



End-of-life care preferences for people with advanced cancer and their families in intensive care units: a systematic review

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Received: 18 July 2018 / Accepted: 25 April 2019 / Published online: 17 May 2019
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Abstract

Background Advanced cancer patients' end-of-life care preferences in oncology units, medical-surgical units, nursing homes and palliative care services have been established. However, less is known about end-of-life care preferences of patients with advanced cancer in intensive care units and their families.

Aim To explore end-of-life care preferences of patients with advanced cancer and their families in intensive care units and if these align with essential elements for end-of-life care.

Design Electronic databases were searched up to February 2018. Reference lists of retrieved articles were screened for potential studies.

Results A total of 112 full text articles were retrieved. Of these, 12 articles reporting outcomes from 10 studies were eligible for inclusion. The majority were retrospective chart reviews ($n = 7$) and conducted in developed countries ($n = 9$). Care preferences change over time with deteriorating physical condition. Ongoing patient-centred communication and shared decision-making are critical as is teamwork and involvement of a palliative care team. Marital status, gender and ethnicity appear to influence care preferences. Of those studies examining patient preferences and/or the receiving of their preferences, these could be aligned with approximately half of the Australian essential elements for end-of-life care.

Conclusions Providing end-of-life care for patients with advanced cancer in intensive care units is challenging. No studies have investigated prospectively the end-of-life care preferences of patients and their families in this acute setting. Further research is required to determine the elements of care preferences for patients with advanced cancer and their families in intensive care units in developing countries.

Keywords End-of-life care · Terminal care · Advanced cancer · Intensive care unit

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s00520-019-04844-8>) contains supplementary material, which is available to authorized users.

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Introduction

Intensive care is an essential part of hospital care as it provides the most technologically advanced treatments to sustain and save life; however, it is costly and resource-intensive [1]. While this care is most often limited to patients with an acute critical illness, it is quite common for patients diagnosed with advanced cancer to experience an episode of illness from a complication that results in the need for intensive care [2]. Moreover, it is not unusual for advanced-cancer patients to receive end-of-life care (EOLC) in the intensive care unit (ICU) in developing countries due to the limited availability of palliative care services [3]. Cancer is the second most common cause of death, accounting for 13% of deaths worldwide [4]. The incidence of advanced cancers varies by country but appears to be increasing in both developed and developing countries [3, 5], and this has implications for the provision of EOLC services [6].

EOLC differs between developing and developed countries in relation to the availability of resources and guidelines [7]. For this review, developed countries are those with advanced development of palliative care activism at end of life (EOL) as part of mainstream service provision in health services [7]. These include countries such as Australia, Japan, the United Kingdom (UK) and the USA. Developing countries are those with no known or minor development in palliative care activities at EOL that are not well supported [7], such as Brazil, Indonesia, and Saudi Arabia.

Several developed countries have clearly formulated guidelines and frameworks to support the implementation of EOLC in acute settings [5, 8–10]. Likewise, ethical consensus statements for EOLC in ICUs have been developed by intensive and critical care societies, predominantly in developed countries [5]. The Canadian Nurses Association emphasises a holistic care provision approach that focusses on comfort, continuity, palliation and assisting EOL patients to feel well-supported until death, in all practice settings, including ICU [9]. In the UK, there is a quality standard that covers the guidelines for adults who are approaching EOL and who are likely to die within 12 months, regardless of their condition or setting. In addition, the National Institute for Health and Care Excellence (NICE) provides guidelines for improving the provision of EOLC in the last 2 to 3 days of life in a clinical setting, such as the ICU [10]. Specific NICE guidelines have been formulated to cover EOLC for specific cancer types, such as advanced breast cancer, and aim to improve patient outcomes and quality of life [10]. To the best of our knowledge, there are no guidelines specifically for EOLC of patients in ICUs in developing countries.

Advanced cancer patients' EOLC preferences in general and clinical settings, such as oncology units, nursing homes, and palliative care services have been established [11–14]. Less is known on the EOLC preferences of advanced cancer

patients in ICUs. Therefore, the aim of this review was to explore EOLC preferences from the perspective of patients with advanced cancer and their families in ICUs and identify if these align with essential elements for safe and high-quality EOLC (Table 1). Gaining a deeper understanding of EOLC preferences may lead to improved care provision and processes for patients with advanced cancer and their families in ICUs, particularly in developing countries.

