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Measuring Experience With End-of-Life Care: A Systematic Literature Review

Jessica Penn Lendon, PhD, Sangeeta C. Ahluwalia, PhD, MPH, Anne M. Walling, MD, PhD, Karl A. Lorenz, MD, MSHS, Oluwatobi A. Oluwatola, BS, Rebecca Anhang Price, PhD, MS, Denise Quigley, PhD, MA, and Joan M. Teno, MD, MS

VA Greater Los Angeles (J.P.L., A.M.W., K.A.L.), Los Angeles, California; David Geffen School of Medicine at UCLA (A.M.W.), Los Angeles, California; RAND Corporation (O.A.O., D.Q., S.C.A., A.M.W.), Santa Monica, California; RAND Corporation (R.A.P.), Arlington, Virginia; and Brown University (J.M.T.), Providence, Rhode Island, USA

Abstract

Context—Increasing interest in end-of-life care has resulted in many tools to measure the quality of care. An important outcome measure of end-of-life care is the family members' or caregivers' experiences of care.

Objectives—To evaluate the instruments currently in use to inform next steps for research and policy in this area.

Methods—We conducted a systematic review of PubMed, PsycINFO, and PsycTESTS® for all English-language articles published after 1990 using instruments to measure adult patient, family, or informal caregiver experiences with end-of-life care. Survey items were abstracted and categorized into content areas identified through an iterative method using three independent reviewers. We also abstracted information from the most frequently used surveys about the identification of proxy respondents for after-death surveys, the timing and method of survey administration, and the health care setting being assessed.

Results—We identified 88 articles containing 51 unique surveys with available content. We characterized 14 content areas variably present across the 51 surveys. Information and care planning, provider care, symptom management, and overall experience were the most frequent areas addressed. There was also considerable variation across the surveys in the identification of proxy respondents, the timing of survey administration, and in the health care settings and services being evaluated.

Conclusion—This review identified several comprehensive surveys aimed at measuring the experiences of end-of-life care, covering a variety of content areas and practical issues for survey administration. Future work should focus on standardizing surveys and administration methods so that experiences of care can be reliably measured and compared across care settings.

Address correspondence to: Jessica Penn Lendon, PhD, VA Greater Los Angeles, 11301 Wilshire Blvd, Los Angeles, CA 90073, USA. jessicapenn@gmail.com or jessica.lendon@va.gov.

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Keywords

End-of-life care; assessment; family caregivers

Introduction

The 2010 Affordable Care Act's emphasis on health care quality through payment reform underscores the need to systematize approaches to assess performance and quality of care. This is particularly relevant to evaluating care at the end of life, a time period with considerable variation in health care utilization and quality^{1,2} and when health care systems are challenged to respond effectively to the intense needs of seriously ill persons. Evaluating the end-of-life care experience presents unique challenges, including the frail and impaired condition of most patients that may preclude their participation in the assessment process and compels a reliance on proxy (i.e., family member or informal caregiver) reporting,³⁻⁵ In addition, end-of-life care encompasses a wide range of services important to patients and families, from symptom management to spiritual support to bereavement care,^{6,7} necessitating a multidimensional assessment approach. Because transitions in care are frequent⁸ and use of various settings is common, assessment approaches also must capture organizational diversity, be applicable across multiple settings, and pose questions that enable the respondent to differentiate between care received in different settings.

Despite these challenges, surveys of experience of end-of-life care have been developed and used for quality improvement and research purposes. A better understanding of existing evaluation approaches and surveys can help to identify gaps in measurement and inform future policy decisions regarding quality and performance improvement. To identify all available surveys that cover this important component of quality, we undertook a comprehensive literature review of existing publicly available surveys and measures of patient, family, or informal caregiver experience and satisfaction with care at the end of life. Our review characterizes the areas of care that are included in available surveys and describes how proxy respondents are identified, the timing and method of survey administration, and the type of health care setting being assessed.

Methods

Search Strategy

We systematically reviewed the published literature on patients', families', or informal caregivers' experiences with end-of-life care.⁹⁻¹¹ We searched PubMed, PsycINFO, and PsycTESTS[®] for English-language articles published between January 1, 1990 and June 6, 2012. We further limited our search to studies of adults (aged older than 18 years) and used a combination of the following search terms to identify the various ways end-of-life care is conceptualized in the literature: "hospice" OR "palliative care" OR "end of life care" AND questionnaire OR telephone OR phone OR email OR survey OR surveys OR tool OR tools AND experience OR quality of health care OR experiences OR experienced OR satisfaction OR satisfied OR unsatisfied AND patient OR patients OR mother OR father OR mom OR

dad OR parent OR parents OR guardian OR guardians OR caregiver OR caregivers OR spouse OR wife OR husband OR partner.

