

Review Article

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What do we know about experiencing end-of-life in burn intensive care units? A scoping review

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Abstract

Objectives. The aim of this article is to review and synthesize the evidence on end-of-life in burn intensive care units.

Methods. Systematic scoping review: Preferred Reporting Items for Systemic Reviews extension for Scoping Reviews was used as a reporting guideline. Searches were performed in 3 databases, with no time restriction and up to September 2021.

Results. A total of 16,287 documents were identified; 18 were selected for analysis and synthesis. Three key themes emerged: (i) characteristics of the end-of-life in burn intensive care units, including end-of-life decisions, decision-making processes, causes, and trajectories of death; (ii) symptom control at the end-of-life in burn intensive care units focusing on patients' comfort; and (iii) concepts, models, and designs of the care provided to burned patients at the end-of-life, mainly care approaches, provision of care, and palliative care.

Significance of results. End-of-life care is a major step in the care provided to critically ill burned patients. Dying and death in burn intensive care units are often preceded by end-of-life decisions, namely forgoing treatment and do-not-attempt to resuscitate. Different dying trajectories were described, suggesting the possibility to develop further studies to identify triggers for palliative care referral. Symptom control was not described in detail. Palliative care was rarely involved in end-of-life care for these patients. This review highlights the need for early and high-quality palliative and end-of-life care in the trajectories of critically ill burned patients, leading to an improved perception of end-of-life in burn intensive care units. Further research is needed to study the best way to provide optimal end-of-life care and foster integrated palliative care in burn intensive care units.

Introduction

Burns are traumatic injuries that represent a personal catastrophe (Brusselsaers et al. 2010), having physical, psychosocial, and economic consequences (AbdelWahab et al. 2018; Sierra Zúñiga et al. 2016; Spronk et al. 2020). Advances allowed to extend the lives of patients whose burn injuries would have previously been invariably fatal (Kamolz 2010; Kearney et al. 2018; Lee et al. 2014).

Burns are a global public health problem, accounting for around 300,000 deaths annually (Forbinake et al. 2020; Stokes and Johnson 2017; WHO 2018). Evidence shows that 25% of patients aged 45–65 years with severe burns die (Ray et al. 2017). Moreover, burns are among the leading causes of disability-adjusted life years and morbidity, causing unbearable suffering (Bayuo et al. 2019; WHO 2018, 2019). Patients who survive burn injuries are often left with symptoms, rehabilitation needs, and quality of life challenges (Cook et al. 2020).

Patients' circumstances in burn intensive care units (Burn ICUs) can change rapidly (Higginson et al. 2013b). Symptom management and communication in this context are very challenging. Furthermore, it is paramount to identify and optimally address patients' specific needs, including the declination that may occur before death (Cohen-Mansfield et al. 2018; Fanning et al. 2017; Ray et al. 2017).

End-of-life care requires a specific set of competencies to enable improved quality of life, comfort, and family support. Nonetheless, end-of-life care is often neglected (Higginson et al. 2013a), particularly in Burn ICUs where it is rarely studied and frequently perceived as a clinical failure. End-of-life care processes in Burn ICUs can be challenging, raising relevant ethico-clinical questions about decision-making processes, informed consent, patient autonomy, patient–family–clinician relationship, and medical futility (Kerever et al. 2019;

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Teven and Gottlieb 2018). A timely recognition of the end-of-life stage allows patients and families to discuss values and preferences and make advance care plans, and clinicians to introduce appropriate, proportionate care (Stow *et al.* 2018). Protocols for decision-making and goals of care for critically burned patients at the end-of-life are feasible and improve end-of-life processes (Cook *et al.* 2020).

Palliative care (PC) improves patients and caregivers' quality of life (Krug *et al.* 2016; Perpina-Galvan *et al.* 2019; Sawatzky *et al.* 2017), promotes cost savings (O'Connor *et al.* 2018; Ruiz *et al.* 2017; Sawatzky *et al.* 2017), and relieves suffering (Streeck 2019). It may be provided both to patients who are likely to die within a short period of time and to seriously ill patients at any stage of their disease (Hua *et al.* 2014).