Methods

In conducting this review, we applied the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [15]. Electronic searches of PubMed, CINAHL, Medline, Scopus, Web of Science, the Joanna Briggs Institute and Google Scholar were conducted up to February 2018. Keywords and subject headings (MeSH or CINAHL headings) included “end-of-life care”, “good death”, “palliative care”, “end of life”, “hospice”, “last hours care”, “terminal care”, “advanced cancer”, “late stage cancer”, “solid tumours”, or “haematological malignancies”, “intensive care unit”, “critical care unit”, “patients”, “humans”, “carers”, “adults” and “families”. The Boolean operators OR, AND, NOT were applied. Reference lists of retrieved articles were screened for eligible studies. The search was limited to English language publications and due to the rapidly changing environment in cancer care treatments, to articles published between 2006 and 2018. To maximise effectiveness of search strategies, the literature search was undertaken in consultation with an expert health librarian.

Eligibility criteria

Primary quantitative and qualitative studies pertaining to adults with advanced cancer (stage III and stage IV of solid tumours or haematological malignancies that have been described as advanced) and/or their families, who experienced intensive care in a general or oncology hospital ICU, were eligible for inclusion. In this review, families refer to an “informal carer” which “includes any person, such as a family member, friend or neighbour, who is giving regular, ongoing assistance to another person without payment for the care given” [16] (p1). Studies not published in English that did not focus on adults (≥ 18 years of age) with advanced cancer in ICUs were excluded. Grey literature, conference proceedings, theses, and textbooks were excluded.

Study selection and data extraction

Search results were managed through Endnote (version X6). Once duplicates were removed, two reviewers (HY, KN) independently screened titles and abstracts. Full-text articles

Table 1 An overview of the 10 essential elements for safe and high-quality end-of-life care [8] (adapted from ACSQHC with permission) and the elements identified from the included studies in this review

Essential elements	Patient preferences	Family preferences
A. Processes of care		
1. Patient-centred communication and shared decision-making (<i>Patients are part of decision-making about EOLC</i>).	✓	
2. Teamwork and coordination of care (<i>Clinicians work together to provide EOLC</i>).	✓	
3. Components of care (<i>Clear goals improve quality EOLC</i>).	✓	✓
4. Use of triggers to recognise patients approaching the end of life (<i>Triggers identify when patients need EOLC</i>).		
5. Response to concerns (<i>Clinicians get help to rapidly respond to patient suffering</i>).		✓
B. Organisational prerequisites		
6. Leadership and governance (<i>policies and systems to EOLC</i>).		
7. Education and training (<i>Clinicians have the skills and knowledge to provide EOLC</i>).		✓
8. Supervision and support for interdisciplinary team members (<i>clinicians providing EOLC are supported</i>).		
9. Evaluation, audit and feedback (<i>The quality EOLC is measured and improved</i>).	✓	
10. Systems to support high-quality care (<i>systems align with NSQHS standards to improve outcomes</i>).		

EOLC End-of-life care; NSQHS National Safety and Quality Health Service; ✓: this element identified in this review

were assessed for inclusion by two reviewers (HY, KN) and discrepancies resolved by discussion or by a third person (RC). A data extraction spreadsheet was designed, and data extraction completed by two reviewers (HY, KN) independently for each included study.

Quality assessment and risk of bias

Two reviewers (HY, KN) independently appraised each study for risk of bias and quality assessment. For quantitative studies, the Effective Public Health Practice Project: Quality Assessment Tool for Quantitative Studies was used [17]. This instrument has good inter-rater reliability and validity and guides methodological quality and risk of bias assessment using eight component ratings, resulting in an overall quality score of strong, moderate or weak. The standard quality assessment criteria for evaluation of qualitative studies [18] was selected; however, no qualitative studies were eligible for inclusion in this review.