We also searched the gray literature (e.g., New York Academy of Medicine Gray Literature Report, Google, and the National Quality Measures Clearinghouse) using a similar search strategy for surveys or measures of family or informal caregiver experiences of end-of-life care. To identify additional resources, we reference-mined articles identified through the initial search and drew on members of our study team who are experts in the area of end-of-life care quality measurement (K. A. L. and J. M. T.) and an additional expert reviewer.

Article Selection

We included articles that 1) measured areas of patient, family member, or informal caregiver satisfaction and experience with end-of-life care and 2) included survey questions or instruments regarding patient/caregiver satisfaction or experience with end-of-life care. We excluded studies of pediatric populations and health care provider satisfaction with end-of-life care. Two reviewers, S. C. A. and A. M. W., a health services researcher and a palliative care clinician, respectively, with systematic review methodology experience first conducted independent dual review of identified references by title and abstract. Articles selected for full-text review were divided and independently screened by three reviewers (S. C. A., A. M. W., and R. A. P.). All articles included after full-text screening were divided and abstracted by study, survey, and survey question into a data abstraction file.

Data Analysis

First, we abstracted survey items from all 51 surveys in all of the selected articles to provide a general overview of the content areas covered by each survey. The research team first developed an initial list of potential content areas based on 1) our combined expertise in end-of-life care and 2) the National Consensus Project for Quality Palliative Care¹² and the National Quality Forum.¹³ Three reviewers (S. C. A., A. M. W., and J. P. L.) independently coded a sample of survey questions and met to review differences in coding and reach consensus on a revised coding scheme. The same reviewers repeated this process with a second sample of survey questions to develop a final coding scheme. The remaining survey questions were then divided between the reviewers and coded according to this scheme, with regular group meetings to review the process and achieve agreement. One reviewer (J. P. L.) conducted a final quality check by reviewing each of the survey items within each content area for consistency. Items that were misclassified were reconciled and reclassified into the most appropriate content area based on the final coding scheme.

Second, for feasibility, we used a subset of surveys that were published in two or more selected articles and abstracted more detailed information about: 1) *who* the respondents of the surveys were and how they were identified, 2) *where* the care was provided (e.g., inpatient hospice, intensive care unit [ICU], or in-home), 3) *when* the survey was administered (e.g., before patients' death or 2–4 weeks after death), and 4) *how* the survey was administered (e.g., telephone or face-to-face interview). These data were abstracted by two reviewers (A. M. W. and J. P. L.).

Results

Literature Flow

The Medline search identified 2097 articles and the PsycINFO/PsycTESTS search identified 892 articles (Fig. 1). After comparing results and removing duplicates, we identified 2094 unique articles, which we further narrowed to 215 relevant articles after title screening. Abstract screening reduced the number to 96 articles and a detailed article review found 84 articles that met inclusion criteria. We obtained additional surveys, measures, and reports from a search of the gray literature and other methods described previously. We reviewed these other sources, resulting in five additional articles, nine new surveys not identified in the literature review, and two toolkits that combined surveys and related resources identified elsewhere in our search. We excluded the toolkits from further study to avoid duplication. Of the 88 articles (Appendix lists the complete citations for the included articles; available from jpsmjournal.com) identified through the published and gray literature searches, and the nine surveys identified through the gray literature search, we identified 51 unique surveys containing 1256 unique survey questions that were available for abstraction of the survey content. Of these 51 surveys, a subset of 12 surveys (identified as used in more than two selected articles) were selected to abstract additional information on survey methods and administration.

Content Areas of Surveys

The qualitative categorization of survey content resulted in 14 areas described in Table 1: bereavement support, caregiver support, environment, financial needs, information and care planning, overall experience, symptom management, personal care, provider care, psychosocial care, quality of death, responsiveness and timing, spiritual/religious/existential care, and other (relating to demographic questions or questions not directly related to the experience of care).

Table 2 shows information about the unique items and content areas of each survey. None of the 51 identified surveys included all 14 content areas. Three surveys addressed 12 content areas (Family Evaluation of Hospice Care [FEHC], After-death Bereaved Family Member Interview [ADBFI], and Satisfaction scale for Family members receiving Inpatient Palliative Care [Sat-Fam-IPC]), two surveys addressed 11 areas (Family Assessment of Treatment at End of Life [FATE] & FATE-Short Form [FATE-S] and Canadian Health Care Evaluation Project), and four surveys addressed nine content areas (Quality of Dying and Death, Family Satisfaction with Care Questionnaire, Good Death Inventory, and Steele 2002 Patient satisfaction survey). Half ($n/4$ 25) of the surveys were limited to five or fewer content areas, indicating their narrow scope.

