Systematic Literature Review

Preferences for Palliative and End-of-Life Care: A Systematic Review of Discrete Choice Experiments

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A B S T R A C T

Objectives: Understanding what matters most to patients and their caregivers is fundamental to delivering high-quality care. This systematic review aimed to characterize and appraise the evidence from discrete choice experiments eliciting preferences for palliative care.

Methods: A systematic literature search was undertaken for publications up until August 2022. Data were synthesized narratively. Thematic analysis was applied to categorize attributes into groups. Attribute development, frequency, and relative importance were analyzed. Subgroup analyses were conducted to compare outcomes between patient and proxy respondents.

Results: Seventeen studies spanning 11 countries were included; 59% of studies solely considered preferences for patients with cancer. A range of respondent groups were represented including patients (76%) and proxies (caregivers [35%], health providers [12%], and the public [18%]). A total of 117 individual attributes were extracted and thematically grouped into 8 broad categories and 21 subcategories. Clinical outcomes including quality of life, length of life, and pain control were the most frequently reported attributes, whereas attributes relating to psychosocial components were largely absent. Both patients and proxy respondents prioritized pain control over additional survival time. Nevertheless, there were differences between respondent cohorts in the emphasis on other attributes such as access to care, timely information, and low risk of adverse effects (prioritized by patients), as opposed to cost, quality, and delivery of care (prioritized by proxies).

Conclusions: Our review underscores the vital role of pain control in palliative care; in addition, it shed light on the complexity and relative strength of preferences for various aspects of care from multiple perspectives, which is useful in developing personalized, patient-centered models of care for individuals nearing the end of life.

Keywords: discrete choice experiments, palliative care, relative attribute importance, systematic review, trade-offs.

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Introduction

Key to providing high-quality care at the end of life is an understanding of what is most important to patients and their family caregivers. Patients nearing the end of life can be faced with complex and at times difficult choices about the type of care they would like to receive. In addition to survival time, choices may be influenced by considerations around quality of life (QoL), pain management, time available to spend with loved ones, and a preference for time and place of death.[1-8] In some situations, patients may experience a loss of capacity for decision making, requiring family caregivers to act as surrogate decision makers.[9]

Discrete choice experiments (DCEs) are a robust survey methodology to elicit and quantify stated preferences and explore trade-offs between the attributes (characteristics) of 2 or more alternative hypothetical scenarios.[10,11] They are based on Lancaster's theory that goods and services can be described by their essential characteristics, and the value that an individual places on a particular good or service can therefore be derived from the given combination of these characteristics.[12] This evidence can provide important insight into what matters most to patients, in situations where difficult or complex trade-offs need to be made.

Although systematic reviews of DCEs have been conducted in various clinical domains,[13-15] the field of palliative care has not yet seen a comprehensive synthesis or appraisal of the available evidence. This study aimed to fill this gap by reviewing and comparing studies that use DCEs to elicit preferences for palliative care.

Methods

The protocol for this systematic review was registered with the International Prospective Register of Systematic Reviews (reference: CRD42022302133). We have reported our findings in

accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement.[16]

Systematic Literature Search

A preliminary scoping search was performed to identify appropriate search terms and the type of studies that were likely to be available. The research team discussed and approved the list of key search terms, which were subsequently reviewed by a research librarian at the Queensland University of Technology. The search included terms relating to (1) DCE study designs and (2) end-of-life or palliative care. Search terms for DCE study designs were based on previous reviews including de Bekker-Grob et al[17] and Clark et al,[18] whereas terms for end-of-life care have included all relevant MeSH terms. The full electronic search strategies for all included databases can be found in Appendix Table 1 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005.

The final search was executed in May 2022, using database-tailored search terms in 6 electronic databases (PubMed, Embase, Web of Science, CINAHL, EconLit, and APA PsycINFO). To ensure literature search saturation, a keyword search of Google Scholar was conducted, as well as forward and backward citation checking of all included articles.

Eligibility Criteria

Studies were included if they met the following criteria:

- *Study design and setting*: empirical research studies eliciting stated preferences using a DCE design. There were no restrictions placed on type of respondent (eg, patients, caregivers, clinicians, or the public), study setting, language, or time of publication.
- *Intervention*: studies focusing on palliative care, including end-of-life care. We adopted the definitions of "end of life" and "end-of-life care" used by the Australian Commission on Safety and Quality in Health Care[19] with full definitions provided in Appendix Table 2 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005.
- *Outcomes*: studies reporting experimental design, preferences, or attribute rankings (elicited using DCEs) for palliative and end-of-life care.

Studies were excluded if they were:

- Editorials, review papers, conference proceedings/abstracts, letters, comments/opinions, books, and gray literature.
- DCE studies eliciting preferences specific to decisions around intensive care interventions (eg, life support) and voluntary assisted dying or euthanasia. These types of decisions were considered out of scope for this review, where the focus was on palliative models of care.

Study Identification and Selection

Database results were exported to an EndNote (Version 22; Clarivate Analytics) library where duplicates were removed. The remaining articles were exported to Rayyan Intelligent Systematic Review software (https://www.rayyan.ai/) for screening. Screening of eligible studies was conducted in 2 steps: initial screening was performed based on article titles and abstracts to check for inclusion eligibility and marked "include," "exclude," or "unsure"; then, further in-depth screening was undertaken by reviewing full-text copies of each publication. After each stage, the 2 authors (M.K. and Q.X.) independently screened compared results, with any remaining discrepancies discussed with a third author (H.E.C.) for a final decision.

Data Extraction

Data extraction was performed using a customized template in Microsoft Excel (Microsoft Corporation) developed in alignment with the research aims and informed by previously published systematic reviews of DCEs.[7,8,20,21] Extracted data spanned 4 key categories: study characteristics, participant characteristics, attribute information, and study findings. A full list of data fields that were extracted is provided in Appendix Table 3 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005. Data extraction was performed by 2 reviewers (Q.X. and M.K.) and the results were then verified by a third reviewer (H.E.C.). Regular meetings between reviewers were held to discuss any queries or issues arising during the extraction and to harmonize interpretation of the extraction template. A full version of the data extraction file is available upon request.

Quality Appraisal

A risk of bias assessment of the included articles was conducted using a checklist specifically designed for DCEs by Lancsar and Louviere.[22] A "not reported" response to the signaling questions of each domain was considered when insufficient data were described to permit a judgment.[23] This assessment was independently performed by 2 reviewers (H.E.C. and Q.X.), and any discrepancies were resolved by discussion. For studies published after 2011, we assessed whether adherence to the ISPOR—The Professional Society for Health Economics and Outcomes Research 2011 checklist was explicitly noted within the article.[24]

Data Analysis

Data were collated and synthesized using narrative and descriptive summaries. No attempt at meta-analysis was made given the heterogeneity across included studies. Consistent with the aims of this review, detailed consideration was given to attribute development, significance, and relative importance.

