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Review Article

What Aspects of Quality of Life Are Important From Palliative Care Patients' Perspectives? A Systematic Review of Qualitative Research



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Abstract

Context. Despite the availability of numerous tools professing to measure quality of life (QOL) in the palliative care setting, no single instrument includes all patient-valued domains.

Objectives. To identify which aspects of QOL are important from palliative care patients' perspectives, aiding coverage, and content validity evaluation of available tools.

Methods. A systematic review and synthesis of qualitative research was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. ASSIA, CINAHL, Cochrane library, Embase, Medline, PsycINFO, and PubMed were searched from database inception to December 31, 2015. Published, peer-reviewed, English-language articles reporting primary qualitative data investigating QOL domains in adults with a progressive, life-limiting illness were included. Studies a priori exploring a chosen aspect of QOL were not included. Articles scoring ≤ 2 on reporting quality were excluded. Framework synthesis was used to identify key themes across the studies.

Results. Overall, 3589 articles were screened and 24 studies were included. Eight important aspects of QOL were identified: physical; personal autonomy; emotional; social; spiritual; cognitive; healthcare; and preparatory. All but one study discussed spiritual aspects, whereas only six studies mentioned cognitive aspects.

Conclusion. A broad range of domains are important to the QOL of people with life-limiting illnesses receiving palliation. Refinement of measures is needed to help ensure services address issues valued by patients such as preparation for death and aspects of health care provision, elements which are seldom included in currently available preference-based measures used to inform value for money decisions in palliative care. *J Pain Symptom Manage* 2016;52:318–328 © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

End of life, quality of life, hospice, palliative care, review, qualitative, framework synthesis

Introduction

Despite the proliferation of instruments purporting to measure quality of life (QOL) in palliative care, no single instrument comprehensively captures all salient aspects of QOL from the perspectives of people with a life-limiting illness.^{1,2} This is possibly driven by the absence of a universally accepted definition of “quality of life” more generally and the historical development

of the concept across a number of disciplines.³ For example, topics such as existential issues like hope and dignity are missing from the European Organization for Research and Treatment of Cancer Quality of Life 15 items,⁴ one of the most widely used palliative care QOL questionnaires, whereas another key aspect, the ability to finalize personal and financial affairs in preparation for death, is also not explicitly captured by this, nor other commonly used instruments such

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as the Functional Assessment of Chronic Illness Therapy—Palliative Care.^{5,6} In a recent systematic review of palliative care QOL instruments,⁷ the authors concluded that the McGill Quality of Life Questionnaire had the best measurement properties, yet important patient-valued aspects such as quality of care and financial issues are absent from this tool.⁸

The psychometric properties of construct validity, reliability, and responsiveness⁶ are often assessed during the development and validation process of QOL instruments. However, the concept of content validity is less often given explicit consideration.⁹ This property describes the ability of an instrument to measure the concept it was designed to capture.^{10,11} Content can be developed inductively using qualitative research methods, deductively from existing literature and instruments, or using both approaches.¹²

Guidelines on the development of patient-reported outcomes suggest qualitative data derived from a sample of the target population are essential for the rigorous development of the content of such instruments^{11,13} as these data help ensure the final measurement tool is comprehensive and includes relevant patient aspects, improving responsiveness to change.¹² The ability of a QOL instrument to detect clinically important changes is fundamental, particularly when comparing the relative costs and benefits of alternative courses of action in the health care setting. If evaluation measures used in research and clinical practice do not include aspects valued by patients, palliative care and other health professionals may fail to address complex issues such as preparation for death, instead focusing solely on managing physical symptoms. Consequently, this could limit the potential beneficial impact of palliative and end-of-life care on patient-valued outcomes.⁵

There is emerging evidence in the literature to suggest important aspects of QOL may vary across settings.^{14–16} In the palliative care setting and particularly in the last weeks of life, factors such as diagnoses, proximity to death, and broader social changes such as increasingly dispersed families may influence the relative importance of individual QOL domains. Although many palliative care QOL questionnaires were originally designed for populations with advanced cancer, palliative care service provision often includes other life-limiting illnesses such as heart failure, chronic obstructive pulmonary disease, AIDS, and neurological disorders. Alternative aspects of QOL may be relevant for these types of patients. Following news of a terminal diagnosis, financial issues may become more important as death approaches with individuals wishing to secure the future of their loved ones. Furthermore, smaller, more geographically dispersed families, higher divorce rates and changing communities¹⁷ could reduce the availability of informal caregivers, leading to a greater number of people living

on their own with different needs and priorities when compared to those with spousal or familial support.¹⁸

To date, there is no systematic review and synthesis of qualitative data investigating what aspects of QOL are important to people with a progressive, life-limiting illness from their own perspective to inform the evaluation of the coverage and content of palliative care QOL instruments. Albers et al.² reviewed the literature to identify the QOL domains most important to people with life-limiting illnesses. However, the search was not systematic and did not comprehensively capture all relevant evidence from the perspective of patients alone. Shahidi et al.⁸ proposed eight important domains of QOL (physical condition and symptoms; psychological status; existential; relationships and support; quality of care; physical environment and living facilities; hobbies and daily activities; and finances) based on a content analysis of responses to the open-ended question in the Quality of Life in Life-Threatening Illness—Patient version questionnaire. However, participants completed this final question after responding to previous items enquiring about physical, psychological, cognitive, existential, relationships, health care, and environment domains. Consequently, responses may have been influenced by the preceding questions.

The primary aim of this systematic literature review was to determine which aspects of QOL are important from palliative care patients' perspectives, aiding coverage, and content evaluation of tools measuring QOL in the palliative care setting. The secondary aim of the review was to compare and contrast important aspects of QOL according to country of origin, primary diagnosis, living arrangements, and proximity to death in an exploratory analysis.

Methods

The systematic review was conducted and reported according to the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement.¹⁹

Search Strategy and Selection Criteria

A comprehensive search of the literature was conducted from database inception to December 31, 2015 (ASSIA, CINAHL, Cochrane library, Embase, Medline, PsycINFO, and PubMed) to identify relevant published studies meeting the a priori inclusion criteria. The search strategy was informed by published qualitative research search filters^{20–23} and the CareSearch[®] palliative care quality of life topic search filter.²⁴ Key words and MeSH terms included palliative, terminally ill, qualitative, quality of life, and quality of dying (see example, [Appendix](#), available at

jpsmjournals.com). Search terms were selected according to population (palliative), intervention (qualitative interviews or focus groups), and outcome (quality of life).

Published, peer-reviewed, English-language articles reporting primary qualitative data from in-depth or semistructured interviews, or focus group discussions (including mixed-methods studies) explicitly investigating QOL domains in adults with a life-limiting illness receiving palliation were included. For the purposes of this review, investigations into the quality of death or dying and the constituents of a "good death" were included as these studies were considered to represent explorations of QOL at the end of life.