Fig. 2 displays contents areas and their distributions among the 51 surveys. Information and care planning were the most frequent content area, present in 45 (88%) of the 51 surveys. Provider care ($n/4$ 35; 68.6%), symptom management ($n/4$ 30; 58.8%), overall experience ($n/4$ 28; 55%), and spiritual/religious/existential concerns ($n/4$ 26; 51%) were present in more than half of the surveys. Several areas were less frequent (i.e., covered in 16 or fewer

surveys) among the identified surveys: other, personal care, bereavement care, quality of death, financial needs, and environment.

Detailed Abstraction From Survey Subset

We identified 12 of the 51 surveys that were used in two or more articles and abstracted more detailed information from the articles about the methods and administration of these surveys (Table 3).

Survey Proxy Respondents

Most articles ($n = 26$; 46%) reported that the surveys were administered to “family members” or “close relatives.” The next frequent designation was “caregiver” ($n = 17$; 30%), followed by designations specified as “health care proxy,” “decision-making surrogate,” “Power of Attorney,” or “medical contact” ($n = 10$; 17%). Specific descriptions about how the family member or caregiver was identified by the researchers (or health care entity administering the survey) were rare. The few articles in which a more detailed explanation was provided reported that family member respondents were identified by 1) contacting the person who signed the death certificate, 2) determining the “next of kin” or “health care proxy” from the patients’ medical records, and 3) determining which family member “knew the most about the patient at the end of life.” The remaining four (7%) articles administered the survey to patients before death.

Timing of Survey Administration

There was considerable variation in timing of survey administration across articles and among the same surveys, indicating that there is little consensus about when each survey should be administered. Surveys were administered to patients before death (i.e., 2–7 days after do-not-resuscitate order) in four (7%) articles and 37 (65%) articles administered surveys after death. However, the timing of survey administration was not described in 16 articles (43%). Among the articles reporting about after-death surveys, the shortest time frame was three to six weeks and the longest time frame was up to 372 days after death; most ($n = 21$; 56%) of these articles administered surveys approximately within one to six months after death.

Method of Survey Administration

We examined the specific method of survey administration reported by the articles, which included in-person paper survey or interview ($n = 23$; 40%), mailed paper survey ($n = 20$; 35%), telephone interview ($n = 19$; 33%), and one (2%) article reported using computers for survey administration. Among these, eight (14%) articles reported using a mixed mode design (i.e., a combination of the above survey modes, such as in-person and telephone interviews). Two (3.5%) articles did not report the survey administration method.

Health Care Setting of Survey Administration

As reported in the articles, inpatient hospitals, ICUs, and trauma centers were the most frequent health care services and settings evaluated ($n = 21$; 37%). Articles that specifically mentioned hospice and palliative care services including inpatient and outpatient home-

based care settings were the next most frequent ($n = 16$; 28%). Other settings included Veterans Affairs medical centers ($n = 8$; 14%); nursing homes and long-term care facilities ($n = 6$; 11%); cancer centers ($n = 4$; 7%); and geographic areas, health districts, or “last place of care” ($n = 5$; 9%). Six (11%) articles assessed more than one type of setting and three (5%) articles did not report the health care setting. Several surveys are care service and/or setting-specific, including the FEHC, which is designed to evaluate hospice care within a variety of settings from inpatient to home-based hospice care. Furthermore, Family Satisfaction in the ICU, End of Life Care in Acute Care Hospitals, Sat-Fam-IPC were developed to assess specific types of end-of-life care settings (ICU, acute care, and inpatient palliative care, respectively).

Discussion

The increasing interest in quality measurement of end-of-life care has resulted in the use of many survey instruments to measure satisfaction with and experiences of care, an important component of quality for this field.⁴⁻⁶ The unique contexts of end-of-life care raise several important challenges to the development of a quality assessment tool focused on the family, informal caregiver, and patient experiences of care. This systematic review of articles and surveys evaluated instruments currently in use, within the context of these challenges, to inform next steps in research and policy.

We found variation in content areas of all available surveys, suggesting that some surveys in use are more comprehensive than others. There is heterogeneity in the content covered in each of the surveys, but we did find certain content areas to be consistent across surveys, perhaps suggesting greater prioritization of these areas within the field. Some examples of content areas captured in most surveys include: “information and care planning,” “provider care,” “overall experience,” “symptom management,” and “psychosocial care.” This finding is expected since previous research on the aspects of end-of-life care deemed most important to patients, families, and providers appraised these content areas as very important.⁵⁻⁷ However, other aspects that also were considered important, such as financial needs, environmental aspects of the care setting, and caregiver and bereavement support were rarely assessed in the available surveys. These areas of end-of-life care are highly salient to family members and caregivers of the patients.^{6,7} Future work should investigate the suitability of including these topics in surveys to encourage their use for quality improvement and accountability of health care organizations.