Attributes across the studies were thematically classified into categories and subcategories to enable more comprehensive synthesis of evidence across studies. The classification process was informed by previous DCE studies.[8,20,25,26] A set of predefined attribute categories included (1) clinical outcomes, (2) service quality, (3) service delivery, (4) psychosocial support, (5) communication, (6) financial outcomes, (7) service availability, and (8) psychological outcomes. Subcategories were further specified following data extraction using inductive thematic analysis.

The overall importance of attributes was assessed in terms of the relative attribute importance scores[27-29] as well as using willingness-to-pay (WTP) estimates where available.[30,31] Where studies did not explicitly state the importance or ranking of attributes, the "range method" recommended by the ISPOR Conjoint Analysis Good Research Practices Task Force was used to infer the relative importance of attributes.[32] This method involved estimating the difference between the highest and the lowest level coefficients reported within each attribute-specific level range. The overall relative importance across all attributes was then calculated by dividing this range by the sum of all included attribute level ranges.[7,20] In principle, attributes with a greater distance between the most and least preferred level are relatively more important than the other included attributes, given the range of included levels.

Descriptive subgroup analyses were conducted based on types of respondent perspective: patient versus nonpatient (proxy),

with proxy perspectives including caregivers, healthcare providers, and the public and country level (high-income vs lower-middle-income countries).

Results

Eligible Studies

The electronic database search yielded a total of 2673 records, from which 1115 duplicates were removed (Fig. 1). Of the remaining 1558 records, 1397 were excluded in the title/abstract screening. Five additional records were identified through hand searching with 3 eligible for full-text screening. After a review of the full text of the remaining 167 records, a total of 17 studies were included.[27-31,33-44]

Characteristics of the Included Studies

The included articles were published between 2005 and 2022, with 82% published between 2014 and 2022 (Table 1). Studies included participants from 11 different countries. Seven of these studies (41%) included a solely Europe-based population (United Kingdom [n = 3],[33,39,44] Germany [n = 2],[36,41] Spain [n = 1],[37] and Portugal [n = 1][40]), with the other studies originating elsewhere from Asia (Singapore [n = 2][30,31] and China [n = 2][34,42]), Oceania (Australia [n = 3][28,35,38]), and North America (United States [n = 1][29] and Canada [n = 1][43]), and 1 study including participants from multiple countries including the United Kingdom, Singapore, India, Kenya, and United States.[27] After accounting for studies with multiple respondent groups, there were 21 separate country-specific populations, of which only 4 (19%) were in low- to middle-income settings.

All studies focused on deriving preferences for adult participants, except for Boyden et al[29] where the DCE was focused on parents' preferences for their children younger than 25 years. More than half of included studies (n = 10, 59%) solely considered patients with cancer. Patient respondents were considered in 13 of 17 articles (76%),[30,31,33-41,43,44] of which 3 studies (23%) reported that individuals with cognitive impairment were excluded,[30,31,42] and the remaining 10 studies not reporting on cognitive status. Proxy respondent samples were included in 10 articles (59%)[27-31,37,38,40,42,43] and comprised caregivers, healthcare providers, or the general population.[27-29,42] Six studies (35%) were conducted in more than 1 population, including combinations of patients and caregivers (n = 3, 18%),[31,38,40] patients and healthcare providers (n = 1, 6%),[37] patients and the general population (n = 1, 6%),[30] and patients, healthcare providers, and the general population (n = 1, 6%).[43] Of note, low- to middle-income countries generally adopted proxies as opposed to patient cohorts when generating preferences. Overall, 27 separate DCE results were extracted based on the respondent perspective (patient, 44%; proxies, 56%).

Identification and Selection of Attributes and Levels

The total number of attributes included per DCE varied from 3 to 20 (mean, 6.9; median, 6), with the mean levels per attribute typically ranging from 2 to 4 levels (n = 14, 82%). All studies reported the use of a literature review to inform the development of attributes and levels, with approximately half of the studies (n = 8, 47%) also applying qualitative research methods. Qualitative methods most commonly took the form of patient interviews or focus groups (n = 9, 53%) and clinical expert consultation (n = 8, 47%).

Figure 1. Flow of studies into the systematic review for narrative synthesis, informed by PRISMA guidelines.
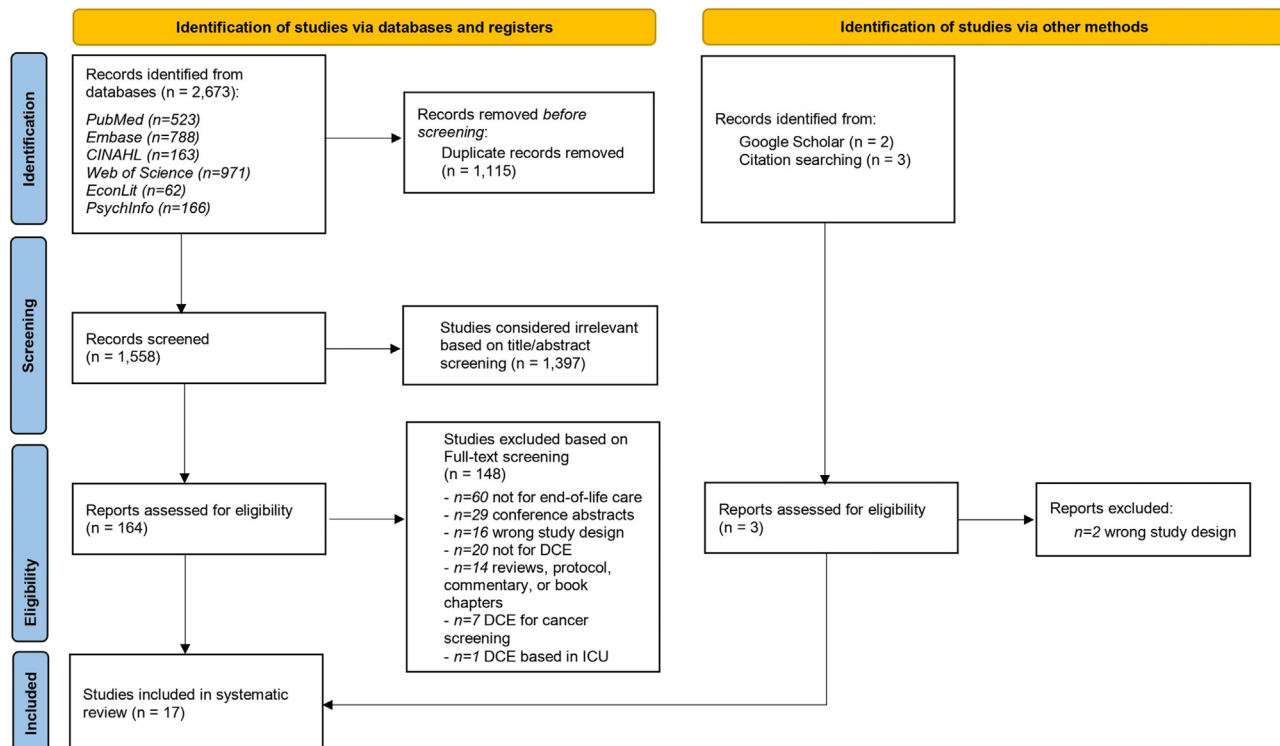

PRISMA indicates Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Table 1. Study characteristics.

