower rates of hospital admission in United States (44–50) versus Ontario (67–79) in last month of life Rates of chemotherapy use higher in United States (10–15) versus Ontario (6–9) in last month of life

COPD: chronic obstructive pulmonary disease; ED: emergency department/emergency room; ESRD: end-stage renal disease; FFS: fee for service; GP: general practitioner; HAH: hospital at home; HF: heart failure; HMO: Health Maintenance Organization; ICD: International Classification of Diseases; ICU: intensive care unit; MCO: Managed Care Organization; NHI: National Health Insurance; NSCLC: non-small-cell lung cancer; SPCS: specialist palliative care services; VHA: Veterans' Health Administration; CPR: cardiopulmonary resuscitation.

^aTime period for outcome measures are the same as the end-of-life period unless otherwise stated.

^bStudy compares cancer patients with non-cancer medical conditions/causes of death. Studies shaded in gray used indicators/markers of care to examine resource utilization.

Table 7. Studies reporting resource use and costs (n = 19).

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Au (2006), ²⁷ United States ^b	Compare resource utilization and costs in patients dying of airways disease versus lung cancer (6 months)	Died between April 1997 and September 2001; actively receiving care for lung cancer or COPD (N = 349)	Outpatient visits; inpatient hospitalizations; outpatient pharmacy Costs associated with healthcare	COPD patients received care consistent with prolonging life; lung cancer patients received palliative care Expenditures greater in COPD patients
Berger (2004), ⁷⁶ United States	Examine opioid prescribing (12 months)	Died between 1 January 1998 and 31 December 1999. Metastatic cancer; > 1 paid pharmacy claim for opioid in last 12 months of life. Excluded if multiple tumor sites; not continuously enrolled in fund for last 12 months of life (N = 704)	Opioids use (number of prescriptions; days of therapy) Total healthcare costs	Opioid use increased in the last 6 months of life Healthcare costs increased rapidly in last 3 months of life
Carlson (2010), ⁵⁰ United States	Determine the association between hospice disenrollment and healthcare services and expenditures (6 months)	Died between 1998 and 2002; primary cancer diagnosis; used hospice in last 6 months of life. Excluded if enrolled in MCO (N = 90,826)	ED, ICU, inpatient hospitalizations from hospice enrollment to death Total expenditures and average per day expenditures from hospice enrollment until death Hospice use by state and insurance type Hospital and physician expenditures (comparison by state, cause of death (cancer vs non-cancer), hospice enrollment status)	Patients who disenrolled from hospice had higher healthcare use and expenditures than patients who remained enrolled until death Expenditures lower in cancer patients receiving hospice care compared without hospice care Last month of life most expensive period across all causes of death
Emanuel (2002), ⁸⁰ United States ^b	Examine the impact of hospice use on expenditures (12 months)	Died in 1996; full entitlements; continuously enrolled in Medicare FFS Parts A&B for last 12 months of life. Excluded if ESRD program (N = 15,208)	Hospital admissions and length of stay Medications and physician visits Costs associated with health services	Prescriptions and physician visits increased but acute care and hospital stays decreased as death approached Acute care services accounted for most (67%) of healthcare expenditures at the end-of-life; physician visits (10%) Total expenditures decreased with increased age (driven by reductions in hospital stays as people age) Expenditures in cancer patients higher than non-cancer patients
Fassbender (2005), ²⁸ Alberta	Examine the impact of palliative care service on resource use and expenditures (12 months)	Died between April 1998 and March 2000; cancer diagnosis; residents of Edmonton and Calgary Health Regions at death; valid Personal Health Number (N = 16,282)	Hospital days and days with at least 1 GP visit, last 6 months of life Hospital admissions; opioids; ICU; artificial ventilation; last week of life Total expenditures associated with healthcare services in last 6 months and last month of life	
Gielen (2010), ²⁹ Belgium ^b	Examine age variation in healthcare utilization and expenditures in cancer and non-cancer patients (6 months)	Died between June 2005 and June 2006; cancer registration in or after 2000 or received chemotherapy, radiotherapy, or oncology consult in last 6 months of life. Excluded if incomplete claims (N = 11,219)		