We also uncovered variation in practice regarding how family or informal caregiver respondents are identified, the timing and method of survey administration, and the type of health care setting being assessed. The process for identification of proxy respondents was not described clearly by many studies, whereas others indicated that the respondent included the patients’ surrogate or “next of kin” as reported in medical records. There is no uniform way of identifying the family or caregiver respondent for these surveys. Given difficulty in establishing valid survey responses from bereaved family members or informal caregivers,⁷ the strategic identification of proxy respondents, and their impact on valid and reliable quality measurement is an area worthy of future research.

The reported timing of administration of after-death studies varied substantially from three weeks to one year after death. This variation was likely influenced, in part, by the variation in care settings, the purpose of research for each of the studies, and the availability of after-death data (e.g., the Regional Study of the Dying used samples of death certificates from 20 health districts in the United Kingdom^{14–16}). Some research has shown that timing of after-death surveys may influence the reliability of caregivers' perceptions of their loved ones' pain severity and other physical symptoms at four and nine months.¹⁷ However, several other studies found similarity in assessments administered to bereaved family at earlier versus later timing after death.^{18–20} Regardless of when surveys are administered, efforts should be made to standardize timing of after-death surveys used for quality to improve comparability of assessments.

Our review found that the family is a critical target for assessing end-of-life care experience and the reliance on proxy respondents for after-death surveys is likely because of the advanced stage of illness (e.g., dementia) or intensive treatment (e.g., feeding tube or respirator) that prohibits pre-death, patient-administered surveys. This raises the question of how best to evaluate the patient's care and assess informed and patient-centered decision making around goals of care and end-of-life interventions. Our review suggests that future research should investigate strategies to identify the optimal survey respondent and timing for after-death surveys with the goal of balancing the collection of accurate information without burdening bereaved family members.

After-death family and informal caregiver experience surveys also have been administered using in-person, telephone, and mailed interviews, with much variation across the different surveys. Understanding how survey administration affects reports of family or informal caregiver experience will be important if such surveys are to be used broadly to measure quality. Furthermore, the diversity of health care delivery systems for end-of-life care (e.g., residential and nursing home facilities, hospitals, ICUs, and home-based or outpatient hospices) presents challenges to the comparability of a uniform assessment across care services and settings. Studies should investigate whether experience of care can be adequately compared across care settings and consider the use of different survey versions tailored to capture the specific needs or aspects of different care settings. This is particularly important for emerging models of care, such as Accountable Care Organizations, which present both risks and opportunities to provide care that is simultaneously high quality and cost-efficient.

Our review has some limitations. Although we used three different databases of published literature and supplemented our primary search with reference-mining and expert guidance, as with any systematic literature review, our search strategy may have missed some relevant articles. Our review may omit relevant surveys not published in the peer-reviewed literature and does not include newer surveys developed and described after our literature search. The heterogeneity found among articles and surveys was too great to conduct a meta-analysis. There was limited information provided in the published studies about how assessment surveys are used in practice by health care institutions versus by researchers. Understanding how health care institutions administer and use these surveys for quality improvement and

reimbursement practices is important for further development of comprehensive surveys; future research is needed to address these issues.

A crucial aspect for quality measurement of care provided to patients with advanced illness is understanding and improving the patient and family experience of care provided at the end of life. This comprehensive review of the literature identified several surveys aimed at measuring the patient's, bereaved family member's, or informal caregiver's experience and satisfaction with end-of-life care. We identified variation in areas covered as well as practical issues such as method and timing of administration of surveys. Further research should focus on standardizing surveys and administration methods so that experiences of care can be measured reliably and be fairly compared across institutions and care settings.

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Appendix: Citations of the 88 Articles Included From the Systematic Review

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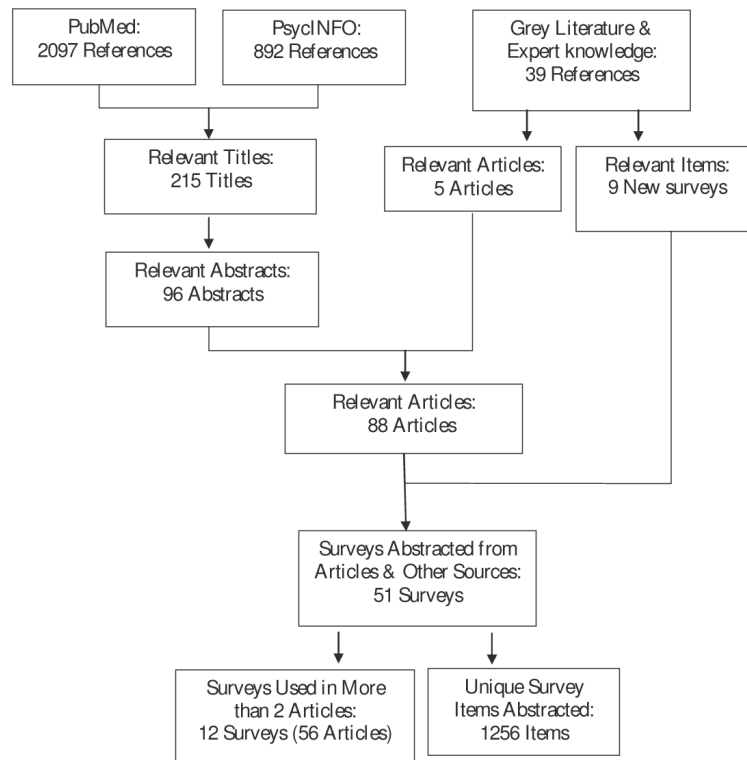