Essential elements framework

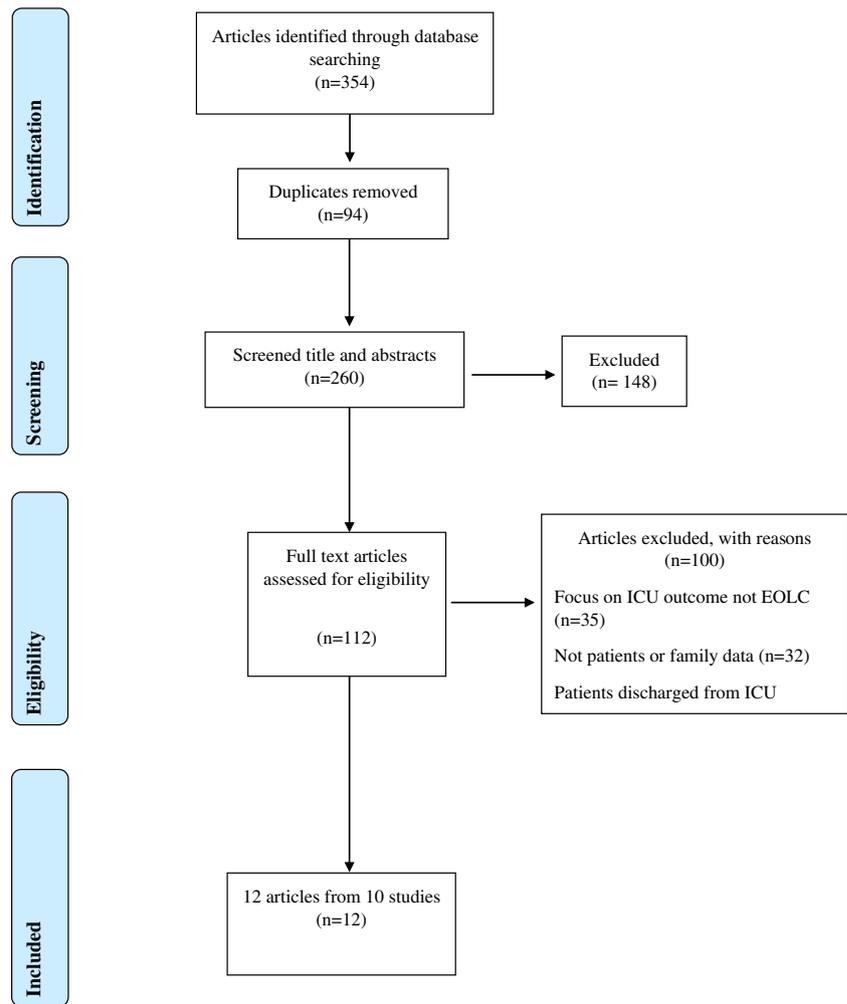
The “National consensus statement: essential elements for safe and high-quality end-of-life care” [8], developed by the Australian Commission on Safety and Quality in Health Care (ACSQHC), was the framework used to identify if patient and/or family preferences aligned with EOLC essential elements. Ten essential elements for providing high-quality EOLC in acute settings, as opposed to palliative care settings, are specified in this statement (Table 1).

Results

A total of 354 articles were identified and following removal of duplicates and screening, 112 full-text articles were reviewed. Of these, 12 articles reporting outcomes from 10 studies were assessed as eligible for inclusion (Fig. 1). Studies were categorised by type and included seven retrospective chart reviews [19–25], two prospective cohort studies in four published articles [26–29] and one cross-sectional survey [30]. Balboni et al. [27], Loggers et al. [28] and Sharma et al. [30] each published from the “Coping with Cancer” study.

Of the 12 articles, nine included patients [19–25, 28, 29], two included patients and family dyads [26, 27] and the remaining study involved families of patients with and without cancer who died in an ICU [30]. Additionally, Cruz et al. [21] examined the written medical chart documentation to determine families’ preferences for aggressive treatment. Eleven articles reported outcomes of studies conducted in developed countries [19, 21–30] and one in a developing country [20]. The quality of studies varied with eight being assessed as weak [19–25, 30], one as moderate quality [28] and the remaining as strong quality [26, 27, 29]. A score of weak was assigned if the study had two or more weak ratings were assigned. The included studies rated weak based on selection bias, study design and/or data collection. Hwang et al. (2015) was rated moderate based on one weak rating for withdrawals as approximately only 30% of participants completed the study. The remaining studies had no weak ratings and the individual components of study design, selection, confounders, blinding, data collection methods and follow-up were rated as either strong or moderate. Study characteristics

Fig. 1 Literature search: screening, inclusion and exclusion



and key findings were synthesised narratively and are presented in Table 2.