Characteristics	Overall (N = 17)
Year of publication	
2005-2007	1
2008-2010	1
2011-2013	1
2014-2016	3
2017-2019	3
2020-2022	8
Source of publication	
Palliative care journals	3
Health economics journals	1
Other clinical journals	11
Other public health/epidemiology journals	2
Country*	
UK	3
Singapore	2
Australia	3
Germany	2
China	2
USA	1
Spain	1
Canada	1
Portugal	1
Multicountry (UK, Singapore, Kenya, India, and USA)	1
Continent*	
Europe	8
Asia	6
America	3
Australia	3
Africa	1
Country level*	
High-income countries	17
Low- to middle-income countries	4
Responder type	
Patient	7
Caregiver	2
General public	2
Patient + caregiver	3
Patient + general public	1
Patient + healthcare provider	1
Patient + healthcare provider + caregiver	1
Patient group	
Patients with cancer entirely	10
Patients with cancer (> 50%)	2
Life-limiting illness[†]	4
Not clear	1
Sample size	
Mean	432
< 100	6
100-500	7
500-1000	1
> 1000	3
Response rate	
< 60%	3
60%-80%	7
80%	3
Not clear	4
Age group	
Adults	*16*
Children or adolescents < 25 years	*1*

Table 1. Continued

Characteristics	Overall (N = 17)
Survey administration method	
Self-completed (post)	1
Self-completed (online)	6
Interviewer administered/in person	9
Not clearly reported	1
Attribute selection process*	
Literature research/review	17
Expert consultation	9
Focus group or patient interviews	8
Number of attributes	
3	5
4	1
5	1
6	3
7	3
7	3
7	3
> 7	4
Mean levels per attribute	
0-2	1
2-4	14
4-6	1
6-8	1
Number of choices sets	
< 36	8
37-64	3
> 64	3
Not clearly reported	3
Number of choices per respondent	
8 or less choices	9
9-16 choices	6
Not clearly reported	2
Number of alternatives	
2	12
3	4
Not clearly reported	1
Analysis model*	
Mixed logit model	5
Probit model	2
Multinomial logistic regression	5
Conditional logit model	1
Latent-class analysis	1
Cumulative link model	1
Not clearly reported	1

*Some studies fall into multiple categories; thus, N > 17. Proxy perspective includes the perspectives from carers, healthcare providers, or the general population.
[†]Specific clinical conditions are not reported.

Attribute Classification

In total, 117 individual attributes were reported. A summary of the attribute classification analysis is presented in Table 2.

Of the 8 attribute categories, clinical outcomes (covering QoL, pain management, adverse effect, and length of life) were the most common, appearing in 70% of studies (n = 12) (Fig. 2A). Service availability attributes (including access to care) were also frequently included, occurring at least once in 10 studies (59%). Other commonly included attribute categories included service delivery (n = 9; 53%), financial outcomes (n = 8; 47%), and communication (n = 6; 35%). Attributes within the psychosocial

support and psychosocial outcomes were least commonly considered (n = 3, 17%).

Of the 21 subcategories, length of life and access to care were the most frequent, appearing in 59% of studies (n = 10) (Fig. 2B). Other commonly reported attribute subcategories across studies included cost (47%), timely information (35%), QoL (29%), pain control (29%), adverse effects (29%), and place of death (29%).

Proportion of attribute subcategories among all attribute preference estimates

The proportion of attribute subcategories considering multiple respondent perspectives and multicountries that considered in several studies is presented in Table 3. Overall, 190 individual attribute preferences were extracted (Appendix Table 4 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005). Length of life (10%), quality to care (10%), cost of care (9%), access to care (8%), and timely information (8%) were the most frequently reported attribute subcategories. The frequency of individual attributes varied by respondent perspective or country level. Length of life (13%), access to care (16%), cost of care (11%), and QoL (10%) were most frequently reported subcategories in DCEs conducted from patient perspective, whereas quality of care (16%) and emotional support (13%) were more commonly reported in studies using proxy respondents. Length of life (10%), access to care (10%), and cost of care (9%) were the most frequently reported attribute subcategories in studies from high-income countries, whereas quality of care (17%), cost of care (11%), and emotional support (11%) were the most frequent from lower-middle-income countries.

Significance of Attributes

All but 2 studies[37,40] reported on the statistical significance of attributes, equating to a total of 93% of attribute preferences (109 of 117) being reported alongside their respective significance levels (Table 2). Attributes were generally found to be statistically significant across studies, indicating they were considered important to respondents, with just 9 of 109 attributes (8%) with reported significance levels found to be nonsignificant. Four attribute categories (financial outcomes, service quality, psychosocial support, and psychosocial outcomes) were consistently significant across studies where they appeared.

Relative Attribute Importance

There was substantial variation in the relative importance ranking of attributes across studies. In total, there were 25 "most important" (rank 1) attribute categories (Fig. 3). Pain control was the most frequently top ranked subcategory, both in the absolute number of studies reporting this attribute as most important (n = 8) and in the relative proportion of studies that found this to be the most important attribute when included (80%). QoL, cost of care, and length of life were also typically high-ranked attribute subcategories. The relative attribute importance scores for each attribute are presented in Appendix Table 4 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005. The full list of attribute subcategory ranking frequencies is presented in Appendix Table 5 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005.

A subgroup analysis of the frequencies of importance ranks for attribute subcategories by respondent perspective is presented in Appendix Figure 1 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005. QoL was the most important attribute from the patient perspective, followed by pain control. From the proxy perspective, pain control was the most important, followed by cost of care. Length of life was the third most important

attribute for both perspectives. Other important attributes to patients were access to care, timely information, adverse effects, cost of care, and staff quality. Proxy respondents identified quality of care, care delivery, QoL, staff quality, and understanding patients' needs to be other important attributes.