Fig. 1.
Literature flow.

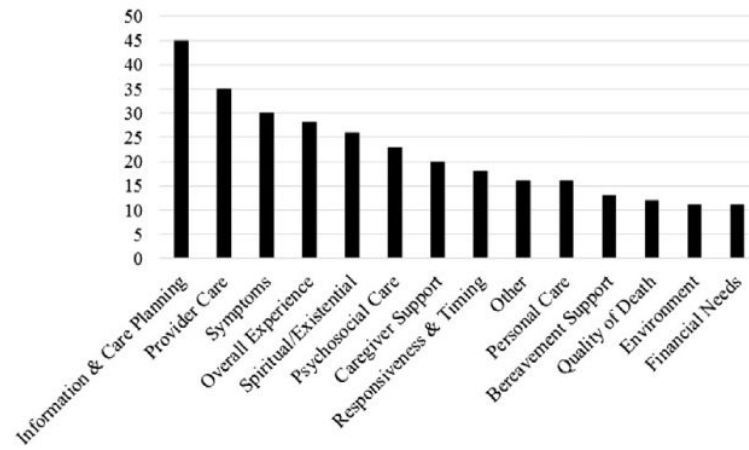


Fig. 2. Frequency of each content area among 50 surveys.

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Table 1

Content Areas of Surveys and Their Definitions

Content Area	Definition
Bereavement support	Related to support and services provided to family after death of patient
Caregiver support	Related to support and services available or provided to caregiver
Environment	Related to room, noise, comfort of facility
Financial needs	Related to patient's financial needs, health care costs, and funeral planning
Information and care planning	Related to advance care planning, communication, and decision-making between patient, family & providers, discussing goals/preferences for care, information related to informal care for patient at home
Overall experience	General assessments of care received; overall experience
Personal care	Related to the quality of personal care provided in facility or home (bathing, eating, and so on)
Provider care	Related to quality of and satisfaction with care given by specified provider (doctor, nurse, social worker, staff, and so on)
Psychosocial care	Related to emotional well-being, social support, social needs, and whole-person needs of patient
Quality of death	Related to experience of care received immediately before dying for patient/family (e.g., "During the final hours of your family member's life .")
Responsiveness and timing	Related to responsiveness to needs of patient/caregiver, including availability of hospice staff and timing of hospice referral
Spiritual, religious, and existential care	Related to religious aspects of care and/or patients' spiritual/existential needs and well-being
Symptom management	Related to experience and management of symptoms such as pain and shortness of breath
Other	Demographic information about patient or type of facility (unrelated to satisfaction or experience with care)

Table 2

Content Areas of Available Surveys

Survey Name	# of Studies	Citation Number ^a	Total Unique Abstracted Questions	Total Domains Covered	Information and Care Planning	Provider Care	Symptom Management	Overall Experience	Spiritual, Religious, and Existential	Psychosocial Care	Caregiver Support	Responsiveness & Timing	Other	Personal Care	Bereavement Support	Quality of Death	Environment	Financial Needs	Frequency of Unique Abstracted Survey Questions by Content Area
Family Satisfaction with Advanced Cancer Care	10	4, 14, 31, 45, 46, 51, 52, 56, 70, 71	30	6	14		9			1	1	4		1					1
Family Evaluation of Hospice Care	8	19, 57, 68, 69, 72, 81, 82, 87	56	12	18	3	10	3	4	5	5	1	2	1	2				2
After-death Bereaved Family Member Interview	9	5, 8, 9, 18, 32, 36, 65, 73, 80	74	12	30	2	14	2	6	6	3	1	1	5	1	3			3
Quality of Dying and Death	6	35, 42, 49, 62, 63, 65	48	9	4		6		15	12			3	1		4			3
Family Assessment of Treatment of End-of-Life	4	15, 28, 53, 75	58	11	19	4	11	4	3	2			4	3	3		1		4
Views of Informal Carers Evaluation of Services	4	3, 10, 20, 59	45	6	11	6	25	1						1					1
End of Life in Dementia—Satisfaction with Care, Symptom Management, & Comfort Assessment in Dying	3	18, 44, 84	41	7	4	1	27	3	4	1				1					1
Quality of End-of-Life Care and Satisfaction with Treatment	3	7, 78, 79	47	5		14		3	1	18		11							
Family Satisfaction in the ICU	3	21, 34, 49	25	7	11	2		5	1		2					1			3
Regional Study of Care for the Dying	3	24, 25, 26	4	1				4											
End of Life Care in Acute Care Hospitals (Caregiver and Patient Versions)	2	39, 40	43	8	20	7	1		5	7	1								1
Satisfaction scale for Family members receiving Inpatient Palliative Care	2	60, 61	57	12	11	8	3		2	2	3	6	6	1	3				4
Primary Caregiver Satisfaction with Hospice Social	1	6	12	7	3			1	1	2	2				2				1