Of those studies examining patient and family preferences, these could be aligned with some of the ten ACSQHC consensus statement essential elements [8] and are presented in Table 1. Most of the elicited preferences sit within the ‘processes of care’ category, and just two studies [23, 31] in line with organisation prerequisites of education and training, evaluation, audit and feedback. Notably, the organisational prerequisites of leadership and governance, supervision and support for interdisciplinary team members and systems to support high-quality care were not evident.

Patient preferences of EOLC and the essential elements

Patient-centred communication and shared decision-making

Eight articles from six studies [20, 21, 23, 25–29] identified that EOL communication and shared decision-making, particularly around Do Not Resuscitate (DNR) orders and

withholding of treatments, are critical to improving the quality of EOLC in ICUs for people with advanced cancer. Importantly, where communication and shared decision-making occurred, this resulted in more consistent patient and family decisions concerning life sustaining measures at the end of life such as the use of mechanical ventilation and less aggressive treatment at EOL in the ICU [20, 21, 23, 25–29]. EOL discussions should occur early and well before the patient has an episode of deterioration resulting in ICU admission [21, 27]. If EOL discussions are delayed or only take place on ICU admission, some patients would not be able to participate due to their condition status [21, 27].

A number of studies identified individual factors that influence EOL discussion and decision-making: marital status [28], gender [29], race [27]. Hwang et al. [29] found that married people were more likely than unmarried people to change their care preferences over the course of illness, particularly when there was physical deterioration. This study was conducted in Korea in which decision-making involves interdependence among family members; consequently, this cultural construct may have contributed to the findings [28].

Table 2 Characteristics and key findings of included studies including quality ratings and assigned quality EOLC elements

Author, country and quality level	Aim	Design and method	Participants	Findings	Assigned essential elements for delivering safe and high-quality end-of-life-care
Romano, et al. 2017. [19] Country: USA Quality rating: weak	To assess the effect of a comprehensive early palliative care program on ICU use	Retrospective chart review of cases (received palliative care intervention) and concurrent controls (received standard care)	275 case patients and 195 controls	Participation in a palliative care program significantly reduced ICU use at the EOL for patients.	Teamwork and coordination of care
Cruz et al. 2015. [20] Country: Brazil Quality rating: weak	To identify the predisposing factors involved in the institution and maintenance of futile intensive care support in terminally ill cancer patients to whom no additional treatment for the malignant disease would be offered	Retrospective chart review of patients classified as cases (medical futility) and controls (palliative care) Also undertook qualitative analysis of medical chart documented discussions/written notes	38 case patients and 238 controls	Predisposing factors in medical futility were lack of palliative care team consultation. Qualitative analysis themes included physicians lacking proactive attitudes in considering prognosis and communication with families.	Patient-centred communication and shared decision-making; teamwork and coordination of care
Miller et al. 2015. [21] Country: UK Quality rating: weak	To explore the quality of transition to EOLC for cancer patients in the ICU	Retrospective chart review of patients classified as EOLC cohort 'cases' and full active ICU care cohort 'controls' Also undertook qualitative analysis of medical chart documented discussions/written notes	38 case patients and 47 controls	97.4% (37/38) EOLC cohort had clear documented evidence of transition from full active care to EOLC with 76.3% (29/38) dying in ICU. However, in 51% (19/37) of cases, the patient was too unwell to be involved in discussion of transition to EOLC. Quantitative and qualitative analysis demonstrated there was collaborative decision-making between teams, patients and families during transition to EOLC. Advanced EOLC planning for patients with progressive disease prior to acute deterioration is important to enable patients' wishes to be fulfilled, and ceiling for treatments agreed.	Patient-centred communication and shared decision-making; teamwork and coordination of care
Hwang et al. 2015. [28] Country: Korea Quality rating: moderate	To investigate the stability of preferences regarding treatment in the ICU, and identify the factors associated with changes in preferences in terms of quality of life (QOL)	Prospective cohort study. Patients who completed questionnaires at baseline and at 2-months	141 patients	79.7% (102/128) of patients had not discussed ICU care near death with their physicians. The attitudes of terminally ill cancer patients regarding ICU care at the EOL were not stable over time, and changes in their QOL were associated with a tendency to change their preferences about ICU care. Married patients were more likely to change their preferences in either direction regarding ICU care than unmarried patients. Patients with deteriorating 'global QOL' and physical function were more likely to 'reject' ICU care	Patient-centred communication and shared decision-making; teamwork and coordination of care
Sharma et al. 2015. [29]	To determine whether gender differences exist in the receipt of ICU care near death and the	Cohort study – 'Coping with Cancer Study' Sample were patients who completed a	353 patients	Women were more likely to have a DNR order and express a preference for palliative	Patient-centred communication