Studies which investigated living with a terminal diagnosis more generally; a priori determined or distinct items and dimensions of QOL such as grief, hope, spirituality, or quality of care; needs; proxy responses; or included a preconceived list of QOL domains or a structured QOL questionnaire administered to participants before the qualitative interview were excluded. In the absence of an explicitly stated palliative care context, articles were included if the study population was identified as "advanced," "terminal," "end of life," or "end-stage" (>50% participants) for cancer and noncancer life-limiting diagnoses.

The titles and abstracts were reviewed by two researchers to assess eligibility for inclusion in the review. Full-text articles were retrieved where the abstract contained insufficient information. If necessary, corresponding authors were contacted by the lead investigator (N. M.) to ascertain whether studies met inclusion criteria, for example, ordering of structured and semistructured questions in the interview process. A third researcher (S. B.) independently reviewed a randomly selected subset of citations (10%), and any disagreement was resolved by discussion among the research team. Agreement between the reviewers was assessed using the Kappa statistic to determine if further duplicate reviewing was required (Kappa <0.4, i.e., fair agreement).²⁵ The reference lists of the included articles were reviewed for additional literature unidentified by the search (pearling).

Quality Assessment

Evaluating the quality of studies in qualitative evidence synthesis remains controversial.²⁶ There is a wide range of possible quality criteria,^{27,28} and there is a lack of consensus regarding which criteria should be applied to determine quality.

Critical appraisal of qualitative research is frequently hampered by inadequate reporting.²⁹ Judgments about methodology, conduct, and trustworthiness can only be made with adequate reporting of

the study and, if aspects are not reported, no assumption can be made as to whether that work has been done. Quality of reporting criteria was considered to foreshadow critical appraisal criteria given the latter relies on the former. Consequently, articles were included if sufficient details were provided to allow quality assessment using Carroll et al.'s reporting quality criteria.²⁹ Studies scoring less than 2 on the four-point scale were excluded, that is, studies that did not report sufficient details about the research question and design, selection of participants, methods of data collection, and methods of analysis. The threshold for exclusion was chosen through discussion among the research team as a means of screening out poorly reported studies.

Data Extraction and Analysis

The following study characteristics were extracted from the articles: publication date, country of origin, diagnosis, sample size, recruitment setting, living arrangements, time until death, method of data collection, type of analysis, and research focus. Verbatim quotations from study participants and themes and findings clearly supported by the study data were analyzed in QSR International's NVivo version 10, 2012 (Doncaster, Australia) using framework synthesis to identify important aspects of QOL.³⁰ When aggregated study findings were presented, for example, patient, informal carer, and nurse interview data, only data attributed to patients' perspectives were extracted for analysis.

Framework synthesis is based on framework analysis and involves five key stages for synthesizing qualitative studies: familiarization with the literature; development of an initial thematic framework; indexing; charting; and mapping and interpretation.^{30,31} Evidence reported in studies is combined to generate a revised conceptual model, a predominantly deductive process. This framework synthesis approach was taken to augment existing inductively developed conceptual models of QOL in palliative care. Secondary thematic analysis³² was used to construct new themes inductively when relevant data from included studies did not translate into preexisting themes.

First, all included articles were read and key ideas, recurrent themes, and issues were noted (familiarization) before initial themes were developed from the notes and study findings (initial thematic framework). The data from each study were then coded in detail and organized using this framework, including matching text and verbatim quotations to themes (indexing and charting). Subthemes were identified and categorized, and new themes were developed when data did not translate into the initial thematic framework. Themes and subthemes were reviewed in light of the research question and the body of data. The coding

framework was then reevaluated and refined (mapping and interpretation) until agreement was reached among the research team. The pattern of themes was compared by key study characteristics (country of origin, primary diagnosis, living arrangements, and time until death) in an exploratory analysis.

Results

Study Selection

The results of the literature search and selection process are summarized in [Figure 1](#). Overall, 3589 citations were identified by the database search after duplicates were removed. Following assessment of the title and abstract, 3372 citations were excluded mainly because determination of QOL domains was not the

explicit focus of the investigation (45.1%) or the study participants did not have a life-limiting illness for which they were receiving palliation (30.0%). Consideration of the full-text articles ($N = 217$) resulted in 24 included articles, all of which met the study reporting assessment criteria threshold (≥ 2). Interrater reliability for included articles between reviewers was moderate ($\text{Kappa} = 0.6$).

Study Characteristics

[Table 1](#) summarizes the key characteristics of the included studies. A complete list of included studies and their individual characteristics are reported in [Table A1](#) (available at jpsmjjournal.com). The studies were published between 1992 and 2015 in 10 countries and were most commonly conducted in the