Survey Name	# of Studies	Citation Number ^a	Total Unique Abstracted Questions	Total Domains Covered	Information and Care Planning	Provider Care	Symptom Management	Overall Experience	Spiritual, Religious, and Existential	Psychosocial Care	Caregiver Support	Responsiveness & Timing	Other	Frequency of Unique Abstracted Survey Questions by Content Area					
														Personal Care	Bereavement Support	Quality of Death	Environment	Financial Needs	
Client-centered care questionnaire	1	12	15	1	15														
Reid-Gunzlach Satisfaction with Services	1	13	36	4		27		7				1	1						
Client Satisfaction Survey	1	13	13	3	4	1		8							2				
Quality of dying in long-term care	1	18	9	4	3	1		3											
Primary Care Assessment Survey	1	29	8	5	3	2				1		1	1						
Canadian Health Care Evaluation Project	1	38	73	11	20	13	2	7	10	7	6	2	2		2			2	2
Family Satisfaction with Care Questionnaire	1	43	36	9	18	2	3	2	2	2	3						2		2
Admission and follow-up patient satisfaction questionnaire	1	83	15	4	4	6			1			4							
Care Evaluation Scale	1	86	5	3	2	2		1											
Family Perception of Care Scale	1	85	27	8	10		2	1	1	4	4				3				2
Caregiver Satisfaction survey (Steele 2002)	1	76	15	7	3	3	2	5	1		1	2	1						
Good Death Inventory (Miyashita, 2008b)	1	88	54	9	4	7	4		14	11					3		7	3	1
Adams (2009) survey	1	1	1	1									1						
Addington-Hall (1995) survey	1	2	23	4	8		1							10					4
Billings (1999) survey	1	11	36	7	14	1	3	5			1						2		
Casarett (2003) survey	1	16	7	3	4		2	1											
de Vogel-Voogt (2007) survey	1	22	8	2	2	7			1										
Denner (2002) survey	1	23	3	4	1			2											
Field (1998) survey	1	27	22	6	3	9	1			1			6						2
Flock (2011) survey	1	30	25	6	8	4	10	1	1			1							
Grande (2009) survey	1	33	8	5	3	2							1				1		1
Hanson (2008) survey	1	37	16	4		1	9	1						5					

Survey Name	# of Studies	Citation Number ^a	Total Unique Abstracted Questions	Total Domains Covered	Information and Care Planning	Provider Care	Symptom Management	Overall Experience	Spiritual, Religious, and Existential	Psychosocial Care	Caregiver Support	Responsiveness & Timing	Other	Personal Care	Bereavement Support	Quality of Death	Environment	Financial Needs	Frequency of Unique Abstracted Survey Questions by Content Area	
																			2	1
Patient Judgment of Hospice Quality (Heyland, 2005)	1	41	4	3	1	1														2
Lecouturier (1999) survey	1	47	19	5	7	6		4				1	1							
Ledeboer (2008) survey	1	48	10	5	4	1				3					1					1
Marco (2005) survey	1	54	10	8	2	2	1	1	1				1							1
Merrouche (1996) survey	1	55	12	7	2	3	1	1	1	1	1		2		1					1
Nolen-Hoeksema (2000) survey	1	64	4	2				1			3									
Norris (2007) survey	1	65	14	4	8	2	2	2		2										
O'Mahony (2005) survey	1	66	21	8	7	1	3	3	1	3	1	2								
Shirjo (2010) survey	1	74	37	8	14		1	1	2		6			6	5	1				2
Patient satisfaction survey (Steele 2002)	1	76	20	9	2	3	5	2		1	1	4	1							1
Satisfaction with day hospices by caregivers (Myashita 2008)	1	58	19	8	5	2	1			4	4		1	1						1
Family Perception of Physician-Family Caregiver Communication	other source		7	1					7											
Hospice Report Card	Other source		14	7	2	1	3	2	1		4									
National Association of Home Care and Hospice Bereavement Survey	Other source		15	4	1			1					5		8					
Palliative Care Outcomes Scale	Other source		12	5	1		6			3		1								1
Press-Ganey Hospice Survey	Other source		43	8	5	11	2	3	3	4		13			1					
Total Number of 51 surveys			1256		45	35	30	28	26	23	20	18	16	16	13	12	11	11		

^aCitation numbers correspond to citations in the Appendix, available at jpsmjjournal.com.