Table 2 (continued)

Author, country and quality level	Aim	Design and method	Participants	Findings	Assigned essential elements for delivering safe and high-quality end-of-life-care
Country: USA Quality rating: strong	association between EOL discussions and the receipt of EOL ICU care	baseline assessment, subsequently died and had complete post-mortem data		EoL care. Men were more likely than women to receive intensive, non-beneficial ICU care near death. Patients more likely to have received ICU EoL care had not had an EoL discussion. Gender differences in the effects of EOL discussions on EOL care likely contribute to and may even explain gender differences in the receipt of ICU care in the last week of life.	and shared decision-making
Balboni et al. 2013. [26] Country: USA Quality rating: strong	To determine whether spiritual support from religious communities influences terminally ill patients' medical care and quality of life (QoL) near death	Cohort study – 'Coping with Cancer Study' Dyads (patients interviewed pre-death and post-mortem data obtained from their medical chart; caregivers interviewed post patient death to indicate QoL near death.	343 patients and a nominated caregiver.	Patients who received spiritual support from religious communities are more likely to have aggressive treatment at EOL and die in ICUs and less likely to receive hospice care. Patients who are spiritually supported by ICU staff are more likely to have hospice care and less likely to have aggressive treatment and die in ICUs. No significant relationships between patients baseline spiritual support from religious communities regarding QoL near death.	Patient-centred communication and shared decision-making; components of care
Blechman et al. 2013. [22] Country: USA Quality rating: weak	To assess the quality of EOLC received by patients admitted to the ICU in the last 2 weeks of life	Retrospective electronic medical records chart review	69 patients	Only a small percentage of patients had quality indicators met: <ul style="list-style-type: none"> • Prognostication 67% • Advance care planning 32% • Goals of care 42% • Caregiver needs 0% • Coordination of care 7% • Palliative care consultations 41% Quality indicators for EOLC were unmet in cancer patients admitted to the ICU in the last two weeks of life.	Teamwork and coordination of care; evaluation, audit and feedback
Kinoshita and Miyashita, 2012. [30] Country: Japan Quality rating: weak	The secondary objective of this study was to assess the quality EOL for dying patients with cancer in the ICU.	Cross-sectional mailed survey design	152 bereaved family of cancer patients who died in ICU	Bereaved family of cancer patients evaluated lower than non-cancer patients for doctors dealing promptly with comforting systems; nurses had adequate knowledge and skills. Families evaluated symptom management and doctors' and nurses' skills as low. There is a need for improvement of EOLC of cancer patients and to conduct further research to explore	Responding to concerns; education and training

Table 2 (continued)

Author, country and quality level	Aim	Design and method	Participants	Findings	Assigned essential elements for delivering safe and high-quality end-of-life-care
Fu et al. 2011. [23] Country: USA Quality rating: weak	To assess outcomes of patients who required admission to an ICU after referral for an early clinical trial because they did not respond to conventional therapy	Retrospective chart review	212 patients	<p>quality-improvement interventions for bereaved families of cancer patients in ICU. Advanced directives were more likely to be in place for</p> <ul style="list-style-type: none"> • Men than women • White Americans than non-whites <p>No differences were seen in those having a do not resuscitate order with a similar number for men and women having DNR order; change in status during admission was seen with more non-whites than whites.</p> <p>Association between ethnicity and life-supportive therapy withdrawal –white patients were 2.52 times more likely to have life-supportive therapy withdrawal than other races.</p>	<p>Patient-centred communication and shared decision-making</p>
Cesta et al. 2009. [24] Country: USA Quality rating: weak	To evaluate the factors associated with life-supportive therapy withdrawal and length-of-stay of adult patients in the ICU	Retrospective chart review.	267 patients	<p>Components of care</p>	Components of care
Loggers et al. 2009. [27] Country: USA Quality rating: strong	To examine predictors of intensive EOL care for black and white advanced cancer patients	<p>Cohort study – ‘Coping with Cancer Study’ Dyads (patients interviewed pre-death and post-mortem data obtained from their medical chart; caregivers interviewed post patient death to confirm care received in last week of life and to evaluate QoL)</p>	<p>Total of 302 (68 Black and 234 white) patients and a nominated caregiver</p>	<p>Racial differences: black patients were three times more likely than white patients to request aggressive treatment at EOL. White patients with a preference for aggressive treatment were three times more likely to receive it than black patients. White patients who had EOL communication and shared decision-making did not receive aggressive treatment at EOL.</p>	<p>Patient-centred communication and shared decision-making Components of care</p>
Delgado-Guay et al. 2008. [25] Country: USA Quality rating: weak	To characterise the distress symptoms, interventions and outcomes of patients who were admitted to ICU and referred to PCT	Retrospective chart review	88 patients	<p>ICU patients who are referred to the PCT have severe physical and emotional distress symptoms. Small number of referrals to PCT from ICU staff. PCT involvement facilitated discussion and having DNR orders put in place for 70% ($n = 62$) of patients. PCT involvement improved management (i.e. pain, sleep, anxiety)</p>	<p>Patients centred communication and shared decision-making Teamwork and co-ordination of care</p>