While there is not a consensual list of triggers for PC consultation in intensive care units (ICUs), it is possible to identify the following: (i) ICU after 10 or more days of hospitalization; (ii) patients over 80 years old, with 2 or more life-threatening comorbidities, where we may include burned patients; (iii) diagnosis of active stage IV malignancy metastatic disease; (iv) status after cardiac arrest; and (v) diagnosis of intracerebral hemorrhage requiring mechanical ventilation (Bradley *et al.* 2010; Hua *et al.* 2014; Norton *et al.* 2007). Identifying scores with the Acute Physiology and Chronic Health Evaluation III, the Burns Wean Assessment Program, the Therapeutic Intervention Scoring System, and the Wean Index may enable to explore appropriate interventions for each stage of a patient's burns and predict weaning outcomes (Burns *et al.* 2010; Gilani *et al.* 2014; Jeong and Lee 2018; Singh *et al.* 2018; Todd *et al.* 2019). Evidence suggests that end-of-life decision-making protocols were associated with increased utilization of comfort-focused treatments in Burn ICUs (Cook *et al.* 2020) and proportionate care (Abdelrahman *et al.* 2018; Collins *et al.* 2013). Anticipating the identification and referral of patients in ICUs who have PC needs and require care planning can optimize end-of-life care and avoid in-hospital death (Gao *et al.* 2013; Sierra Zúñiga *et al.* 2016).

Repeated exposure to death and grief may lead health-care professionals to occupational stress and burnout (Shorter and Stayt 2010; Velarde-Garcia *et al.* 2016). These work-related problems can cause emotional disengagement, causing a negative impact on patients and families' quality of life (Shorter and Stayt 2010). Preventive measures, such as ICU working groups, improving communication and shared decision-making during end-of-life care, preventing and managing conflicts within the team, and also integrating a PC approach in ICUs should be used (Le Gall *et al.* 2011; Martins Pereira *et al.* 2016; Moon and Kim 2015). Integrating PC can foster the discussion of care goals within the multidisciplinary team, helping patients, families, and professionals to better cope with and manage end-of-life issues (Coffey *et al.* 2011).

End-of-life care after making end-of-life decisions (e.g., withdrawing life-sustaining treatments) remains under-analyzed and needs further research (Martins Pereira *et al.* 2018; Penders *et al.* 2020). Multiple predisposing factors and circumstances may shape the nature of care of the dying and the grief process of their loved ones (Shorter and Stayt 2010).

A recent systematic review concluded that integrating PC in Burn ICUs improves patients' comfort, decision-making processes, and family care (Ribeiro *et al.* 2019). However, it seems to be mostly confined to the end-of-life period, suggesting that it is not fully integrated in the care process (Bayuo *et al.* 2019). Although this integration is perceived as an opportunity to improve end-of-life care and the dying and death processes, it is still underutilized

and under-protocolized (Lilley *et al.* 2018), warranting further research.

Objectives

The objective of this study is to review, appraise, and synthesize the existing evidence about end-of-life in Burn ICUs.

Methods

A systematically conducted scoping review was performed as the general purpose was to identify and map the available evidence about end-of-life care in Burn ICUs (Munn *et al.* 2018). We used the Preferred Reporting Items for Systemic Reviews extension for Scoping Reviews (PRISMA-ScR) as reporting guideline (Moher *et al.* 2009; Tricco *et al.* 2018) and followed Arksey and O'Malley (2005) as a methodological framework, with the refinements proposed by Levac *et al.* (2010). This framework is particularly useful when a body of literature has not yet been comprehensively reviewed. It may also be undertaken as an exercise to summarize and disseminate research findings, identify research gaps, and make recommendations for further research (Arksey and O'Malley 2005; Khalil *et al.* 2016; Levac *et al.* 2010; Munn *et al.* 2018; Peters *et al.* 2015, 2021a, 2021b).