Table 3

Detailed Abstraction From Survey Subset (12 Surveys and 51 Articles)

Survey	Citation	Who: Respondent	When: Timing of Survey Administered	Where: Health/Care Context/ Setting	How: Mode of Survey Administration
After Death Bereaved Family Member Interview (<i>n</i> ¼ 9)	Arcand et al, 2009	Close relatives	10 weeks–3 months after death	Nursing home	Telephone interview
	Baker et al, 2000	Surrogates: person responsible for making decisions in the event the patient unable	4–10 Weeks after death	Hospitals	Telephone interview
	Bakitas et al, 2008	Contact person identified in patient's medical record	3–6 Months after death	Cancer centers	Telephone interview
	Cohen et al, 2012	Caregivers defined as the person most involved in the resident's care during the last month of life and who also visited at least once during this time	Not reported	Long-term care setting	Telephone interview
	Gelfman et al, 2008	Family members	3 Months–200 days after death	Medical Center	Telephone interview
	Hallenbeck et al, 2007	Family member listed with contact telephone number in patient records	At least 3 months after death	Veterans Affairs (VA) inpatient hospice	Telephone interview
	Shega et al, 2008	Primary caregivers	2–6 Months after death	Geriatrics clinics (enrolled and not enrolled in hospice)	Telephone interview
	Teno et al, 2001	Family member	3–6 Months after death	Nursing homes, an outpatient hospice service, and an academic medical center	Telephone interview
End-of-Life Care in Acute Care Hospitals (<i>n</i> ¼ 2)	Heyland et al, 2009	Patients and caregivers	Not reported	Inpatient, outpatient, home care programs at medical center	In-person interview
	Heyland et al, 2005	One family member who made at least one visit to the patient	3–6 Weeks after death	University-affiliated intensive care units (ICUs)	In-person interview
EOLD-Satisfaction with Care & Comfort Assessment in Dying (<i>n</i> ¼ 3)	Cohen et al, 2012	Caregivers most involved in care during the last month of life and visited at least once	Not reported	Long-term care settings	Paper (mailed)
	Kiely et al, 2006	Residents or health care proxies (if resident died before follow-up)	Baseline and quarterly for up to 18 months before death; proxies 2 and 7 months after death	Nursing homes	In-person interview
	van der Steen et al, 2009	Family caregiver most involved in the last months of life	2 Months after death	Nursing homes	Paper (mailed, at site)
Family Satisfaction with Advanced	Aoun et al, 2010	Patient carer	Not reported	Inpatient and home-based palliative services	Paper (at site)

Survey	Citation	Who: Respondent	When: Timing of Survey Administered	Where: Health/Care Context/ Setting	How: Mode of Survey Administration
Cancer Care (n¼ 10)	Carter et al, 2011	Caregivers	Not reported	Oncology outpatient clinic	Computer
	Follwell et al, 2009	Oncology patients	Not reported	Hospital	In-person interview
	Kristjanson et al, 1997	Family members	36 Hours after admission to palliative care unit; 2 weeks after admission to home care program	Inpatient medical units, palliative care units, and home care programs	In-person interview
	Lo et al, 2009a	Patients and primary caregivers	Not reported	Hospital	Paper (at site)
	Lo et al, 2009b	Oncology patients	Baseline, 1 week, and 1 month after Oncology Palliative Care Clinic consultation	Hospital	Paper (at site)
	Meyers and Gray, 2001	Primary caregivers	Not reported	Hospice organizations	Telephone interview
	Ringdal et al, 2003a	Family members who were close to patients	1 Month after death	Palliative medicine unit in hospital	Paper (mailed)
Family Assessment of Treatment of End-of-Life survey (n¼ 4 or 5??)	Ringdal et al, 2003b	Family members	1 Month after death	Hospital	Paper (mailed)
	Alici et al, 2010	Family members (next of kin, primary contact in EMR, Power of Attorney for Health Care)	6–10 Weeks after death	VA facility where patient received care in the last month of life—inpatient or outpatient	Telephone interview
	Casarett et al, 2010	One family member per patient	Approximately 6 weeks after death	VA acute and long-term care	Telephone interview
	Finlay et al, 2008	Next of kin	Approximately 6 weeks after death	VA medical centers	Telephone interview
	Lu et al, 2010	Family members	Approximately 10 weeks after death	VA medical centers	In-person interview
Family Evaluation of Hospice Care (n¼ 8)	Smith et al, 2011	Family members in the medical record at VA or another family member identified by original informant	Approximately 6 weeks after death	VA medical centers	Telephone interview; Mailed paper
	Connor et al, 2005	Bereaved family members	1–3 Months after death	Hospice	Paper (mailed)
	Mitchell et al, 2007	Bereaved family members	1–3 Months after death	Hospice	Paper (mailed)
	Rhodes et al, 2008	Family members	Not reported	Hospice	Paper (mailed)
	Rhodes et al, 2007	Family member	1–3 Months after death	Hospice	Paper (mailed)