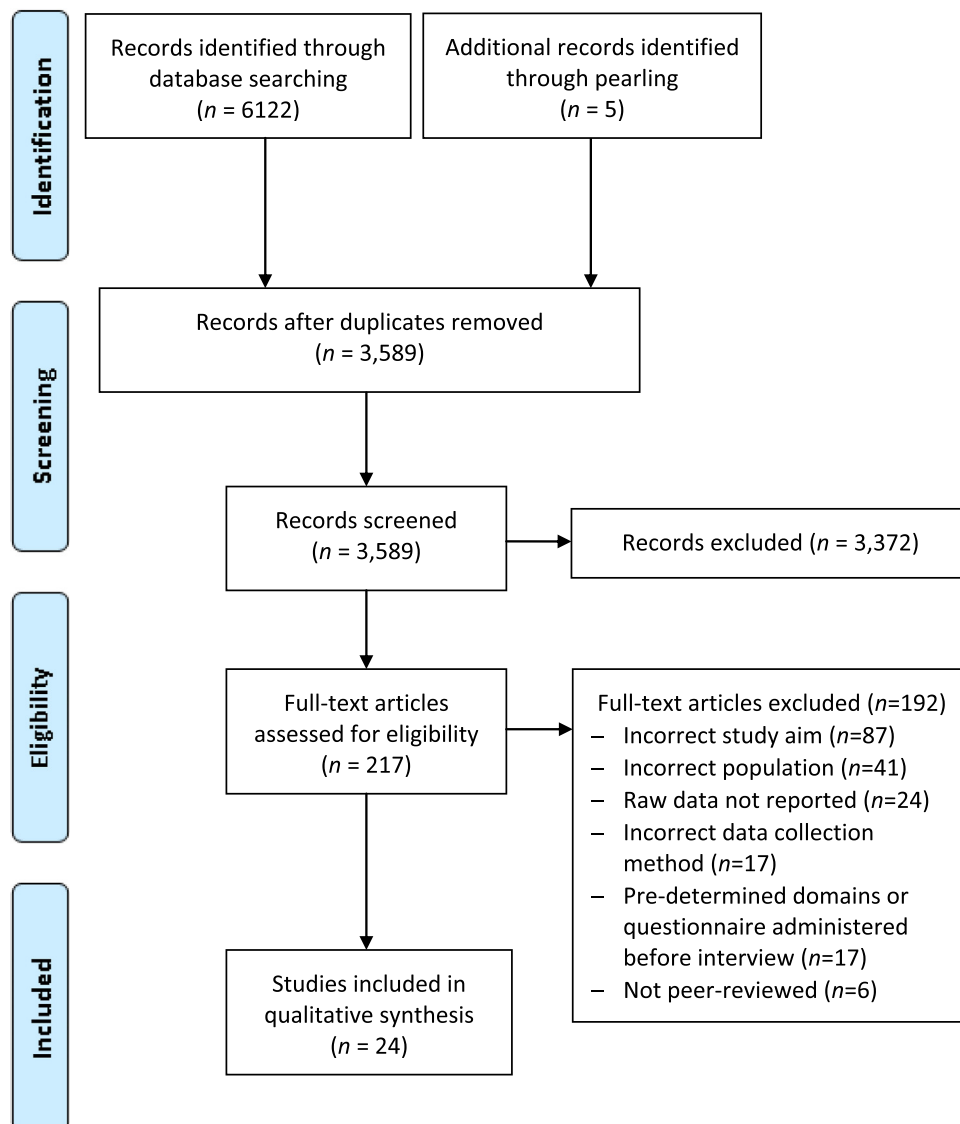


Fig. 1. Study selection process for the systematic review. Adapted from Moher et al.¹⁹

Table 1
Key Characteristics of the Included Studies (N = 24)

Country	Number of Studies	Setting	Number of Studies	Diagnoses	Number of Studies	Focus	Number of Studies	Type of Analysis	Number of Studies
Australia	1	Community	12	Cancer	16	QOL ^a	17	Thematic	6
England	5	Hospital	3	HF	2	GD	7	Content	6
U.S.	6	Hospice	3	AIDS	2			Grounded theory	4
Canada	3	Mixed	6	COPD	1			Coding ^b	3
Germany	1			Mixed	3			Hermeneutic	1
New Zealand	1							IPA	1
Netherlands	2							Not stated	3
South Africa	1								
Sweden	3								
Korea	1								

QOL = quality of life; HF = heart failure; GD = good death; COPD = chronic obstructive pulmonary disease; IPA = interpretative phenomenological analysis.

^aOne study investigated well-being.

^bFurther details about the analytical process were not provided in the publications.

U.S. ($n = 6$), England ($n = 5$), Canada ($n = 3$), and Sweden ($n = 3$). The studies included participants diagnosed with cancer ($n = 16$), heart failure ($n = 2$), AIDS ($n = 2$), chronic obstructive pulmonary disease ($n = 1$), or mixed populations ($n = 3$) and most focused on investigating QOL domains ($n = 17$). Seven studies explored the constituents of a good death. Half of the studies recruited participants from a community setting. Only three studies were conducted in a hospice, although another six studies recruited participants from a mix of settings. Most of the studies used in-depth and semistructured interviews to collect data ($n = 18$), four studies used focus groups, one used interviews and focus groups, and one study chose storytelling. Altogether, 483 individuals from across the studies contributed to the qualitative data analysis.

Aspects Quality of Life Important From Palliative Care Patients' Perspectives

Eight important aspects of QOL were identified following framework synthesis: cognitive; emotional; health care; personal autonomy; physical; preparatory; social; and spiritual. The coding framework, including themes and subthemes, is presented in Table A2 (available at jpsmjournal.com). The analysis indicated intrinsic characteristics such as individual values, personal qualities, characteristics, and attitudes may influence which aspects of QOL are important to individuals.

Table 2 summarizes important aspects of QOL identified by individual studies. Only the studies by Cohen et al.³⁴ and Osborne et al.⁴⁷ included all eight aspects. All but one study reported that spiritual, physical, and social aspects were important, whereas only a quarter

Table 2
Important Aspects of Quality of Life by Individual Included Studies

Study	Cognitive	Emotional	Health Care	Personal Autonomy	Physical	Preparatory	Social	Spiritual
Adorno 2014 ³³								
Carter 2004 ³⁴								
Cohen 2002 ³⁵								
De Jong 2009 ³⁶								
Goldstein 2006 ³⁷								
Gott 2008 ³⁸								
Gourdji 2009 ³⁹								
Greisinger 1997 ⁴⁰								
Jansen van Rensburg 2013 ⁴¹								
Kim 2009 ⁴²								
Locker 2015 ⁴³								
Masson 2002 ⁴⁴								
Melin Johansson 2006 ⁴⁵								
Melin Johansson 2008 ⁴⁶								
Osbourne 2014 ⁴⁷								
Payne 1996 ⁴⁸								
Pierson 2002 ⁴⁹								
Rowland 2014 ⁵⁰								
Sherman 2001 ⁵¹								
Steinhauser 2000 ⁵²								
Stridsman 2015 ⁵³								
Treloar 2009 ⁵⁴								
Vig 2003 ⁵⁵								
Willems 2004 ⁵⁶								

Shaded cells represent important aspects included in the study.

of studies highlighted cognitive aspects. Most studies reported emotional ($n = 20$) and personal autonomy ($n = 19$) aspects. Approximately half of the studies identified aspects of health care provision ($n = 13$), including access, continuity, quality, and place of care as influencers and three quarters ($n = 18$) reported preparatory aspects.

The following sections provide examples from the articles of the identified important aspects of QOL.

Cognitive Aspects. "Being mentally alert"⁴⁹ (p. 590) and having the ability to read and watch television contributed to QOL. Respondents reported a fear of losing cognitive capacity and the detrimental effect this would have on their QOL. "I was really afraid that with the tumour of the brain ... I've always been articulate and that's very important to me, to be well aware of what's going on ..." ³⁵ (p. 53)

Emotional Aspects. Individuals expressed how their emotional state plays an important role in their QOL. Emotions such as sadness, anxiety, despair, frustration, fear, guilt, happiness, and uncertainty were vocalized. "I panic and get frightened when I'm alone and when I don't know what symptoms I will have or how long I will live. I am frustrated because I don't know what will happen to me." ⁴⁰ (p. 152) Others emphasized how essential it is to stay positive. "It sometimes feels hard to keep your spirit up or get on with things ... when you're as old as I am anyway. But it's better to try and find some quality in life instead of going around feeling upset and sad and not wanting to do things." ⁴⁵ (p. 395)

Aspects of Health Care. Aspects of health care included access, coordination, continuity, and quality of care. Having ready access to care when needed helped individuals feel secure. Fewer visits to health care facilities with minimal waiting time improved QOL. Participants highlighted the importance of their relationship with health care staff and the value of consistency, whereas frequent changes in staff members caused participants stress and anxiety. "They were going to switch ... people on you if they could, but I told them either get the same person every time or I don't need anybody at all." ⁴⁹ (p. 53) Staff members' knowledge, experience, and attitudes toward patients had a substantial impact on how the individual was feeling.