EOL end of life, EOLC end-of-life care, ICU intensive care unit, QoL quality of life, LOS length of stay, PCT palliative care team, PCU palliative care unit

The importance in revisiting care preferences over time was also highlighted [28]. Sharma et al. [30] reported gender played a role in EOLC. Men were less likely to engage in discussions around EOLC and were therefore more likely to receive aggressive treatment as their preferences were unknown [29]. Although, men who had discussed EOLC were less likely to receive aggressive treatment than those who had not [29].

Loggers et al. [28] interviewed patients to ascertain EOLC preferences and informal caregivers on whether care preferences were received by the patient at and around their time of death. Race was found to influence EOLC preferences, with black Americans less likely to have a DNR order, but more likely to receive aggressive treatment at EOL and die in ICU compared to white Americans. It was hypothesised that black Americans do not wish to appear to ‘give-up early’. However, compared to white Americans who preferred aggressive EOLC, black Americans were less likely to have these preferences met [27].

Components of care

Three articles from two studies examined cultural and spiritual factors associated with EOLC preferences [24, 26, 27]. Balboni et al. [27] investigated whether there was a difference between spiritual support provided by religious communities and medical teams. It was found that those who received spiritual support from religious communities were more likely to receive intensive EOLC and die in the ICU. On the other hand, patients who received spiritual support from medical staff were less likely to have intensive EOLC in the ICU [26]. As medical staff were more aware of the patient’s medical needs and outcomes, the researchers suggested medical staff realistically addressed issues of death and dying, resulting in less aggressive treatments at EOL [26].

Loggers et al. [28] and Cesta et al. [25] found differences in care decisions of dying patients based on race. Loggers et al. [28] suggested differences in preferences for aggressive treatment and not receiving care may be as a result that caregivers and clinicians pay greater attention to autonomy, care preferences and choices of EOLC of white patients than black patients [27]. Cesta et al. [25] reported that white patients were more likely to have life-supportive therapy withdrawal at EOL than other races. Patients who opted for life-supportive therapy withdrawal had longer length of stay in ICU, compared to patients who did not undergo life-supportive therapy withdrawal. This may be due to physicians and family members choosing life-supportive therapy withdrawal only after a patient had been in the ICU for several days and had shown no response to therapy [24].

Teamwork and coordination of care

Six studies [19–22, 25, 28] described regular documentation of patients’ symptoms is important to provide sufficient

management and coordination of appropriate EOLC planning. Two studies [22, 28] noted that early documentation before a patients’ health deteriorates is important so that they can express their EOLC preferences. Blechman et al. [23] noted that the absence of clarity of care goals and documentation of patient’s preferences may lead to ineffective and burdensome medical care at EOL [22].

Three studies [19, 20, 25] highlighted the importance of multidisciplinary teamwork in palliative care integration in ICUs to meet patient’s preferences of EOLC. Delgado-Guay et al. [26] suggested the integration of interdisciplinary and collaborative approaches is critical in helping patients and families consider decision-making options, while balancing the benefits of treatment with the goal of an improved quality of life for people with advanced cancer in ICUs. Additionally, the findings suggested that multidisciplinary teamwork, including the involvement of a palliative care team (PCT), is important when discussing both therapeutic and non-therapeutic interventions to meet patient’s EOLC preferences in ICU. PCT involvement allows for additional pharmacological and non-pharmacological interventions to improve outcomes in EOLC and less aggressive EOL interventions [19, 21, 25]. A lack of PCT consultation was associated with medical futility by increased use of aggressive life support measures including invasive mechanical ventilation for advanced cancer patients [20].