Table 7. (Continued)

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Guest (2005), ³¹ United Kingdom	Assess resource use of analgesia and palliative care (start of strong opioid to death, ≤ 33 months)	Died between 1 January 1998 and 30 September 2000; read code of malignant neoplasm; advanced cancer patients; received transdermal fentanyl or sustained-release morphine as first strong opioid (N = 96)	Mean monthly resource use: opioid prescriptions; GP, nurse, outpatient visits; number of hospitalizations Costs associated with resource use	Hospitalizations accounted for majority of end-of-life costs (up to 71%); and opioids accounted for up to 17% of total costs Less than one-third receive slow-release morphine as their initial opioid despite recommendation in UK clinical guidelines End-of-life care and associated costs were different by cancer type: colon cancer was least expensive and ovarian was most expensive
Guest (2006), ³⁰ United Kingdom	Patterns of resource use costs of palliative care by cancer type (start of strong opioid to death, ≤ 33 months)	Died between 1 January 1998 and 30 September 2000; read code of malignant neoplasm; received transdermal fentanyl or sustained-release morphine as first strong opioid (N = 547)	Mean monthly resource use: GP, prescriptions, hospitalizations, and outpatient visits Costs associated with resource use	Expenditures decrease with increasing age; reduced hospital and ICU use with increasing age (all causes of death) Reduced aggressive hospital services with increasing age for all causes of death except cancer
Levinsky (2001), ⁵⁵ United States ^b	Examine patterns of expenditures and aggressiveness of medical care (12 months)	Died in 1996; continuously enrolled in Medicare FFS Parts A&B for last 12 months of life. Excluded if ESRD program, managed care plan (N = 11,879)	Total expenditure by age, sex, race, place, and cause of death (six causes of death including cancer) Expenditure by service type Hospital services (including ICU) by cause of death (use of aggressive hospital services) Expenses per patient Inpatient use—average bed days, percentage of decedents with >60 hospital days (by age and cause of death)	Utilization and costs decline with increasing age in those who died from cancer Cancer ranked second highest expenditures per capita (after kidney disease) Expenditures decrease with age Colon cancer and bladder cancer cause higher expenditures than liver cancer Lower expenditures in home hospice than hospital-based hospice
Liu (2002), ⁵⁶ Taiwan ^b	Examine healthcare use and expenditures (12 months)	Died in 1999; NHI beneficiaries; cause of death malignant neoplasms or other chronic diseases. Survivor cohort: alive through 31 December 1999 (N = 2332)	Expenditures per patient: home hospice care and inpatient services (last 8 weeks of life) Expenditures for conventional versus hospice care: total and per inpatient day (last week of life) Hospital days and hospice services (last 8 weeks of life)	Expenditures decrease with age Colon cancer and bladder cancer cause higher expenditures than liver cancer Lower expenditures in home hospice than hospital-based hospice
Lo (2002), ³² Taiwan	Examine utilization and expenditures for terminal care (12 months)	Died in 1997 of cancer; NHI beneficiaries; at least 1 NHI claim in 12 months before death (N = 26,809)		

(Continued)

Table 7. (Continued)