Search strategy

Searches were performed in 3 databases, as recommended by the Joanne Briggs Institute (JBI) Reviewers' Manual (JBI 2015), as follows: PubMed, Web of Science, and EBSCO. MeSH terms or other possible terms related to the following 3 core sets/dimensions were used: Phenomenon of interest – end-of-life, dying, and death; Patient group – burned patients; and Context – (Burn) ICUs. The strategies were adapted as necessary for each database. No limit was placed on the year of publication or language of published articles. Thus, any document from inception until July 2020 was eligible for selection. Searches were updated in September 2021. Full search strategies and histories are provided in the Appendix.

Eligibility criteria

Population: Articles related to end-of-life for patients aged 18 and above, in Burn ICUs in English, Spanish, German, or Portuguese.

Intervention: Articles describing characteristics or care interventions in patients dying in Burn ICUs.

Comparator: No comparator was considered.

Outcome: The description of end-of-life in Burn ICUs.

Design: All research designs and types of articles were considered, except for systematic reviews.

Study selection

Titles and abstracts of retrieved articles were independently screened for relevance by 2 reviewers (A.F.R. and S.M.P.). Relevant publications, potentially eligible for inclusion, were read in full-text by 2 researchers (A.F.R. and S.M.P.), summarized, and discussed with a third researcher (P.H.-M.). Disagreements were resolved by discussion until reaching consensus among these 3 researchers (A.F.R., S.M.P., and P.H.-M.). Summary tables were presented to