Evaluation, audit and feedback

Blechman et al. [23] audited the medical records of advanced cancer patients admitted to an ICU against patient-specific measures to assess the quality of EOLC in the UK. These markers included assessment and documentation of patient’s care goals, advance directives, caregivers stress and comfort care orders [22]. The results showed that quality indicators were rarely met, the quality of EOLC planning and documentation was poor, and they advocate that careful planning is required to implement good EOLC by documenting patient’s goals and values.

Family preferences of EOLC and the essential elements

Components of care

Balboni et al. [27] proposed that identifying spiritual needs for patients can enable families to make better, more suitable decisions for their loved ones. They also reported that medical staff providing spiritual support for families was less likely to elicit aggressive treatments at EOL including resuscitation and ventilation compared to families who had spiritual support from religious communities. The reasoning was that religious congregants consider medicine as a primary divine intervention, and they ask

families to have hope for all time (miracle healing) and therefore informal caregivers are more likely to request intensive care for their loved ones [26]. The study [20] conducted in the predominantly Roman Catholic country of Brazil found that ICU physicians face difficulties in proposing EOLC decisions to family members of ICU patients, including withholding or withdrawing medical treatment. Futile treatments may also reflect physicians lacked proactive attitudes in considering prognosis and talking to families [20].

Responding to concerns

A Japanese study [31] utilising a cross-sectional anonymous questionnaire found that families of patients with advanced cancer dying in ICU felt their concerns of poor physical care and symptom management for their loved one was not managed well. This resulted in increased anxiety for the family [30]. The families of patients who died of cancer, evaluated care and response to symptoms of discomfort lower than families whose loved one died of other reasons. The researchers highlighted that responding to families' psychological needs are important for EOLC [30]. Challenges existed as ICU is designed to maintain life with the primary emphasis on recovery or cure [30].

Education and training: physicians' and nurses' skills

Kinoshia and Miyashita [31] also report that families of patients with cancer dying in ICU evaluated nurses' knowledge and skills, admission time and consideration of the health of the family lower than families of non-cancer patients [30]. Respondents likewise reported that ICU doctors and nurses have insufficient knowledge and skills in relation to providing support and management of stress to family members of patients with advanced cancer receiving EOLC in ICU.

Discussion

The purpose of this review was to explore EOLC preferences for people with advanced cancer in ICUs from the perspective of patients and their families and identify if these sit within essential elements for EOLC. No studies included in this review have investigated prospectively the preferences of both patients and families regarding preferences of EOLC in ICU. While several studies [26–28] undertook interviews with patients to ascertain EOLC preferences, these interviews were conducted prior to admission to an ICU. When a patient is in a stable condition, their preferences of EOLC are reported to be different to when their condition deteriorates and receiving care in ICU [31]. Thus, it is unknown if these preferences reflect what patients want from EOLC in ICUs. Future research exploring EOLC preferences of patients with advanced

cancer in ICUs will provide valuable information to guide ICU EOLC policies for this group of patients.

Most of the studies included in this review were retrospective chart reviews, in which researchers extracted care preferences and the care received from documentation in the medical chart. Retrospective reviews have many limitations, including inaccurate, incomplete, as well as a variance in the quality of the information recorded by health professionals [32]. In addition, retrospective reviews are intended to interpret what another person has written and are therefore subject to recall biases. However, prospective studies overcome these biases because they can generate a richer understanding of needs and preferences about EOLC elements directly from the patient's perspective, compared with retrospective reviews. Prospective studies also can integrate suggestions for improving EOLC from the patients' views, which is not possible with retrospective reviews.

Studies involving informal caregivers were undertaken after the death of their loved one and seeking to confirm whether this care was in line with the patients' preferences [26, 27]. These interviews rely on the recall of the informal carer. Recalling information after a stressful event or under grief may result in recall bias [33]. Family carers reported that it would have been better to talk about their experiences when the actual events took place or during early stages of bereavement rather than recalling this information at a time after their patients' deaths [31]. This may be because the carers may express their feelings and experiences of a live event more accurately without forgetting important information. Therefore, it is unclear whether the perceptions of EOLC are influenced by the level of distress of and recall by informal caregivers.