Marginal WTP

The marginal WTP estimates for level changes in specific attributes, converted to a common currency unit of 2022 US$, are summarized in Appendix Table 6 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005. Of the 8 studies (47%) including a cost attribute, only 5[30,31,34,39,42] calculated WTP estimates. Costs were typically expressed as the cost of care/treatment or out-of-pocket costs. All 5 studies asked respondents to consider their WTP from an individual out-of-pocket perspective. For all included studies, the highest WTP was to reduce pain (n = 3, ranging between $12 332 and $100 211), followed by WTP for dying at home (n = 4, $4892-$89 242) and WTP for 1 additional life-year (n = 2, $2091-$80 867). Other WTP estimates were reported for good quality of care (n = 2, $6445-$58 043), improved QoL (n = 1, $27 963-$38 854), and avoidance of severe adverse events (n = 1, $7166-$10 791). Only 2 studies compared the WTP estimates among different stakeholders; these findings suggested that caregivers had a relatively higher WTP for end-of-life care than patients and patients had relatively higher WTP than the general public (Appendix Table 6 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005).[30,31]

Quality Assessment

A full summary of the Lancsar and Louviere[22] quality assessment checklist is presented in Appendix Table 7 in Supplemental Materials found at https://doi.org/10.1016/j.jval.2023.07.005. Overall, we found that the methodological quality of the included studies was good, but varied across domains. For most studies, data collection methods (eg, evidence-based attribute and level selection) were well reported and considered appropriate. Nevertheless, reporting and justification of both qualitative and statistical analysis methods were more limited. There was a lack of detailed reporting and justification across included studies on specific checklist items including sample size calculations, experimental design, and piloting processes. Of the 15 DCE studies published after 2011, only 4 (26.7%) explicitly noted adherence to the ISPOR checklist in conducting or reporting on their study.[30,31,33,40]

Discussion

This is the first study to systematically review, characterize, and appraise the evidence from DCEs on preferences for palliative and end-of-life care. Our findings suggest a growing recognition of the importance of this field, evidenced by the increasing number of DCE studies published in recent years. Nonetheless, most of these studies were narrowly concentrated on adult patients with cancer and high-income contexts, indicating a potential lack of generalizability in current literature. Clinical outcomes, including QoL, pain control, and life length, were the most frequently included attribute types, whereas attributes relating to psychosocial support/outcomes were largely absent, which may have resulted in partially representative stated preferences. Both patients and proxy respondents prioritized pain control over additional survival time; nevertheless, divergences in the emphasis on other attributes such as access to care and timely information (prioritized by patients), as opposed to cost and quality of care (by

Table 2. Results of attribute classification.

Author, date	No. of attributes	Attribute wording (direct from study)	Category	Subcategory	Statistical Significance	No. of levels	Level range
Johnston et al, 2022[33]	4	Focus of care	Clinical outcome	Length of life + QoL	Yes	3	Making life longer/making QoL better/both
		Financial support for informal carers	Financial outcome	Financial support	Yes	3	Not paid/service provided in free-time/ government support
		Availability of the palliative care team	Service availability	Access to care	Yes	2	Office hours/anytime
		Cost of care	Financial outcome	Cost	Yes	2	Hospital is free (home is not free)/hospital is free (home is free)
Leng et al, 2022[34]	6	QoL associated with treatment	Clinical outcome	QoL	Yes	4	Low (score 4)/moderate (score 6)/good (score 8)/ very good (score 10)
		Life extension	Clinical outcome	Length of life	Yes	4	4, 6, 10, 16 months
		Rate of adverse reactions	Clinical outcome	Adverse effect	Yes	4	None (0%)/low (10%)/moderate (50%)/high (90%)
		Place of death	Service delivery	Place of death	Yes	2	Hospital/home
		Out-of-pocket cost	Financial outcome	Cost	Yes	4	$1512, $6050, $12 100, $21 174
		Hospitalization days	Clinical outcome	Treatment quality	No	4	< 7, 7-10, 11-30, >30 days
Sepulveda et al, 2022[27]	13	Managed pain and discomfort	Clinical outcome	Pain control	Yes	5	From strongly disagree to strongly agree
		Clean and safe space	Service quality	Quality of care	Yes	5	From strongly disagree to strongly agree
		Treated kindly	Service quality	Staff quality	Yes	5	From strongly disagree to strongly agree
		QoL extending treatments	Clinical outcome	Length of life	Yes	5	From strongly disagree to strongly agree
		Clear and timely information	Communication	Timely and thorough information	Yes	5	From strongly disagree to strongly agree
		Asked enough questions	Communication	Understand patients' needs	Yes	5	From strongly disagree to strongly agree
		Cope emotionally	Psychosocial support	Emotional support (from healthcare providers)	Yes	5	From strongly disagree to strongly agree
		Care was well coordinated	Service quality	Quality of care	Yes	5	From strongly disagree to strongly agree
		Preferred place of death	Service delivery	Place of death	Yes	5	From strongly disagree to strongly agree
		Costs were not a barrier	Financial outcome	Cost	Yes	5	From strongly disagree to strongly agree
		Contact with family	Psychosocial support	Emotional support (from family)	Yes	5	From strongly disagree to strongly agree
		Spiritual needs	Psychosocial support	Emotional support (from healthcare providers)	Yes	5	From strongly disagree to strongly agree
		Nonmedical concerns	Service quality	Quality of care	Yes	5	From strongly disagree to strongly agree
Kenny et al, 2021[28]	12	The cost to the patient	Financial outcome	Cost	Yes	3	$0, $500, $4000
		The patient feeling	Psychosocial outcome	Patient feeling	Yes	3	Calm/calm some of the time but anxious at other times/anxious
		pain control measures	Clinical outcome	Pain control	Yes	3	Completely pain free/moderate pain during the day/moderate pain all of the time
		The informal carer feeling	Psychosocial outcome	Staff quality	Yes	3	In control/in control some of the time but felt stressed at other times/stressed all of the time
		The accommodation type	Service quality	Quality of care	Yes	2	A single room/a shared room
		When at home, nurses visited hours	Service availability	Access to care	Yes	3	20, 10, 4 hours per week