The location of health care service provision also was advanced as a notable aspect of QOL. "She [wife] cannot give me the care that you get in a hospital like this, so there is a marked, marked difference between the care I received at home and the care I am receiving here." ⁴⁹ (p. 54) Others valued home-based care and the chance to die at home. "There's

these big horrible windows, and all you can see out of them is sky. I mean it's just horrible, I mean ... here [home] there are the trees, and there's squirrels and there's birds. You know, it's quite pleasant, I mean I'd rather die looking at that view than looking out of [name of hospital] windows. Oh God, it were horrible." ³⁸ (p. 1117)

Aspects of Personal Autonomy. Personal autonomy included facets such as having choice and control. For example, the ability to make choices concerning treatment decisions and daily activities on a palliative care unit gave participants a feeling of control and empowerment. ³⁹ Maintaining independence contributed toward a sense of normalcy, whereas diminishing independence led to loss of dignity and feelings of frustration. Participants stressed how important having control was to their QOL. "My responsibilities toward my life, my body, my decisions—I'm in control of that ... I am the one that will say what I want ... He has given me a tool that will give me QOL till the end, and I think this is a great gift that I have received." ³⁹ (p. 46)

Furthermore, participants felt that retaining their independence reduced the burden placed on others which was a significant aspect of QOL for people with a life-limiting illness (see social aspects). One patient with lung cancer stated, "I have to learn to be dependent now. It's hard for me to lean on other people, and I don't like that. My daughter helps by taking me to get groceries, and my son stays with me during the day, but I really feel like a burden to them. It makes me nervous to become more dependent on them. I feel more and more useless." ⁴⁰ (p. 152)

Physical Aspects. Individuals commented, across the studies, on the importance of physical health, including the ability to get around and adequate symptom control. The negative impact of side effects on QOL also featured. Patients appreciated having the strength to continue doing the activities they enjoyed such as gardening and well-controlled symptoms facilitated continued engagement with such activities. Uncontrolled symptoms such as breathlessness and fatigue substantially impaired QOL. "I wish I had the energy to do the things I used to do ... each day it seems to be less that I can do ... it's just the inability to do what I thought I would do, [what] I would have liked to have done ... I was busy with interesting work—now I can't do anything." ³⁴ (p. 615)

Preparatory Aspects. Preparatory aspects included elements such as handing tasks over to other family members, organizing funeral arrangements, saying goodbye to family and friends, and resolving outstanding personal issues. Participants wanted to

make plans to assist others after their own death. “I have my will written out, who I want invited to the funeral. I have my obituary. That gives me a sense of completion that I don’t have to put that burden on someone else. It’s to prepare myself for it.”⁵² (p. 827) Participants talked about the kind of arrangements they had already made, the way they had prepared themselves and others for their approaching death and their final responsibilities. “We have spoken about so many things ... we have our own home, have a very large garden and are both avid gardeners; now she [wife] has to do it all by herself. And it may sound a bit strange but we have had time to discuss how to do the chores ... It is maybe a bit weird to say, to organize these materialistic things now, but you worry about it. I don’t think I’m the only one who wants to leave everything behind as good as possible.”³⁷ (p. 381)

Social Aspects. Across the studies, participants stressed how critical their relationships with others were to their QOL, including maintaining intimacy with partners. People often voiced their concerns about becoming a burden to others and how they wished to avoid creating hardship for their family and friends. “My family has spent too much money on my anti-cancer therapy. I am worried about their financial burden.”⁴² (p. 162) Feeling like a burden had a negative impact on participants’ QOL.

Retaining social networks, staying connected and having a role to play in society were also highly valued and promoted a sense of normalcy equated to having QOL. As one patient eloquently stated, “Helping you, I help myself.”³⁹ (p. 43) Aspects such as being treated with respect, maintaining dignity, and receiving support from others helped people feel valued, contributing to a sense of self-worth.

Spiritual Aspects. Spiritual themes were reported in all but one of the included articles. Aspects such as hope, comfort, meaning, and purpose were all raised by participants. Having a purpose, some meaning to life was essential to participants’ QOL “My life has a great deal of meaning. I know that I have served my fellow man, and that’s one of the keys to having a happy life.”³⁵ (p. 150)

Organized religion improved the QOL for some participants by providing emotional support and comfort and a sense of community. Others stated how faith and religion were paramount. “We have a lot of church friends, and we feel that prayer has helped us an awfully lot. I don’t think I could have got through without the support of our church friends.”⁵⁵ (p. 1598)

Finally, participants discussed how the environment, indoor, and outdoor, influenced their spiritual well-being and how they appreciated and needed access

to nature. “To be able to go out, to enjoy the trees and the air and the flowers and the colours, and to hear the birds singing, that’s QOL.”⁴⁹ (p. 54)

The Pattern of Themes According to Study Characteristics

The pattern of themes did not appear to differ by diagnosis, living arrangements, or recruitment setting as virtually all themes were reported for each characteristic category (Table A2, available at jpsmjournals.com). Only studies based in the U.S. ($n = 6$), England ($n = 5$), Canada ($n = 3$), and Sweden ($n = 3$) reported themes on cognition. Unfortunately, insufficient mortality data were provided in the studies to compare key themes by proximity to death.

Discussion

The findings from this systematic review and synthesis of qualitative research suggest physical abilities, personal autonomy, emotional state, socializing, spirituality, cognition, health care provision, and preparation for death are important aspects of quality of life for people with a life-limiting illness receiving palliation from their own perspective.

“Spiritual aspects” were reported in all but one of the included studies, affirming the value of this domain to palliative care patients, together with physical and social domains. Cognitive aspects were only reported in a quarter of the studies. However, participants may just have not discussed this aspect of QOL with the researchers in the other studies. Patients in the studies may have assumed they would remain cognitively intact until their death and cognitive impairment may have only been relevant to some or for those closer to death. Furthermore, this finding may have been confounded by study eligibility criteria as participants were required to have sufficient cognitive ability to participate in interviews or focus groups.

All domains, themes, and aspects of QOL described in a recent nonsystematic literature review identifying the QOL domains most important to incurably ill patients² and a content analysis of responses to the open-ended question in the Quality of Life in Life-Threatening Illness—Patient version questionnaire⁸ were identified in the current framework synthesis. Additional elements of health care service provision such as access to, and continuity of care and cognitive and preparatory aspects were also identified as important in this review.

The findings suggest important aspects of QOL may vary across settings as cognitive aspects were only reported in studies conducted in four of the 10 countries. However, this analysis was exploratory and based on small sample sizes. Further research is

needed to support these findings, particularly as study participants may have considered these aspects were important (or not) but may not have discussed them. Insufficient information was provided in the articles to explore patterns of themes by proximity to death, and further investigation is warranted to determine whether important aspects of QOL may vary across the dying trajectory.