The majority of the studies highlighted the importance of teamwork and coordination of care in providing EOLC for patients and families, which appears to be less evident for patients with advanced cancer in ICUs at EOL as opposed to other settings [13, 34]. Early integration of interdisciplinary and collaborative approaches has been shown to improve teamwork and coordination of care in other settings and when PCTs are more actively involved in EOLC [14]. Likewise, it has been reported that family members of patients dying in an ICU evaluate EOLC less positively than family members of patients dying in a palliative care unit [35]. It appears this is related in part to family's expectations in relation to medical and nursing staff knowledge, skill and understanding of EOLC and also may be linked to the aim of the care and the medical team type [35]. That is, PCT's primary responsibility is to deal with patients and families at EOL and therefore the aim of care is directed and focussed on individuals and the families' preferences of EOLC. Whereas, intensive care overall is acute, short-term care. Thus, longer-term care and providing EOLC in ICU alongside of PCT appears challenging.

Patient-centred communication and shared decision-making are significant cornerstones of quality EOLC

processes from the patient's point of view [21, 29]. Although various communication strategies for handling difficult conversations with patients and families have been formulated [36, 37], most health professionals try to avoid EOL conversations and discussion of prognosis with patients [37]. This is an ethical issue that requires further efforts to rectify. Patient autonomy is limited when there is a lack of communication discussing prognosis and options for treatment, management in care. The EOLC process, including communication and decision-making, is challenging for patients, families and health professionals alike. A number of reviews [38, 39] have indicated the importance of this element in hospital settings and that patients and families generally perceive that patient-centred communication and decision-making, as well as teamwork and coordination of care and management of physical and psychological symptoms, are all elements that require further focus and improvement [38, 40]. A recent systematic review investigating EOLC elements in acute settings highlights the need for more effective communication and that shared decision-making is a crucial element in providing quality EOLC for patients and families [40].

Another significant element of EOLC that ICU patients and their families stress is support for physiological, physical and spiritual needs as highlighted in those studies included in this review. This finding is similar to that of a study conducted in an oncology department in a developing country [39]. While spiritual support is recognised as an important aspect for all patients who are at the end of life, irrespective of the setting, and most guidelines advocate this, the challenge is for health professionals to act and ensure spiritual care is provided to patients and their families [26, 39]. It is important that health professionals are educated or have access to training regarding the influence of spiritual beliefs on EOLC decision-making for patients and families [26].

Of those studies examining patient preferences and/or the receiving of their preferences, these could be aligned with approximately half of the essential elements in the ACSQHC consensus statement. While these essential elements are based on those recommended in Australia and include processes of care (patient focussed) and organisational prerequisites, these are not dissimilar to other countries which also include indicators for the individual patient and that of the health care system [41]. The majority of the studies included in this review reflect individual patient elements, with only two organisational elements raised (education and training and evaluation, audit and feedback). Future studies should ascertain if organisational elements including leadership and governance, supervision and support for interdisciplinary team members and systems to support EOLC are important to patients and their families when they are receiving EOLC in

ICU. Further studies should also examine the influence of these elements on EOLC in ICU.

As this review only includes articles published in English due to limited resources within the scope of this project, studies published in non-English languages and unpublished studies which may have explored the preferences in other cultural contexts is a limitation of this review. Additionally, all but one of the studies was conducted in developed countries. Thus, generalising the results of this review to ICU settings in developing countries may not be appropriate as medical and nursing care contexts, patient and family preferences may differ. However, it is unknown whether patient and family perspectives differ or are similar between developed and developing countries. More research is needed to explore the organisational and processes of care preferences of EOLC in both developed and developing countries, considering cultural differences to guide the formulation and implementation of EOLC approaches in ICU settings.

Conclusion

Despite the majority of studies included in this review being retrospective chart reviews, a number of factors have been identified as influencing EOL decision-making in the ICU setting for patients with advanced cancer. These include race, gender, ongoing open communication with both patients and families and the documentation of care preferences. Providing EOLC for patients with advanced cancer in ICUs is challenging. Few studies have explored families' perceptions of quality EOLC or organisational/system-specific measures that are important to be able to provide holistic quality EOLC. EOLC elements for patients with advanced cancer and their families in ICUs in developing countries are lacking, and further research is required.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

The author(s) also declare that they have full control of all primary data and that they agree to allow the journal to review their data if requested.

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