Table 2. Continued

Author, date	No. of attributes	Attribute wording (direct from study)	Category	Subcategory	Statistical Significance	No. of levels	Level range
		When admitted, same or different nurses were available all of the time and care was provided	Service delivery	Type of healthcare providers	Yes	2	Many different nurses/the same nurses
		Nurses were confident in helping patient and family prepare for death	Service quality	Staff quality	Yes	2	Yes/no
		During the day the patients' conscious	Clinical outcome	Consciousness	Yes	2	Awake/conscious but sleepy
		place of care	Service delivery	Place of care	Yes	4	Most time in home and some time in hospital/most time in home and some time in palliative care unit/most time in hospital and some time in home/most time in palliative care unit and some time in home
		Medical intervention was being given to prolong life	Clinical outcome	Length of life	No	3	No intervention/antibiotics to treat infection/a drip to give fluids
		place of death	Service delivery	Place of death	Yes	3	At home/in hospital/in a palliative care unit
Boyden et al, 2021[29]	20	Physical care: Symptom management	Clinical outcome	Pain control	Yes	NR*	NA
		Psychological and emotional aspects of care: child	Psychosocial support	Emotional support (from healthcare providers)	Yes	NR	NA
		Coordination of care	Service quality	Quality of service	Yes	NR	NA
		Access to care	Service availability	Access to care	Yes	NR	NA
		Psychological and emotional aspects of care: sibling	Psychosocial support	Emotional support (from healthcare providers)	Yes	NR	NA
		Knowledge and skills: providers	Service quality	Staff quality	Yes	NR	NA
		Communication between family and care team	Communication	Timely and thorough information	Yes	NR	NA
		Communication at the end of life	Communication	Timely and thorough information	Yes	NR	NA
		Psychological and emotional aspects of care: parent	Psychosocial support	Emotional support (from healthcare providers)	Yes	NR	NA
		Caregiver support at the end of life	Service quality	Staff quality	Yes	NR	NA
		Continuity of care	Service quality	Quality of service	Yes	NR	NA
		Physical care: Communication	Communication	Timely and thorough information	Yes	NR	NA
		Relationship between family and care team	Psychosocial support	Emotional support (from healthcare providers)	Yes	NR	NA
		Practical aspects of care	Service quality	Quality of service	Yes	NR	NA
		Social aspects of care: parent	Psychosocial support	Social support	Yes	NR	NA
		Ethical and legal aspects of care	Psychosocial support	Social support	Yes	NR	NA
		Social aspects of care: child	Psychosocial support	Social support	Yes	NR	NA

Table 2. Continued

Author, date	No. of attributes	Attribute wording (direct from study)	Category	Subcategory	Statistical Significance	No. of levels	Level range
		Emotional: extended network	Psychosocial support	Emotional support (from healthcare providers)	Yes	NR	NA
		Spiritual and religious aspects of care	Psychosocial support	Social support	Yes	NR	NA
		Cultural aspects of care	Psychosocial support	Social support	Yes	NR	NA
Waller et al, 2021[35]	3	Initiation source	Communication	Timely and thorough information	Yes	2	Patient-initiated disclosure/doctor-initiated disclosure
		Consultation format	Communication	Timely and thorough information	Yes	2	1 consultation/2 consultations
		Information content	Communication	Timely and thorough information	No	2	Median survival time/best-worst-case scenario
Weilandt, 2020[36]	9	Overall response rate	Clinical outcome	Treatment quality	Yes	4	10%-25%, 25%-40%, 40%-55%, 55%-70%
		2-year survival rate	Clinical outcome	Length of life	Yes	4	20%-40%, 40%-50%, 50%-60%, 60%-70%
		Type of adverse events	Clinical outcome	Adverse effect	Yes	NR	Autoimmune disorders that could affect, for example, thyroid gland, bowel or liver rash, photosensitivity reaction and warty hyperkeratosis pyrexia, chills, and flu-like symptoms
		Probability of AE-related treatment discontinuation	Clinical outcome	Treatment quality	Yes	4	3%-10%, 10%-20%, 20%-30%, 30%-40%
		Route of administration	Service delivery	Care delivery	Yes	4	4-6 tablets per day/6-12 tablets per day/ infusions, administered by a physician/injections into the tumor tissue, administered by a physician
		Progression-free survival	Clinical outcome	Length of life	Yes	4	2-4, 5-7, 8-10, 11-13 months
		Frequency of administration	Service delivery	Care delivery	Yes	4	Once daily/twice daily/every 2 weeks/every 3 weeks
		time-to-response	Clinical outcome	Treatment quality	Yes	4	< 4, 4-8, 8-12, 12-16 weeks
		frequency of consultation	Service availability	Access to care	Yes	4	Once a week/every 2 weeks/every 3 weeks/every 4 weeks
Valentí et al, 2020[37]	3	Additional survival time	Clinical outcome	Length of life	NR	6	< 1, 1-3, 6, 12, 36, > 60 months
		QoL	Clinical outcome	QoL	NR	6	It is at 10 and stands at 10/it is at 50 and stands at 50/increase from 40 to 60/increase from 10 to 50/increase from 50 to 90/increase from 10 to 90
		Adverse events	Clinical outcome	Adverse effect	NR	8	Total alopecia/grade 1 peripheral neuropathy/ grade 2 peripheral neuropathy/grade 3 peripheral neuropathy/mild rash/severe rash/ mild vomiting/severe vomiting
Waller et al, 2018[38]	3	Pain	Clinical outcome	Pain control	Yes	3	Mild/moderate/severe
		Consciousness	Clinical outcome	Consciousness	Yes	3	Some/half/most of time
		Extension of life	Clinical outcome	Length of life	No	3	1, 2, 3 weeks
Meads et al, 2017[39]	7	Waiting time	Service availability	Access to care	Yes	3	No wait (immediate)/1-2 days/3-7 days
		Type of healthcare professional	Service delivery	Type of healthcare providers	Yes	3	Specialist pain doctor/specialist nurse/your GP