Maximizing the QOL of patients facing problems associated with life-threatening illness is the *raison d'être* of palliative care.⁵⁷ Consequently, robust, patient-centered QOL outcome measures are essential for assessing the effectiveness and cost-effectiveness of palliative care health care services and interventions. Patient-centered outcome measures (PCOMs) capture health status and well-being from the patient's perspective and focus on concerns important to the patient.⁵⁸ A recent systematic review on the impact of PCOMs on processes and outcomes of palliative care⁵⁹ concluded these types of measure raise awareness of unmet need, improve recognition of symptoms and communication about QOL, and benefit patients' emotional and psychological QOL. These findings are consistent with systematic reviews from other settings and advocate administering PCOMs in research and clinical practice. Furthermore, if outcome measures used in health care service evaluations, including economic evaluations, do not include those things that matter most to individuals with a life-limiting illness, palliative and health care service provision may fail to adequately address those aspects of care most important to patients and families, limiting the beneficial impact of services at an individual and population level.⁵

The findings from this systematic review provide important evidence for evaluating the coverage and content validity of outcome measures from a patient-centered perspective in the palliative care setting, including generic, preference-based measures of health-related QOL generated from instruments such as the EQ-5D, SF-6D, and HUI3, commonly used to inform public funding decisions.⁶⁰ These measures may not be sufficiently sensitive and responsive to the impacts of palliative care interventions as patient-valued aspects of QOL such as spirituality and preparation for death are missing which could in turn lead to misinformed clinical and policy decisions, inefficient and inequitable allocation of scarce public funds, and missed funding opportunities for valuable palliative care programs.

One possible solution is to develop a condition-specific, preference-based instrument (the Pall-U) to measure and value benefits in palliative care economic evaluations. Although the review findings describe which aspects of QOL are important from palliative care patients' perspectives, further research is needed

to develop a descriptive system and establish the relative importance of the different QOL dimensions.⁶¹ Approaches such as cognitive interviewing⁶² and Q methodology⁶³ could be used to refine the choice and wording of the most important domains. Furthermore, although previous evidence suggests maintaining one's dignity and having financial affairs in order are important aspects to most seriously ill patients,⁶⁴ quantitative techniques such as discrete choice experiments are needed to determine the strength of preference for each QOL domain, and trade-offs individuals are willing to make between the domains to produce a single index of benefit for the condition-specific, preference-based instrument. Two preference-based instruments, the ICECAP-SCM⁶⁵ and POSE⁶⁶ have been recently developed and are more relevant for the palliative and end-of-life care setting due to their content. Further research is needed to validate these measures for informing value for money decisions.

Although such condition-specific, preference-based outcome measures enable comparison of the costs and benefits of alternative courses of action within the palliative setting, broader comparison of palliative care strategies with interventions and health care services in other clinical areas to inform resource allocation is unfeasible because of the lack of a common, comparable metric. Typically, guidelines on conducting economic evaluations to inform societal decision making recommend including a generic, preference-based measure such as EQ-5D values in addition to condition-specific measures to facilitate comparison with other cost-effectiveness results.⁶⁷

Another option is to use multiple outcomes cost-effectiveness analysis in cost-disutility space, a new approach for better informing resource allocation decision making under uncertainty.⁶⁸ This novel methodology enables simultaneously consideration of costs and multiple outcome domains and provides summary measures for comparing the cost-effectiveness of strategies with multiple effects across different disease areas. Using this approach, specific measures for key outcome domains missing from generic, preference-based measures, such as preparation for death,⁶ can be compared alongside EQ-5D values and other important domains such as informal caregiver quality of life⁶⁹ and place of care.⁷⁰

Limitations

Although there is a considerable body of research on QOL in the palliative care and end-of-life settings, far fewer studies report primary qualitative data purely from the patient perspective. Furthermore, only studies explicitly investigating QOL domains in adults with a life-limiting illness receiving palliation were included in this review. Articles about needs

assessment, living with a life-limiting illness, and quality of care were excluded but may have contained pertinent data. Recent guidance on establishing confidence in the output of qualitative research synthesis suggests congruity between the study research questions and objectives promotes dependability of qualitative research synthesis findings.⁷¹ Consequently, to promote optimal similarity in context and methodologically robust qualitative synthesis, studies stating an explicit QOL focus were sought. Although there may be overlap in findings from other studies with related objectives such as “lived experience,” inclusion of these studies in the systematic review could reduce the dependability of the qualitative research synthesis findings. Therefore, following deliberation among the research team, these types of study were excluded from the review for methodological reasons. In addition, books and the gray literature were not included in the search. Consequently, the literature search may not have captured all relevant articles and the findings may not include all key aspects of quality of life important from palliative care patients’ perspectives, particularly given these challenges and difficulties with identifying specific palliative care literature²⁴ and qualitative research. Pearling of reference lists did not identify any additional studies, and therefore, it is likely that the most influential qualitative studies were identified. Furthermore, no new important aspects of QOL were identified from five additional studies identified in an updated search of the literature conducted from April 1, 2014 to December 31, 2015, suggesting data saturation was reached.

Only studies which investigated the broader concept of QOL were included in the review to elicit the issues most important to patients without introducing bias from the interviewer. Studies investigating distinct items or dimensions of QOL such as quality of care or spirituality do not elucidate more broadly what aspects of quality of life are most important to people receiving palliative care because specific, key aspects have already been chosen a priori.

Proxy-reported qualitative data were not included in the review because proxy views may not accurately reflect QOL aspects most important to patients.⁶⁴ Insufficient data were provided in the included studies to determine what proportion of participants were within a few weeks of death. Therefore, aspects of QOL important to people whose death is imminent may not be adequately represented in the analysis.

Synthesizing data from the included studies and devising a framework for aspects of QOL important to people with a life-limiting illness receiving palliation were challenging as analyses were rooted in different theoretical frameworks using diverse conceptual models and researchers were from assorted disciplines with varied backgrounds, particularly evident in

the terminology used within each study. There were also difficulties assigning categories and subthemes to individual, broader themes on important aspects of QOL. Categories and subthemes were classified according to the theme they most naturally represented based on the consensus of the research team. For example, dignity was included under feeling valued, relationship with others and ultimately social aspects but could also be considered an element of emotional well-being. Hence, the coding framework is presented in Table A3 (available at jpsmjournal.com) to demonstrate how the research team categorized the data and to enable other researchers to consider how the categorization might align with their own interpretation.

Conclusion

Cognitive, emotional, physical, preparatory, social, and spiritual domains and personal autonomy and health care provision are important aspects of QOL for people with a life-limiting illness receiving palliation. Further refinement of existing QOL measures used in the palliative care setting is suggested to improve sensitivity. Generic preference-based, health-related QOL measures commonly used to inform public funding decisions do not include all of these domains and may fail to adequately inform value for money decisions about palliative care.