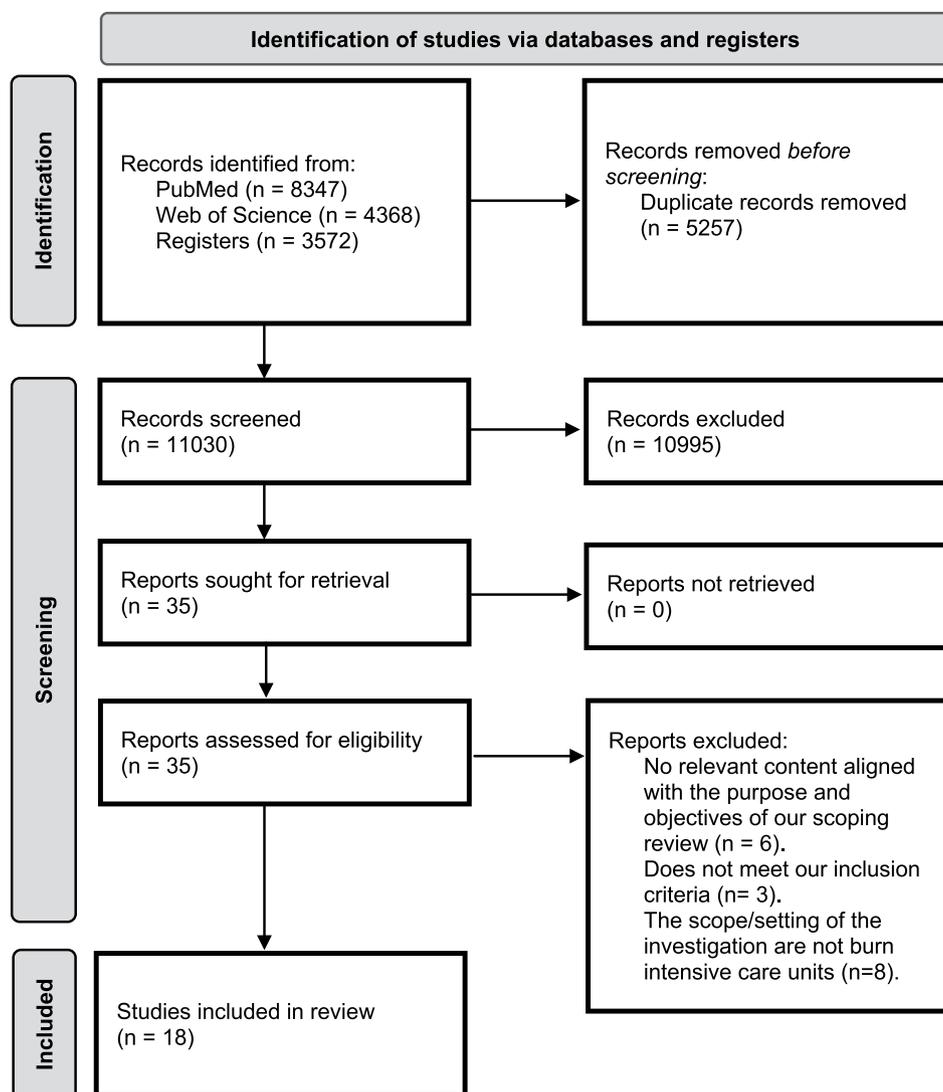


Fig. 1. PRISMA extension for Scoping Reviews (PRISMA-ScR) flowchart.

the other member of the team (R.N.). Figure 1 illustrates the PRISMA-ScR flowchart (Page et al. 2021; Tricco et al. 2018). Endnote X9 was used to remove duplicates and for reference management.

Quality assessment

Although quality assessment is not a required element of a scoping review (Arksey and O'Malley 2005; Brien et al. 2010), as our review has implications for both clinical practice and service organization (JBI 2015; Kazi et al. 2021) we appraised the methodological quality of the articles included in the analysis using Hawker et al. (2002)'s criteria.

Data analysis and synthesis

Data were independently extracted from eligible papers by 3 researchers (A.F.R., S.M.P., and P.H.-M.) using structured data forms purposively developed for this study. These forms were based on and adapted from PICOD's tool (Eriksen and Frandsen

2018; Methley et al. 2014): P = Participants (burned patients), I = Phenomena of interest (end-of-life, dying, and death), C = Context (Burn ICUs), O = Outcomes (end-of-life care), D = Design (all research designs, except systematic reviews, policy reports, or case reports). The forms also included the name of the authors, country, and methodological quality. A narrative and thematic synthesis was performed. First, we performed a textual narrative synthesis, systematizing and reporting on study characteristics, context, quality, and findings, using the scope, differences, and similarities among included articles. Second, a thematic synthesis, in which we grouped and aggregated data into themes, was conducted. No themes were defined *a priori*. The following key themes emerged from the analysis: (i) characteristics of the end-of-life in Burn ICUs, including end-of-life decisions, decision-making processes, causes of death, and trajectories of death; (ii) symptom control at the end-of-life in Burn ICUs focusing on patients' comfort; and (iii) concepts, models, and designs of the care provided to burned patients at the end-of-life, mainly care approaches, provision of care, and PC. Table 1 synthesizes the main findings aligned with Arksey and O'Malley (2005)'s framework.

Table 1. Operationalization of Arksey and O'Malley's framework in this scoping review

Arksey and O'Malley's methodological framework for scoping reviews	Operationalization
(i) Identification of the research question	What are the main characteristics of the end-of-life and end-of-life care in burn intensive care units?
(ii) Identification of relevant studies	Searches were performed in 3 databases, from inception to September 2021.
(iii) Study selection with the establishment of inclusion/exclusion criteria, based on familiarity with the literature	Inclusion criteria: Articles related to the end-of-life in burn intensive care units, full-text available, were published in peer-reviewed journals, in English, Spanish, German or Portuguese were considered eligible. All research designs and types of articles were considered, except for systematic reviews. Exclusion criteria: Patients under 18 years old.
(iv) Charting the data (included: sifting, charting, and sorting information according to key issues and themes)	Charting of the data followed the PICO(D)'s tool. A narrative and thematic synthesis was performed. Three key issues and themes were defined: characteristics of the end-of-life in burn intensive care units; symptomatic control at the end-of-life in burn intensive care units; and concepts, models, and designs of the care provision. Qualitative content analysis approaches were performed to make sense of the wealth of extracted data.
(v) Collating, summarizing, and reporting the results	Three steps were taken to increase the consistency: analyzing the data, reporting results, and applying meaning to the results. The main findings are reported and aligned with the key issues and themes that resulted from the previous step.
(vi) Consultation exercise	This is an additional optional step. This scoping review is part of a larger study on the integration of palliative care in burn intensive care units. It informed further research approaches, namely the development of an interview guide and focus groups.