Table 2. Continued

Author, date	No. of attributes	Attribute wording (direct from study)	Category	Subcategory	Statistical Significance	No. of levels	Level range
		Out-of-pocket cost	Financial outcome	Cost	Yes	3	£0, £10, £30
		Side effects control	Clinical outcome	Adverse effect	Yes	2	Good control/poor control
		Quality of communication	Communication	Timely and thorough information	Yes	2	Good/poor
		Quality of information	Communication	Timely and thorough information	Yes	2	Yes/no
		Level of pain control	Clinical outcome	Pain control	Yes	3	Good/moderate/poor control
Gomes et al, 2017[40]	5	Team's availability	Service availability	Access to care	NR	3	Weekdays 9 AM to 17 PM/weekdays and weekends 9 AM to 17 PM/weekdays and weekends 24/7
		Support for family caregivers	Service delivery	Type of healthcare providers	NR	4	Standard, no extras/standard + short-term respite/standard + brief psychoeducational intervention/standard + both of the extras above
		Homecare support	Service delivery	Place of care	NR	3	Consultancy/consultancy + practical home help/consultancy + practical home help þ advanced technical support
		Information and planning	Communication	Timely and thorough information	NR	4	Standard, no extras/standard þ advanced planning of care/standard þ case conference with general practitioner/standard þ both of the extras above
		Waiting time	Service availability	Access to care	NR	3	3, 6, 9 days
Hofheinz et al, 2016[41]	3	Treatment tolerability (adverse reactions)	Clinical outcome	Adverse effect	Yes	4	No or mild, moderate, severe, very severe adverse reactions
		QoL (in terms of ability of self-care)	Clinical outcome	QoL	Yes	4	No, little, lot of, complete assistance
		Additional survival benefit	Clinical outcome	Length of life	Yes	4	0, 1, 2, 3 months
Malhotra et al, 2015[31]	7	Severity of pain from diagnosis until death	Clinical outcome	QoL	Yes	4	None, mild, moderate, severe
		Amount of care required from family members/friends	Service availability	Access to care	No	4	10, 16, 24, 40 hours/week
		Expected length of survival	Clinical outcome	length of life	Yes	4	4, 6, 10, 16 months
		Quality of healthcare experience	Clinical outcome	QoL	Yes	4	Very good, good, fair, poor
		Expected cost of treatment from diagnosis until death	Financial outcome	Cost	Yes	4	$4000, $10 000, $20 000, $40 000
		Source of payment	Financial outcome	Cost	Yes	4	Own out-of-pocket, family member's out-of-pocket, own Medisave, family member's Medisave
		Place of death	Service delivery	Place of death	Yes	2	Home, institution (such as hospital, hospice, or nursing home)
Finkelstein et al, 2015[30]	7	Severity of pain from diagnosis until death	Clinical outcome	QoL	Yes	4	None, mild, moderate, severe
		Amount of care required from family members/friends	Service availability	Access to care	No	4	10, 16, 24, 40 h/week
		Expected length of survival	Clinical outcome	length of life	Yes	4	4, 6, 10, 16 months
		Quality of healthcare experience	Clinical outcome	QoL	Yes	4	Very good, good, fair, poor
		Expected cost of treatment from diagnosis until death	Financial outcome	Cost	Yes	4	$4000, $10 000, $20 000, $40 000

Table 2. Continued

Author, date	No. of attributes	Attribute wording (direct from study)	Category	Subcategory	Statistical Significance	No. of levels	Level range
		Source of payment	Financial outcome	Cost	Yes	4	Own out-of-pocket, family member's out-of-pocket, own Medisave, family member's Medisave
		Place of death	Service delivery	Place of death	Yes	2	Home, institution (such as hospital, hospice, or nursing home)
Chu, 2013[42]	3	Availability of doctors onsite	Service availability	Access to care	No	3	Full-time 9 AM to 5 PM, full-time = 0, 24 h on call, 24 h = 1, 3), full-time and night time on call
		Attitude of the care and staff	Service quality	Staff quality	Yes	2	Unfriendly staff/friendly staff
		Additional cost per month	Financial outcome	Cost	Yes	4	> HK$1, > HK$100, > HK$300, > HK$500
Davison et al, 2010[43]	6	Who provides comprehensive day-to-day care?	Service delivery	Type of healthcare providers	Yes	4	Group of rotating nephrologists/family physician/family physician and a group of rotating nephrologists/advance nurse practitioner and a group of rotating nephrologists
		How should deceased donor kidneys be allocated for transplantation?	Service delivery	Care delivery	Yes	2	First come, first served/best match
		How should live kidneys for transplantation be obtained?	Service delivery	Care delivery	Yes	4	Family member or emotionally related/Paired kidney exchange/anonymous donor/buy a kidney
		When should end-of-life care discussions (advance care planning) be started?	Communication	Understand patients' needs	Yes	2	Early in illness (eg, onset of dialysis or before initiating dialysis)/late in illness (eg, when health state is obviously failing and death may be imminent)
		How much information on prognosis and end-of-life care issues should be routinely provided?	Communication	Timely and thorough information	Yes	2	Limited information/detailed information
		How should decisions to stop dialysis be made?	Communication	Understand patients' needs	Yes	2	Personal decision/shared decision with the medical team that combines personal preferences and medical facts
Douglas et al, 2005[44]	6	Provision of hairdressing	Service availability	Access to care	No	2	Present/absent
		Provision of bathing	Service availability	Access to care	No	2	Present/absent
		Routine access to a doctor	Service availability	Access to care	Yes	2	Present/absent
		Type of access	Service availability	Access to care	Yes	2	Appointment only/drop-in
		Opening hours	Service availability	Access to care	Yes	2	10 AM to 3 PM/1 PM to 6 PM
		Specialist therapy (such as massage)	Service availability	Access to care	Yes	2	Present/absent

AE indicates adverse event; GP, general practitioner; NA, not available; NR, not reported; QoL, quality of life.
*This study asked parents provide their ratings of the most and least valued domains and no level was reported.

proxies), reflect differing perspectives on what constitutes optimal palliative care.

### The Value of Stakeholder Engagement in Conducting DCEs

Despite wide recognition of the value of consumer engagement in health service design, this has been limited within palliative care settings to date.[45] DCE approaches provide an opportunity to bridge this gap, with best practice guidance for DCE design including the use of qualitative methods when selecting and developing attributes for inclusion,[46,47] yet only half of the studies included in this review reported the use of qualitative methods and there was variation in the quality of reporting. This finding

supports calls for greater transparency in reporting methods and findings of qualitative components.[48,49]

The included studies focused primarily on clinical outcomes, service availability, and monetary attributes. Despite previous research underscoring the importance of emotional wellbeing and access to psychosocial support, these attributes were typically absent from DCE designs.[50-54] Without further assessment of the trade-offs that participants are willing to make for these types of attributes, stated preference data remain limited and may only partially reflect actual preferences for palliative care.

DCE methodology required respondents to possess decision-making capacity. Nevertheless, cognitive impairment is common in palliative care populations, with up to 90% of patients found to be experiencing some form of cognitive impairment before