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References

1. Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: a review. *J Public Health Med* 1997;19:193–199.
2. Albers G, Echteld MA, de Vet HC, et al. Content and spiritual items of quality-of-life instruments appropriate for use in palliative care: a review. *J Pain Symptom Manage* 2010;40:290–300.
3. Barofsky I. Can quality or quality-of-life be defined? *Qual Life Res* 2012;21:625–631.
4. Groenvold M, Petersen MA, Aaronson NK, et al. The development of the EORTC QLQ-C15-PAL: a shortened

questionnaire for cancer patients in palliative care. *Eur J Cancer* 2006;42:55–64.

5. McCaffrey N, Currow DC, Eckermann S. Measuring impacts of value to patients is crucial when evaluating palliative care. *J Pain Symptom Manage* 2009;37:e7–e9.

6. McCaffrey N, Skuza P, Breaden K, et al. Preliminary development and validation of a new end-of-life patient-reported outcome measure assessing the ability of patients to finalise their affairs at the end of life. *PLoS One* 2014;9:e94316.

7. Albers G, Echteld MA, de Vet HC, et al. Evaluation of quality-of-life measures for use in palliative care: a systematic review. *Palliat Med* 2010;24:17–37.

8. Shahidi J, Bernier N, Cohen SR. Quality of life in terminally ill cancer patients: contributors and content validity of instruments. *J Palliat Care* 2010;26:88–93.

9. Lasch K, Marquis P, Vigneux M, et al. PRO development: rigorous qualitative research as the crucial foundation. *Qual Life Res* 2010;19:1087–1096.

10. Bannigan K, Watson R. Reliability and validity in a nutshell. *J Clin Nurs* 2009;18:3237–3243.

11. Patrick DL, Burke LB, Gwaltney CJ, et al. Content validity—establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: part 1—eliciting concepts for a new PRO instrument. *Value Health* 2011;14:967–977.

12. Stevens K, Palfreyman S. The use of qualitative methods in developing the descriptive systems of preference-based measures of health-related quality of life for use in economic evaluation. *Value Health* 2012;15:991–998.

13. Reeve B, Wyrwich K, Wu A, et al. ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. *Qual Life Res* 2013;22:1889–1905.

14. Towers A, Yeung P, Stevenson B, et al. Quality of life in indigenous and non-indigenous older adults: assessing the CASP-12 factor structure and identifying a brief CASP-3. *Qual Life Res* 2015;24:193–203.

15. Maree JE, Jansen Van Rensburg JJ. Suitability of quality-of-life outcome measures in palliative care in the South African setting. *Palliat Support Care* 2016;14:118–128.

16. Osborne L, Bindemann N, Noble JG, et al. Different perspectives regarding quality of life in chronically ill and healthy individuals. *Appl Res Qual Life* 2014;9:971–979.

17. Currow DC. Caregivers' three-cornered hats: their tri-cornes. *Palliat Med* 2015;29:485–486.

18. Aoun S, Kristjanson LJ, Currow D, et al. Terminally-ill people living alone without a caregiver: an Australian national scoping study of palliative care needs. *Palliat Med* 2007;21:29–34.

19. Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PloS Med* 2009;6:e1000097.

20. Walters LA, Wilczynski NL, Haynes RB. Developing optimal search strategies for retrieving clinically relevant qualitative studies in EMBASE. *Qual Health Res* 2006;16:162–168.

21. Wilczynski NL, Marks S, Haynes RB. Search strategies for identifying qualitative studies in CINAHL. *Qual Health Res* 2007;17:705–710.

22. McKibbon KA, Wilczynski NL, Haynes RB. Developing optimal search strategies for retrieving qualitative studies in PsycINFO. *Eval Health Prof* 2006;29:440–454.

23. Wong SS, Wilczynski NL, Haynes RB. Developing optimal search strategies for detecting clinically relevant qualitative studies in MEDLINE. *Stud Health Technol Inform* 2004;107:311–316.

24. Sladek R, Tieman J, Fazekas BS, et al. Development of a subject search filter to find information relevant to palliative care in the general medical literature. *J Med Libr Assoc* 2006;94:394–401.

25. Watson PF, Petrie A. Method agreement analysis: a review of correct methodology. *Theriogenology* 2010;73:1167–1179.

26. Orwin EG. Evaluating coding decisions. In: Cooper H, Hedges LV, eds. *The handbook of research synthesis*. New York: Russell Sage Foundation, 1994.

27. Centre for Reviews and Dissemination. *Systematic reviews: CRD's guidance for undertaking reviews in health care*. York, UK: University of York: CRD, 2008:225.

28. Carroll C, Booth A, Lloyd-Jones M. Should we exclude inadequately reported studies from qualitative systematic reviews? An evaluation of sensitivity analyses in two case study reviews. *Qual Health Res* 2012;22:1425–1434.

29. Carroll C, Booth A. Quality assessment of qualitative evidence for systematic review and synthesis: is it meaningful, and if so, how should it be performed? *Res Synth Methods* 2014;6:149–154.

30. Dixon-Woods M. Using framework-based synthesis for conducting reviews of qualitative studies. *BMC Med* 2011;9:39.

31. Ritchie J, Spencer L. *Qualitative data analysis for applied policy research. The qualitative researcher's companion*. Thousand Oaks, CA: SAGE Publications, Inc., 1994.

32. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77.

33. Adorno G, Brownell G. Understanding quality-of-life while living with late-stage lung cancer: an exploratory study. *J Soc Work End Life Palliat Care* 2014;10:127–148.

34. Carter H, MacLeod R, Brander P, et al. Living with a terminal illness: patients' priorities. *J Adv Nurs* 2004;45:611–620.

35. Cohen SR, Leis A. What determines the quality of life of terminally ill cancer patients from their own perspective? *J Palliat Care* 2002;18:48–58.

36. De Jong JD, Clarke LE. What is a good death? Stories from palliative care. *J Palliat Care* 2009;25:61–67.

37. Goldsteen M, Houtepen R, Proot IM, et al. What is a good death? Terminally ill patients dealing with normative expectations around death and dying. *Patient Educ Couns* 2006;64:378–386.

38. Gott M, Small N, Barnes S, et al. Older people's views of a good death in heart failure: implications for palliative care provision. *Soc Sci Med* 2008;67:1113–1121.