Results

Database searches retrieved a total of 16,287 articles; 35 articles were full-text assessed for eligibility. Eighteen articles were included in our review, as illustrated in the PRISMA-ScR flowchart (Figure 1).

Description of the articles included for analysis and synthesis

Three main themes were identified: (i) characteristics of the end-of-life care in Burn ICUs; (ii) symptom control at the end-of-life in Burn ICUs; and (iii) concepts, models, and designs of the care provided. Other subthemes that emerged within these main topics were comfort care in critically ill burned patients, end-of-life decisions, and trajectories to death in patients with burn injuries. Figure 2 illustrates and synthesizes these themes and subthemes, relating them to main stakeholders.

One of the included articles studied the use of a care pathway, which was a valid tool, improving the quality of end-of-life care (Hemington-Gorse *et al.* 2011). It was based on the Liverpool Care Pathway, which is an evidence-based framework of care for the dying patient, providing guidance on comfort measures, discontinuation of inappropriate interventions, anticipatory prescribing, holistic care, and bereavement care (Al-Benna 2013).

End-of-life decision-making processes were studied in 6 of the selected articles. In 5 of them, retrospective case notes reviews were undertaken, retrieving information from 8,639 patients whose care provision required end-of-life decision-making sustained in burn severity and associated comorbidities (Bartley *et al.* 2019; Hemington-Gorse *et al.* 2011; Ismail *et al.* 2011; Partain *et al.* 2016; Pham *et al.* 2012). In another article, an electronic survey was randomly applied to burn specialists from several countries participating in 2 scientific events (Metaxa and Lavrentieva 2015). Their

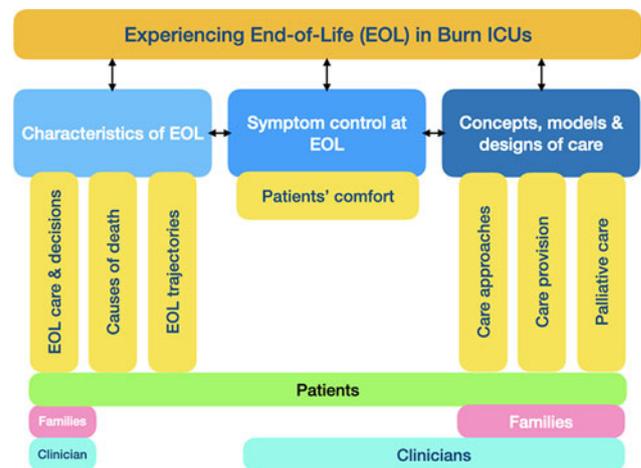


Fig. 2. Experiencing end-of-life in burn intensive care units: synthesis of themes and subthemes.

main concerns in the decision-making processes were the severity of burns, no response to treatment, and poor quality of life.

Another study considered 6,212 cases reported from regional and national Burn Repository databases in the USA. The majority of burn deaths had a specific burn pattern, allowing the distinction and characterization of 4 types of trajectories (Swanson *et al.* 2013). Mortality and acute burden were also studied (Weng *et al.* 2019). Two studies analyzed 7,020 deaths, finding that multiple organ failure was the most common cause of death among burned patients (Bloemsma *et al.* 2008; Dokter *et al.* 2015). To improve the approach for the critically burned patients' families, other studies evaluated the effect of training and early PC consultation programs applied to multidisciplinary teams from trauma/Burn ICUs and implemented gold standards for comfort care for burn

patients (Carmichael et al. 2021a, 2021b; Wessman et al. 2017; Zack-Williams et al. 2021).