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Lunney (2002), ³³ United States ^b	Examine healthcare use and costs by cause of death (12 months)	Medicare claims and eligibility files between 1 1993 and 1 1998; five groups (cause of death from Medicare claims). Excluded if ESRD program, managed care plan; enrolled in HMO (N = 1571)	Hospice and physician nursing home visits Total expenditures and expenditures by service type (hospital inpatient, physician payments; average cost per person) Hospital days, re-admissions, and associated costs in the last 3 months of life	Expenditures in last year of life reduced with increasing age across all decedent groups Cancer ranked second highest total expenditures (after organ failure)
Miccinesi (2003), ⁵⁹ Italy	Examine hospital care in cancer patients who did versus did not receive palliative home care (12 months)	Died in 1997; residents of Florence; cancer cause of death (N = 3423)		Inpatient utilization and costs lower in patients receiving palliative care
Seow (2008), ⁶³ United States	Evaluate palliative cancer care pilot program (last 8 days–25 months of life)	Died between 1 January 2005 and 28 February 2007; enrollees of Medicaid insurance program administered by MCO; current cancer diagnosis; date of enrollment or refusal to omega life program; died while insured by MCO. Excluded if referred to program 1 week or less before death (N = 89)	Total hospital admissions from referral date (or rejection of palliative care program) until death Cumulative total inpatient days Total cost of hospital admissions	Palliative care program reduced hospital admissions at the end-of-life compared to usual care
Serra-Prat (2001), ³⁴ Spain	Examine end-of-life resource use and costs (1 month)	Died in 1998 from cancer; palliative treatment in the last month of life; living in Mataro. Excluded if received active treatment in last month of life; diagnosed less than 1 month before death; or missing data (N = 155)	Hospital admissions, ED, outpatient visits, palliative care, and home care Mean cost per patient associated with resource use	Reduced resource utilization and costs in those receiving home care
Sharma (2008), ⁷⁰ United States	Examine trends in ICU use (6 months)	Died between January 1993 and December 2002; diagnosed between 1992 and 2002 and died within 1 year of diagnosis; stage IIIb or IV lung cancer; enrolled in Medicare Parts A&B for last 12 months of life. Excluded if enrolled in HMO any time from date of diagnosis to death (N = 45,627)	ICU use: length of stay, predictors of use, services while in ICU Hospice enrollment Hospital and total expenditures	ICU and hospice use increased over the study period ICU more common in patients aged <85 years of age, less advanced disease, non-white, higher comorbidity burden Costs higher in those who used ICU at end-of-life

Table 7. (Continued)

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Shugarman (2007), ³⁵ United States	Examine age and gender differences in service use and expenditures (12 months)	Died between 1 January 1996 and 31 December 1999; diagnosed with colorectal cancer; continuously enrolled in Medicare Parts A&B for 36 months prior to death. Excluded if ESRD program; eligible for Medicare due to disability or in managed care; "other" race (N = 6657)	Resource use: inpatient, outpatient, home-care, physician services, skilled nursing, and hospice Expenditures associated with resource use Explored age and gender differences	Expenditures decrease with increasing age for both men and women Largest proportion of spending for inpatient services and physician services Older cohorts (≥ 74 years of age) less likely to use inpatient and outpatient services
Shugarman (2008), ³⁶ United States	Examine age and gender differences in service use and expenditures (12 months)	Died between 1 January 1996 and 31 December 1999; diagnosed with lung cancer 3 years before death; continuously enrolled Medicare Parts A&B for 36 months prior to death. Excluded if "other race"; eligible for Medicare due to disability or in managed care; if another condition dominated care in the last 12 months of life (claims data); ESRD program (N = 13,120)	Resource use: inpatient, outpatient, home-care, physician services, skilled nursing, and hospice Expenditures associated with resource use Explored age and gender differences	Overall expenditures lower for older decedents: lower costs driven by less inpatient/outpatient services and nursing and hospice use at the end-of-life Expenditures on average higher for females
Walker (2011), ⁷⁸ Ontario	Examine health system costs of end-of-life and palliative care (6 months)	Died between 2002 and 2003; cancer as cause of death. Excluded if cancer not diagnosed before death; died within 30 days of major surgery; invalid health insurance number in last 6 months of life; died outside Ontario or residence unknown (N = 43,802)	Expenditures per patient by cancer site and location of death Costs by service type Prescriptions and expenditures by age and cancer diagnosis (limited to those eligible for Ontario drug benefit, >65 years of age)	Institutional care accounted for the majority (75%) of expenditures, followed by physician services (5%) and drugs (5%) Total cost varied by location of death and cancer diagnosis

COPD: chronic obstructive pulmonary disease; ED: emergency department/emergency room; ESRD: end-stage renal disease; GP: general practitioner; FFS: fee for service; HMO: Health Maintenance Organization; ICU: intensive care unit; MCO: Managed Care Organization; NHI: National Health Insurance.