39. Gourdji I, McVey L, Purden M. A quality end of life from a palliative care patient's perspective. *J Palliat Care* 2009;25:40–50.
40. Greisinger AJ, Lorimor RJ, Aday LA, et al. Terminally ill cancer patients: their most important concerns. *Cancer Pract* 1997;5:147–154.
41. Jansen van Rensburg JJ, Maree JE, van Belkum C. Quality of life from the perspective of the palliative care patient in a resource-poor community in South Africa. *Palliat Support Care* 2013;11:21–28.
42. Kim SH, Choi YS, Lee J, et al. Reliability and validity of the Hospice Quality of Life Scale for Korean cancer patients. *J Pain Symptom Manage* 2009;37:156–167.
43. Locker LS, Lubbe AS. Quality of life in palliative care: an analysis of quality-of-life assessment. *Prog Palliat Care* 2015;23:208–219.
44. Masson JD. Non-professional perceptions of 'good death': a study of the views of hospice care patients and relatives of deceased hospice care patients. *Mortality* 2002;7: 191–209.
45. Melin-Johansson C, Axelsson B, Danielson E. Living with incurable cancer at the end of life—patients' perceptions on quality of life. *Cancer Nurs* 2006;29:391–399.
46. Melin-Johansson C, Odling G, Axelsson B, et al. The meaning of quality of life: narrations by patients with incurable cancer in palliative home care. *Palliat Support Care* 2008;6:231–238.
47. Osborne TR, Ramsenthaler C, de Wolf-Linder S, et al. Understanding what matters most to people with multiple myeloma: a qualitative study of views on quality of life. *BMC Cancer* 2014;14:496.
48. Payne SA, Langley-Evans A, Hillier R. Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. *Palliat Med* 1996;10:307–312.
49. Pierson CM, Curtis JR, Patrick DL. A good death: a qualitative study of patients with advanced AIDS. *AIDS Care* 2002;14:587–598.
50. Rowland C, Danson SJ, Rowe R, et al. Quality of life, support and smoking in advanced lung cancer patients: a qualitative study. *BMJ Support Palliat Care* 2014;0:1–8.
51. Sherman DW. The perceptions and experiences of patients with AIDS: implications regarding quality of life and palliative care. *J Hosp Palliat Nurs* 2001;3:7–16.
52. Steinhauser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. *Ann Intern Med* 2000;132:825–832.
53. Stridsman C, Zingmark K, Lindberg A, et al. Creating a balance between breathing and viability: experiences of well-being when living with chronic obstructive pulmonary disease. *Prim Health Care Res Dev* 2015;16:42–52.
54. Treloar C, Brener L, Butow P, et al. Identifying the needs and quality of life experiences of advanced non-small cell lung cancer patients and their carers. *Aust J Cancer Nurs* 2009;10:23–28.
55. Vig EK, Pearlman RA. Quality of life while dying: a qualitative study of terminally ill older men. *J Am Geriatr Soc* 2003;51:1595–1601.
56. Willems DL, Hak A, Visser F, et al. Thoughts of patients with advanced heart failure on dying. *Palliat Med* 2004;18: 564–572.
57. Palliative Care Australia. Standards for providing quality palliative care for all Australians. Deakin West, ACT, Australia: Palliative Care Australia, 2005.
58. Carr AJ, Higginson IJ. Are quality of life measures patient centred? *BMJ* 2001;322:1357–1360.
59. Etkind SN, Daveson BA, Kwok W, et al. Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review. *J Pain Symptom Manage* 2015;49: 611–624.
60. Marra CA, Woolcott JC, Kopec JA, et al. A comparison of generic, indirect utility measures (the HUI2, HUI3, SF-6D, and the EQ-5D) and disease-specific instruments (the RAQoL and the HAQ) in rheumatoid arthritis. *Soc Sci Med* 2005;60:1571–1582.
61. Brazier J, Ratcliffe J, Tsuchiya A, Saloman J. Measuring and valuing health benefits for economic evaluation. Oxford: Oxford University Press, 2007.
62. Willis GB. Cognitive interviewing: A tool for improving questionnaire design. Thousand Oaks, CA: Sage Publications Inc., 2005.
63. Baker R, Wildman J, Mason H, Donaldson C. Q-ing for health—a new approach to eliciting the public's views on health care resource allocation. *Health Econ* 2014;23: 283–297.
64. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284: 2476–2482.
65. Sutton EJ, Coast J. Development of a supportive care measure for economic evaluation of end-of-life care using qualitative methods. *Palliat Med* 2014;28:151–157.
66. Dzingina MD, Higginson IJ, McCrone P, Murtagh F, BuildCARE. Development of a preference-based outcome measure for use in economic evaluations of palliative care services. Proceedings of the European Association for Palliative Care 14th World Congress May 8-10, 2015, Copenhagen, Denmark. Newmarket, UK: Eur J Palliat Care 2015, May Abstract Number P1–P069.
67. Brazier JE, Rowen D, Mavranetzouli I, et al. Developing and testing methods for deriving preference-based measures of health from condition-specific measures (and other patient-based measures of outcome). *Health Technol Assess* 2012;16:1–114.
68. McCaffrey N, Agar M, Harlum J, et al. Better informing decision making with multiple outcomes cost-effectiveness analysis under uncertainty in cost-disutility space. *PLoS One* 2015;10:e0115544.
69. McCaffrey N, Cassel JB, Coast J. Bringing the economic cost of informal caregiving into focus. *Palliat Med* 2015;29: 866–867.
70. Agar M, Currow DC, Shelby-James TM, et al. Preference for place of care and place of death in palliative care: are these different questions? *Palliat Med* 2008;22:787–795.
71. Munn Z, Porritt K, Lockwood C, et al. Establishing confidence in the output of qualitative research synthesis: the ConQual approach. *BMC Med Res Methodol* 2014;14:1–7.

Appendix
Search Strategy (PubMed Example)

1	Qualitative research Qualitative Research [MeSH Terms] OR Qualitative [text word] OR Interview [text word] OR focus group [MeSH Terms] OR "focus group" [text word]	282,793
2	Palliative care and quality of life ^a (quality of life[mh] AND (advance care planning[mh] OR attitude to death[mh] OR bereavement[mh] OR terminal care[mh] OR hospices[mh] OR life support care[mh] OR palliative care[mh] OR terminally ill[mh] OR death[mh:noexp] OR palliat ^a [tw] OR hospice ^a [tw] OR terminal care[tw] OR 1049-9091[is] OR 1472-684X[is] OR 1357-6321[is] OR 1536-0539[is] OR 0825-8597[is] OR 1557-7740[is] OR 1552-4264[is] OR 1478-9523[is] OR 1477-030X[is] OR 0749-1565[is] OR 0742-969X[is] OR 1544-6794[is] OR 0941-4355[is] OR 1873-6513[is] OR 0145-7624[is] OR 1091-7683[is] OR 0030-2228[is])) OR ((quality of life[tw] OR QoL[tw]) AND (advance care plan ^a [tw] OR attitude to death[tw] OR bereavement[tw] OR terminal care[tw] OR life supportive care[tw] OR terminally ill[tw] OR palliat ^a [tw] OR hospice ^a [tw] OR 1049-9091[is] OR 1472-684X[is] OR 1357-6321[is] OR 1536-0539[is] OR 0825-8597[is] OR 1557-7740[is] OR 1552-4264[is] OR 1478-9523[is] OR 1477-030X[is] OR 0749-1565[is] OR 0742-969X[is] OR 1544-6794[is] OR 0941-4355[is] OR 1873-6513[is] OR 0145-7624[is] OR 1091-7683[is] OR 0030-2228[is]) NOT Medline[sb])	10,580
3	Quality of death "quality of death" [text word] OR "quality of dying" [text word] OR QOD [text word] OR "good death" [text word] OR "bad death" [text word]	916
4	English language English [la]	21,087,748
5	1 AND (2 OR 3) AND 4	820

^aCareSearch[®] Palliative Care PubMed Quality of Life search (<http://www.caresearch.com.au/caresearch/tabid/1741/Default.aspx>).