Finally, 2 articles explored, qualitatively, the experiences of professionals and relatives of patients who were cared in Burn ICUs at the end-of-life. These studies highlight the experiences of “hanging in balance” and managing uncertainty, suggesting the need for a better integration of PC in Burn ICUs (Bayuo et al. 2021a, 2021b).

A summary of the characteristics of the articles included in our analysis and synthesis is presented in Table 2. To better understand end-of-life experiences and care in Burn ICUs, we provide an overview of the content of these articles focusing on the preparation for the end-of-life, provision of end-of-life care, and follow-up for families/professional caregivers (Table 3). Table 4 synthesizes the key themes and subthemes about the end-of-life in Burn ICUs.

What are the main characteristics of the end-of-life and end-of-life care in Burn ICUs?

End-of-life care and decisions

Forgoing (i.e., withdrawing/withholding) treatment is the most frequent decision made in Burn ICUs. Withdrawing treatment is the deliberate cessation of life-sustaining treatment, despite the awareness that this might lead to the patient's death; withholding treatment consists of the decision to not give a life-sustaining treatment. This conceptual clarification was considered to be important as well as do-not-attempt to resuscitate orders (Ismail et al. 2011; Metaxa and Lavrentieva 2015).

It is vital to understand decision-making rationales and provide quality and proportionate care at the end-of-life (Swanson et al. 2013). Encouraging new developments (e.g., better understanding of fluid creep, computer-assisted decision support of fluid resuscitation, and rescue therapies) may improve early end-of-life care, defined as the terminal care provided for patients with early rapid decline of their health status, due to burn shock, and also for those with early organ failure after Burn ICU admission, mainly with sepsis or multiple organ failure (Swanson et al. 2013).

The main reasons to decide between withholding and withdrawing treatment were severity of burns (78%), no response to the treatment (68%), and high probability of dying (68%) (Metaxa and Lavrentieva 2015). The most significant aspects for making end-of-life decisions in burned patients were the likelihood of returning to independent living (Pham et al. 2012) and, for patients aged under 65 years, the size/severity of their burns, and, in older patients, the presence of comorbidities (Ismail et al. 2011).

Physicians in Burn ICUs often experience reluctance to forgo life-sustaining therapies (Metaxa and Lavrentieva 2015), which may delay comfort care (Bayuo et al. 2021a). One study reported that 73% of the participant clinicians considered withholding and withdrawing decisions as being ethically distinct; 30% of these physicians considered that they would forgo (i.e., withhold/withdraw) the treatment of conscious patients without discussing it with their families (Metaxa and Lavrentieva 2015). The same study found that nurses participated in less than 50% of end-of-life decisions and 81% of the intensivists would not forgo treatment if patients' families held a different opinion. When forgoing treatment decisions were made, 42% of the physicians would choose to withhold treatment, 37% to withdraw, and 22% neither of the options, but would apply do-not-attempt-to-resuscitate orders (Metaxa and Lavrentieva 2015). Implementing a protocolized withdrawal procedure allowed to consistently improve the palliation of end-of-life symptoms without hastening death (Pham et al. 2012).

Main causes of death and end-of-life trajectories

The most common comorbidities of burn patients were circulatory and endocrine conditions (Dokter et al. 2015). The most common causes of death were multiple organ failure (Bloemsma et al. 2008; Dokter et al. 2015; Kallinen et al. 2012; Swanson et al. 2013), burn shock (36%), sepsis or multi-organ failure (28%), and lung injuries (14%) (Swanson et al. 2013). Different typical pathways were also identified for burn-related deaths: (i) most patients with burn injuries followed a pattern of steady deterioration and died in an early rapid decline regardless of age, mainly due to burn shock (62%); (ii) sepsis/multi-organ failure were the main causes for early organ failures that lead to patients' deaths; (iii) patients who were stable, until they experienced myocardial infarction or pulmonary embolus and died of late sudden death; and (iv) late terminal illness decline trajectory in patients that initially tolerated resuscitation, but developed subsequent complications, as wound infections or even pneumonia, urging a downward trajectory to death that lasted over than 24 h.