Figure 2. Category of attributes covered. (A) Distribution of attribute categories across 17 studies. (B) Distribution of attribute subcategories across 17 studies.
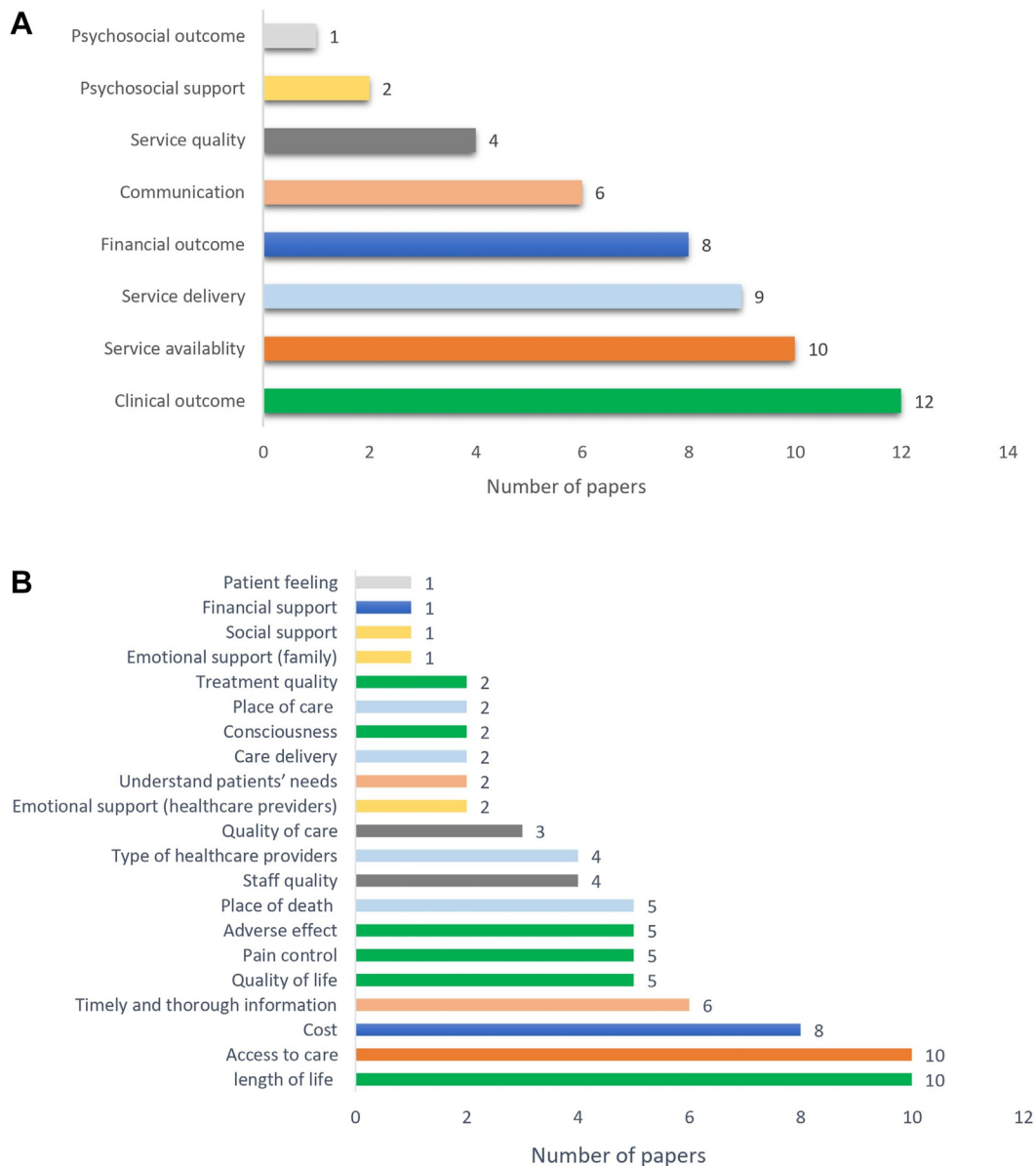
death.[55] Only 3 of the 13 DCE studies with patient respondent samples in this review explicitly excluded individuals with cognitive impairment,[30,31,42] whereas the remaining studies did not report on cognitive status. Preliminary research suggests that the presence of mild cognitive impairment may not significantly affect DCE responses,[56] yet further investigation is warranted to substantiate these findings and determine the most appropriate approaches for conducting DCE research in these cohorts.

Implications for Policy and Clinical Practice

Our findings highlight the need for clinicians to prioritize pain management in the care of individuals facing life-limiting illness. Nevertheless, recent evidence suggests that pain remains a commonly unmet need in these populations.[57] Pain management is especially crucial when illness trajectories are unpredictable and the terminal phase can be sudden.[58,59] Therefore, proactive and anticipatory care is important to optimize both QoL and quality of death in a way that is consistent with patient preferences.[58,60]

Although our findings underscore the importance of QoL for patients nearing end of life, this may be in conflict with a hospital culture of "doing everything possible." There is evidence that extending survival time is often prioritized at the sacrifice of quality, leading to provision of nonbeneficial or "futile" treatments in end-of-life hospital admissions.[61,62] Although the reasons for this are complex, research points to a lack of effective communication, insufficient patient involvement in shared decision-making processes, and an absence of discussion regarding the desired level of prognostic information.[63-65] Therefore, our findings support the development and implementation of processes that enable better understanding of trade-offs associated with their

Table 3. Proportion of attribute preference estimates across subcategories respondent perspective and country level.

Attribute (subcategories)	Overall (n = 190)	Respondent perspective		Country level	
		Patient (n = 79)	Proxy* (n = 111)	High income (n = 155)	Low to middle income (n = 35)
Length of life	19 (10%)	10 (13%)	9 (8%)	16 (10%)	3 (9%)
Quality of care	19 (10%)	1 (1%)	18 (16%)	13 (8%)	6 (17%)
Cost of care	18 (9%)	9 (11%)	9 (8%)	14 (9%)	4 (11%)
Access to care	16 (8%)	13 (16%)	3 (3%)	15 (10%)	1 (3%)
Timely and thorough information	15 (8%)	6 (8%)	9 (8%)	13 (8%)	2 (6%)
Emotional support (from healthcare providers)	15 (8%)	0 (0%)	15 (14%)	11 (7%)	4 (11%)
Quality of life	12 (7%)	7 (9%)	5 (5%)	11 (7%)	1 (3%)
Place of death	11 (6%)	4 (5%)	7 (6%)	8 (5%)	3 (9%)
Pain control	10 (5%)	3 (4%)	7 (6%)	8 (5%)	2 (6%)
Staff quality	10 (5%)	3 (4%)	7 (6%)	7 (5%)	3 (9%)
Understand patients' needs	9 (5%)	2 (3%)	7 (6%)	7 (5%)	2 (6%)
Adverse effect	6 (3%)	5 (6%)	1 (1%)	5 (3%)	1 (3%)
Care delivery	6 (3%)	4 (5%)	2 (2%)	6 (4%)	0 (0%)
Emotional support (from family)	5 (3%)	0 (0%)	5 (5%)	3 (2%)	2 (6%)
Social support	5 (3%)	0 (0%)	5 (5%)	5 (3%)	0 (0%)
Type of healthcare providers	4 (2%)	3 (4%)	1 (1%)	4 (3%)	0 (0%)
Treatment quality	4 (2%)	4 (5%)	0 (0%)	3 (2%)	1 (3%)
Consciousness	3 (1%)	2 (3%)	1 (1%)	3 (2%)	0 (0%)
Financial support	1 (1%)	1 (1%)	0 (0%)	1 (1%)	0 (0%)
Patient feeling	1 (1%)	1 (1%)	0 (0%)	1 (1%)	0 (0%)
Place of care	1 (1%)	1 (1%)	0 (0%)	1 (1%)	0 (0%)
Overall	190 (100%)	79 (100%)	111 (100%)	155 (100%)	35 (100%)