Table A1
 Characteristics of the Included Studies (N = 24)

Lead Author	Publication Year	Country	Sample Size	Recruitment Setting	Patient Population			
					Age, Yrs (%)	Gender, M:F	Ethnicity (%)	Diagnosis
Adorno ³³	2014	U.S.	12	H, Hp, OP	55–64 (25) 65–74 (50) 75+ (25)	12:0	African American (17), Caucasian (75), >1 race (8)	Cancer
Carter ³⁴	2004	NZ	10	H, IP, OP	61–77 (80) <50 (20)	3:7	Anglo-European descent	Cancer
Cohen ³⁵	2002	Canada	60	H, PCU	Mean 68 range 53–86	20:40	NS	Cancer
De Jong ³⁶	2009	Canada	3	H, IP, OP	60–70 (33) 70–80 (67)	1:2	NS	Cancer
Goldsteen ³⁷	2006	Netherlands	13	H	Mean 64.6 range 39–83	10:3	NS	Cancer
Gott ³⁸	2008	England	28	GP	<75 (43) 60–75 (57)	21:19	NS	Heart failure Cancer
Gourdji ³⁹	2009	Canada	10	PCU	Mean 58 range 29–79	5:5	NS	Cancer
Greisinger ⁴⁰	1997	U.S.	74	H, Hp, IP, OP	NS	NS	NS	Cancer
Jansen van Rensburg ⁴¹	2013	South Africa	10	H, OP	30–9 (20), 40–9 (20), 50–9 (40), 60–9 (10), 70–9 (10)	2:8	NS	Mixed
Kim ⁴²	2009	Sweden	5	Hp	Median 65 range 54–76	2:3	NS	Cancer
Locker ⁴³	2015	Germany	3	PCU	55, 65, and 86 yrs	1:2	NS	Cancer
Masson ⁴⁴	2002	Korea	19	Hp	NS	NS	NS	Cancer
Melin ⁴⁵	2006	England	10	H	Mean 61 range 45–78	4:6	NS	Cancer
Melin ⁴⁶	2008	Sweden	8	H	Median = 56 range 35–83	6:2	NS	Cancer
Johansson ⁴⁶ Osbourne ⁴⁷	2014	England	20 ^a	C, Hp, IP, OP	Median 66 range 41–78	10:10	White British (65), white other (5), black African/ Caribbean (25), other (5)	Cancer
Payne ⁴⁸	1996	England	18	PCU	Mean 66 range 30–81	9:9	NS	Cancer
Pierson ⁴⁹	2002	U.S.	35	C	Mean 41	32:2	Non-Hispanic white (69), African American (9), Hispanic (11), Asian or Pacific Islander (6), other (6)	AIDS

Rowland ⁵⁰	2014	England	9	OP	Mean 66 range (57–73)	6:3	NS	Cancer
Sherman ⁵¹	2001	U.S.	17	IP	Mean 43 range 30–66	14:2	Caucasian (53), African American (18), Hispanic (18), mixed ethnic (12)	AIDS
Steinhauser ⁵²	2000	U.S.	14	OP	NS	NS	NS	Cancer, AIDS
Stridsman ⁵³	2015	Sweden	10	C	Mean 68 range 62–77	5:5	NS	COPD
Treloar ⁵⁴	2009	Australia	22	IP	Mean 64 range 37–83	17:5	NS	Cancer
Vig ⁵⁵	2003	U.S.	26	OP	Cancer, mean 71, range 52–86 CHD, mean 71, range 52–86	NS	Caucasian Cancer (50), Caucasian CHD (31), African American CHD (19)	Cancer, CHD (50/50)
Willems ⁵⁶	2004	Netherlands	31	OP	Mean 72 range 46–88	23:8	NS	Heart failure

H = home; Hp = hospice; OP = outpatient clinics; NZ = New Zealand; IP = inpatient admission; PCU = palliative care unit; NS = not stated; GP = general practice; C = community; CHD = coronary heart disease.
^aSemistructured qualitative interviews only.

Table A2
Important Aspects of Quality of Life by Included Study Key Characteristics

Characteristic	Aspect							
	Cognitive	Emotional	Health Care	Personal Autonomy	Physical	Preparatory	Social	Spiritual
Primary diagnosis								
Cancer (<i>n</i> = 16)								
Mixed (<i>n</i> = 3)								
AIDS (<i>n</i> = 2)								
HF (<i>n</i> = 2)								
COPD (<i>n</i> = 1)								
Country								
U.S. (<i>n</i> = 6)								
England (<i>n</i> = 5)								
Canada (<i>n</i> = 3)								
Sweden (<i>n</i> = 3)								
Netherlands (<i>n</i> = 2)								
Australia (<i>n</i> = 1)								
Germany (<i>n</i> = 1)								
Korea (<i>n</i> = 1)								
NZ (<i>n</i> = 1)								
South Africa (<i>n</i> = 1)								
Living arrangements								
Not stated (<i>n</i> = 12)								
Mixed (<i>n</i> = 11)								
Partner (<i>n</i> = 1)								
Setting								
Community (<i>n</i> = 12)								
Hospice (<i>n</i> = 3)								
Hospital (<i>n</i> = 3)								
Mixed (<i>n</i> = 6)								

Shaded cells represent important aspects included in the study with the key characteristic.
HF = heart failure; COPD = chronic obstructive pulmonary disease; NZ = New Zealand.

Table A3
Categories, Subthemes, and Themes

Theme	Subtheme	Category
1. Cognitive		
2. Emotional	Anxiety	
	Depression	
3. Health care	Access to care	Safety
	Continuity of care	
	Place of care	
	Quality	Information
4. Personal autonomy	Independence	Choice
		Control
5. Physical	Mobility	
	Symptoms	Appetite
		Breathlessness
		Dizziness
		Energy
		Fatigue
		Hearing loss
		Memory loss
		Nausea
		Pain
		Poor balance
		Rashes
		Side effects
6. Preparatory	Financial	
	Funeral	
	Resolution	
	Say goodbye	
7. Social	Normalcy	
	Relationship with others	Burden
		Communication
		Family
		Feeling valued
	Friends	
	Loneliness	
	Relationships	Intimacy
	Role	
8. Spiritual	Acceptance	Adjustment
		Peace
	Altruism	
	Attitude	
	Connectedness	
	Environmental	Indoors
		Outdoors
	Existential	Comfort
		Distress
		Expectation
		Fear
		Hope
		Loss
		Meaning
		Purpose
		Strength
		Suffering
		Uncertainty
	Individual	
	Religion	Faith
	Security	
	Values	