Patients with more severe injuries had an early decision for comfort care, experienced a shorter time to death, and fewer interventions, such as surgeries (Bartley et al. 2019; Partain et al. 2016). Nevertheless, as highlighted by family members and professionals, end-of-life trajectories were characterized by uncertainties in the period preceding death. Experiencing the end-of-life trajectory of a loved one with severe burns in a Burn ICU was perceived as journeying through uncertainty, ebbing away, and coming to terms with a loss (Bayuo et al. 2021b).

How is symptom control provided at the end-of-life in Burn ICUs?

Symptom control and patients' comfort

Symptom control is an integrated part of care provision in Burn ICUs. One article highlighted that a large proportion of patients had no comprehensive documentation of the care they received at the end-of-life (Ismail et al. 2011). While there are multiple references to comfort care, there is no mention of specific care interventions (Bartley et al. 2019; Swanson et al. 2013; Wessman et al. 2017). Using a PC framework and approach improves patients' comfort and reduces symptom burden. It also allows highlighting areas where the goals of care have not been attained (e.g., symptoms requiring attention and specific clinical interventions) (Hemington-Gorse et al. 2011). Participants from one study mentioned pain as a physical need, noting how loneliness due to isolation could exacerbate pain. Deteriorating conditions were also noted to be unable to tolerate oral feeding leading to emaciation, and some patients became unconscious with breathing difficulties (Bayuo et al. 2021a).

What are the concepts, models, and designs of care provision at the end-of-life in Burn ICUs?

Care approaches

Most burned patients at the end-of-life in Burn ICUs show early and repeated instability, although a potentially protracted course. More than three-quarters of burn deaths are attributable to failure or significant decompensation beginning in the resuscitation phase (Swanson et al. 2013). The Injury Severity Score and the Abbreviated Burn Severity Score are used to calculate the acuity of multiple organ systems, while the Charlson Comorbidities Index is used to evaluate the burden of preexisting comorbidities

Table 2. Characteristics of the articles ($n = 18$) included for analysis

Authors (year) country	P: Participants	I: Intervention(s)	C: Comparison(s)	O: Outcome(s) related to our research objectives	D: Design	Quality assessment score following Hawker <i>et al.</i> (2002)
Al-Benna <i>et al.</i> (2013) United Kingdom	Not applicable	Not applicable	Not applicable	This letter highlights that more evidence is required to determine if the Liverpool Care Pathway improves end-of-life care, namely in Burn ICUs.	Letter to the Editor	Not applicable
Bartley <i>et al.</i> (2019) United States of America	Medical records of burned patients admitted to the North Carolina Jaycee Burn Center at the University of North Carolina. 8,371 patients were included for analysis.	To evaluate burned patients admitted to the burn intensive care unit and potentially provide objective predictors of withdrawal of life support.	No comparisons	The decision to withdraw life support is a complex and difficult process that must be supported using objective clinical data. Female gender and increasing age were significantly associated with an increased odds of withdrawing life support in burn intensive care units. Overall, increased risk of mortality is likely to predict withdrawal of life support.	Retrospective analysis of all burned patients' records from 2002 to 2012	30
Bayuo <i>et al.</i> (2021a) Ghana	Burn care staff working in a large teaching hospital in Ghana	To explore the end-of-life care experiences of burn care staff and ascertain how their experiences can facilitate the development of clinical guidelines. No specific intervention.	No comparisons	Experiences of burn care staff are complex with 4 themes emerging: (i) evaluating injury severity and prognosis, (ii) nature of existing system of care, (iii) perceived patient needs, and (iv) considerations for palliative care in burns. Guidelines in this regard should focus on facilitating communication between the patient and family and staff, holistic symptom management at the end-of-life, and post-bereavement support for family members and burn care practitioners.	Interpretive descriptive qualitative approach with a sequential 2-phased multiple data collection strategies was employed (face-to-face semi-structured in-depth interviews and follow-up consultative meeting).	30
Bayuo <i>et al.</i> (2021b) Ghana	Family members of injured persons who died in a burn unit in Ghana	To explore the experiences of family members whose relatives died in the burn unit to inform the development of practice recommendations. No specific intervention.	No comparisons	Three themes emerged: reactions following injury occurrence, navigating through the experience, and managing uncertainties about survival.	Face-to-face semi-structured interviews were conducted and followed up with telephone interviews.	28
Bloemsma <i>et al.</i> (2008) The Netherlands	Records from the Rotterdam burn center and the American National Burn Repository. 123,876 patients were admitted, from which 6,932 deaths were studied.	To review and describe the population, compare the results and analyze causes of death following burn injuries in 2 centers.	Compared mortality rates from the mentioned centers.	During the considered time frame, the mortality rate in the Rotterdam burn center was 6.9%; among the patients admitted with an intention to treat it was 4.9%. Multiple organ failure was the most common cause of death (64.9%), and its fatality was due to a final fatal infection in 45.9% of the cases.	Retrospective analysis of mortality data from 1996 to 2006	23