*Proxy perspective includes the perspectives from carers, healthcare providers, or the general population.

treatment and care options, ultimately empowering patients and families to select options that align with their values and preferences to prevent the provision of nonbeneficial treatment.[61,66]

Insights from this review further substantiate the call for enhanced regulatory frameworks to facilitate access to high-quality palliative care.[67] Enhancing health professionals' understanding of this regulatory framework could bolster patient-centered decision making, given that their uncertainties have been correlated with suboptimal pain and symptom management due to apprehension regarding possible repercussions after opioid administration.[68,69] Practically, there are robust legal, ethical, and policy protections for providing adequate pain control, even if an incidental effect is to hasten death by a short period.[67,68]

It is important to note that the findings from DCE studies represent preferences at an aggregate cohort or population level. Nevertheless, preferences for care at the end of life vary across individuals and are influenced by on a range of factors including clinical conditions, respondent type, geographic region, and ethnicity.[70,71] For instance, Sepulveda et al[27] reported that the importance of dying in the preferred place was approximately twice as important in the United States compared with India, whereas the importance assigned to spiritual needs was substantially less for the United Kingdom than in the United States, India, and Kenya. There is also evidence that preferences can change over time within individuals as they approach the terminal phase of illness.[72] Therefore, although DCE findings are useful to

inform system-level policy and planning, it remains important for clinicians to understand what is important to individuals, throughout different stages of their illness trajectory, emphasizing the need for personalized care plans in clinical practice. In cases where patients do not have capacity to participate in end-of-life decision making and their wishes are unknown, information from DCE studies could also help treating clinicians provide more appropriate guidance to substitute decision makers, whose judgments may not always align with the wishes of patients.[73,74]

Strengths and Limitations of This Review

This review provides a comprehensive overview of the current DCE evidence on preferences for palliative and end-of-life care. We applied a rigorous search strategy and have transparently reported our findings in adherence with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement. In addition, despite some heterogeneity in the description of attributes across studies, we were able to thematically identify key attribute categories and subcategories, allowing for a more in-depth synthesis of evidence on the relative importance of key attributes.

There are some limitations to note. Given that most of the included studies investigated preferences within high-income countries, White populations, adults, and patients with cancer, the generalizability of our findings to other settings may be

Figure 3. Frequencies of attribute importance ranks by attribute type (top 10 attributes).
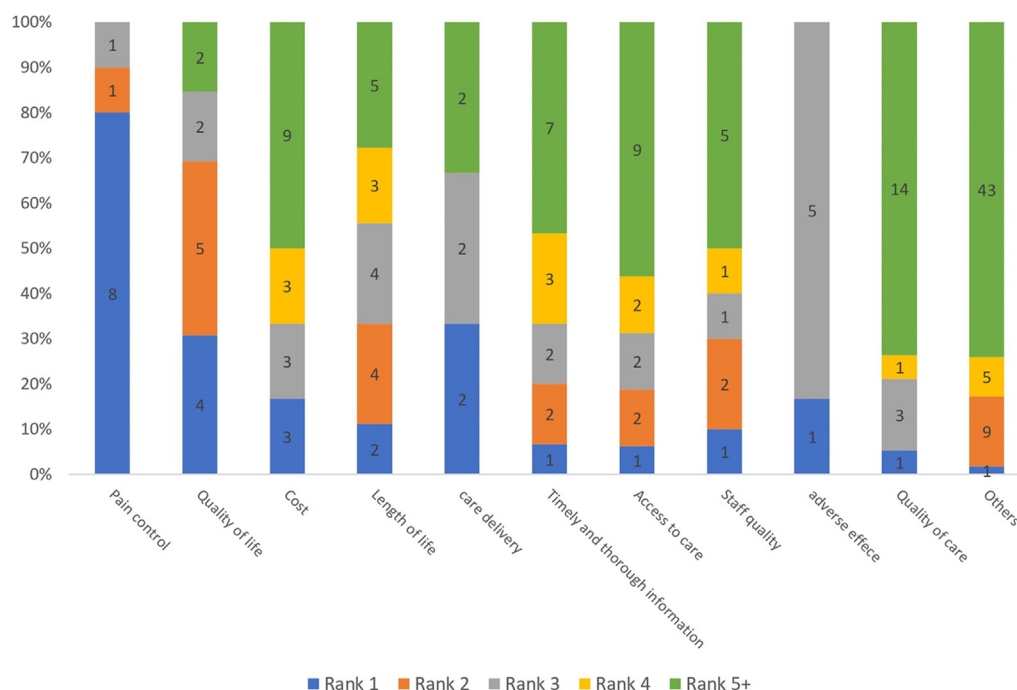
limited. Future DCE studies in this field should be conducted in a broader range of ethnicities, age groups, and health conditions, where there is evidence that preferences may differ.[71] In addition, the subjective nature of our attribute reclassification process means that other classification schemes may also be possible, with subsequent implications for the reported results. Moreover, the absence of trade-offs for psychosocial attributes could lead to the current findings only partially reflecting actual preferences.

Recommendations for Future DCE Research in Palliative Care Settings

Based on the findings of this review, we recommend that future DCE studies conducted in palliative care settings:

- Investigate preferences of individuals across broader range of geographic regions, ethnicities, age groups, and health conditions, including noncancer conditions.
- Investigate the impact of cognitive impairment on the feasibility and validity of DCE responses and explore whether methods can be adapted to better suit these cohorts.
- Prioritize active engagement with patients, carers, and key stakeholders within the attribute development and DCE design process.
- Consider psychosocial outcomes and attributes.
- Consider the use of latent-class models when analyzing DCE response data, to account for potential heterogeneity of preferences within a cohort.
- Adopt transparent reporting practices using established guidelines, such as the ISPOR checklist.[32]
- Investigate and assess the range of methods used for determining relative attribute importance in DCEs, given the identified methodological inconsistencies. This might also involve developing best practice guidelines for calculating attribute importance, enabling more accurate comparisons across different studies.

Conclusion

This systematic review delivers a synthesis of attributes used in DCEs to elicit preferences for palliative care and their relative importance. The results of this systematic review highlight the wide range of important considerations in this setting and the relative strength of preferences for these. We also shed light on differences in stated preferences across both patient and proxy respondent samples. The observed stronger preference for pain management over additional survival time underscores the vital role of symptom control in palliative care. The noticeable differences between patient and proxy perspectives further underscore the need for personalized, patient-centered approaches with early patient engagement in care planning. These insights may inform the development of holistic care models that truly address the needs, values, and preferences of individuals approaching the end of life.

Supplemental Material

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