Survey	Citation	Who: Respondent	When: Timing of Survey Administered	Where: Health/Care Context/ Setting	How: Mode of Survey Administration
	Schockett et al, 2005	Family members identified by hospice	3–6 Months after death	Hospice	Mailed paper; telephone interview
	Teno et al, 2004	Informant listed on the death certificate (usually a close family member) or another person identified by informant	Not reported	Last place of care at which the patient spent more than 48 hours	Telephone interview
	Teno et al, 2007	Family members identified by the hospices	1–3 Months after death	Hospice	Paper (mailed)
	York et al, 2009	Family members or caregivers	Not reported	Hospice-affiliated facilities, homes, hospitals, and LTC facilities	Paper (mailed)
Family Satisfaction in the ICU (n¼ 3)	Curtis et al, 2008	Family members	4–6 Weeks after death	University-affiliated ICU	In-person interview; paper (Mailed)
	Gries et al, 2008	Family members	1–2 Months after death	Medical centers	Paper (mailed)
	Lewis-Newby et al, 2011	Family members	4–6 Weeks after death	Medical center/trauma center	Paper (mailed)
Quality of Dying and Death (n¼ 6)	Hales et al, 2012	Bereaved family members	8–10 Months after death	Hospital/cancer center	In-person interview; telephone interview
	Johnson et al, 2006	Next of kin	12–14 Weeks after death	Hospital	Paper (mailed)
	Lewis-Newby et al, 2011	Family member	4–6 Weeks after death	Medical center/trauma center	Paper (mailed)
	Mularski et al, 2004	Family members	4 Months after death	Medical center ICU; VA ICU	In-person interview
	Mularski et al, 2005	Family members	4–12 Months after death	Medical center ICU; VA ICU	In-person interview
	Norris et al, 2007	Family member	Not reported	Geographic locations	In-person interview
Quality of End-of-Life Care and Satisfaction with Treatment (n¼ 3)	Astrow et al, 2007	Patients	Not reported	Cancer center	In-person interview
	Sulmasy et al, 2002a	Patients with do-not-resuscitate (DNR) order; family members	2–7 Days after DNR order	Hospitals	In-person interview
	Sulmasy et al, 2002b	Patients	Not reported	Hospitals	In-person interview
Regional Study of Care for the Dying (RSCD) (n¼ 3)	Fakhoury et al, 1996	Informal caregivers (defined as relatives or close friends/neighbors)	10 Months after death	Health districts	In-person interview; telephone interview
	Fakhoury et al, 1997a	Bereaved carers, relatives, and friends who knew the most about the last year of life	Not reported (cited another paper reporting on RSCD methodology)	Health districts	In-person interview; telephone interview
	Fakhoury et al, 1997b	Informal caregivers/family members who knew about the	10 Months after death	Health districts	In-person interview; telephone interview

Survey	Citation	Who: Respondent	When: Timing of Survey Administered	Where: Health/Care Context/ Setting	How: Mode of Survey Administration
		last year of life			
Sat-Fam-IPC (n¼ 2)	Morita et al, 2002a	Primary caregivers	Not reported	Inpatient palliative care unit	Paper (mailed)
	Morita et al, 2002b	Family members	Within 1 year after death	Inpatient palliative care unit	Paper (mailed)
Views of Informal Carers Evaluation of Services (n¼ 4)	Addington-Hall et al, 2009	Bereaved relative who registered the death	3–9 Months after death	Hospital; inpatient hospice	Paper (mailed)
	Beccaro et al, 2010	Caregivers	100–372 Days after death	Not reported	In-person interview
	Costantini et al, 2005	Nonprofessional caregiver (defined as child, spouse, family, and friend)	100–372 Days after death	Not reported	In-person interview
	Morasso et al, 2008	Nonprofessional caregivers	100–372 Days after death	Not reported	In-person interview

EMR = electronic medical records; LTC = long-term care.