^aTime period for outcome measures are the same as the end-of-life period unless otherwise stated.

^bStudy compares cancer patients with non-cancer medical conditions/causes of death.

Table 8. Studies reporting costs only (n = 7).

First author (year), setting	Study aim (end-of-life period)	Inclusion criteria (N cancer decedents)	Main outcome measures ^a	Summary of findings
Campbell (2004), ⁹² United States ^b	Estimate effect of hospice enrollment on expenditures in patients dying of cancer versus other causes (12 months)	Died between 1 January 1996 and 31 December 1999; at least 36 months continuous enrollment in Medicare Parts A&B before death. Excluded if ESRD program (N = 65,175)	Effect of hospice enrollment on expenditures: overall and by service type	Hospice enrollment correlated with reduced expenditures in cancer decedents <85 years of age but increased expenditures in non-cancer decedents and those aged >84 years
Hanchate (2009), ⁹³ United States ^b	Examine racial and ethnic differences in costs associated with end-of-life care (6 months)	Died in 2001; enrolled in Medicare Parts A&B for last 12 months of life; positive match in national death index. Excluded if ESRD program or residing in Puerto Rico (N = 34,932)	Medicare expenditures: overall and by service type Impact of patient factors and resource use (e.g. hospice and life-sustaining interventions) on expenditures	Highest expenditures in patients with cancer or chronic liver disease as cause of death
Kardamianis (2007), ⁹⁴ Australia	Estimate hospital inpatient costs (12 months)	Died between 1 January 2002 and 31 December 2003. Excluded if data linkage error (N = 70,384)	Costs associated with inpatient days by 30-day period	Hospital costs decrease with increasing age
Koroukian (2006), ⁹⁵ United States	Examine Medicaid costs for patients dying of cancer (12 months)	Died between July 1992 and June 2002; Medicaid beneficiaries; cancer as underlying cause of death (N = 44,509)	Total expenditures: average expenditures per-person-per-month By service type Predictors of expenditures	Expenditure greater in patients with higher comorbidity burden
Polder (2006), ⁹⁶ the Netherlands ^b	Estimate healthcare costs at the end-of-life (12 months)	Died in 1999; insured during 1998–1999. Excluded if joined insurance fund 1998–1999 (N = 4978)	Expenditures by cause of death and gender	Expenditures for cancer patients decrease as age increases (both males and females)
Polednak (1998), ⁹⁷ United States	Estimate cancer-related charges for hospital care patients dying before 65 years of age (12 months)	Died in 1992; hospital admission with diagnosis of lung or female breast cancer between 1981 and 1992; died in Connecticut. Excluded if data linkage error (N = 862)	Hospital charges attributable to cancer care Total hospital charges for terminal care in the last 12 months of life	No differences in hospital costs in breast or lung cancer patients
Pyenson (2004), ⁹⁸ United States ^b	Compare end-of-life costs by hospice enrollment (from indicative event until death, <2 years)	Died between 1999 and 2000; survived >15 days after indicative event (event signaling terminal phase of care); indicative event before 2000. Excluded if claims outliers <US\$4000 and >US\$115,000 (N = 6762)	Costs for beneficiaries enrolled in hospice versus those not enrolled in hospice by disease cohort Predictors of cost (e.g. hospice status, age, sex, Medicaid dual eligibility)	Costs lower in decedents enrolled versus non-hospice enrolled decedents (except prostate cancer and stroke)

ESRD: end-stage renal disease.

^aTime period for outcome measures are the same as the end-of-life period unless otherwise stated.^bStudy compares cancer patients with non-cancer medical conditions/causes of death.