(Continued)

Table 2. (Continued.)

Authors (year) country	P: Participants	I: Intervention(s)	C: Comparison(s)	O: Outcome(s) related to our research objectives	D: Design	Quality assessment score following Hawker et al. (2002)
Carmichael et al. (2021a) United States of America	Records of deceased burned patients over a 4-year period. A total of 33 patient deaths were reviewed.	To examine the impact of a protocol using recommended “triggers” for palliative care consultation (PCC) at a single academic burn center.	The use of PCC was compared during periods before and after a protocol establishing recommended triggers for early (<72 h of admission) PCC was instituted.	Among patients who survived >24 h, 67% (n = 14/21) had PCC. Frequency of PCC increased after protocol development, with 100% vs 36% of these patients having PCC before death (p = 0.004). However, even during the later period, less than half of patients had early PCC despite meeting criteria at admission.	Retrospective review of patient deaths over a 4-year period	Conference abstract
Carmichael et al. (2021b) United States of America	Records of deceased burned patients over a 4-year period. A total of 33 patient deaths were reviewed.	To examine the impact of a protocol using recommended “triggers” for PCC at a single academic burn center.	The use of PCC was compared during periods before and after a protocol establishing recommended “triggers” for early (<48 h of admission) PCC was instituted.	Among patients who survived >24 h, 67% (n = 14/21) had PCC. Frequency of PCC increased after protocol development, with 100% vs. 36% of patients having PCC before death (p = 0.004). However, even during the later period, only half of the patients had early PCC despite meeting the criteria at admission.	Retrospective review of patient deaths over a 4-year period	Conference abstract
Dokter et al. (2015) The Netherlands	Digital patients' records from the joint burn registry from the Rotterdam and Beverwijk burn centers. 2,730 patients were admitted during the period under analysis. 88 patients' deaths were included in the study.	To determine the mortality and causes of death of burn patients.	Comparisons were established between patients receiving active treatment, the withdrawal of active treatment group, and the palliative care group (for patients receiving no curative care).	Patients in the palliative care group died within 4h as a direct result of their injury (n = 28, 31.8%) and had significantly less comorbidities (35.7%) compared to the withdrawal of care group (86.2%) and the active treatment group (80.6%) (p < 0.001). Most in-hospital mortality occurs early due to palliative care or withdrawal of active treatment (about one-third each). For patients with late mortality, the most common cause of death is multiple organ failure (38.3%).	Retrospective study of burn patients who died between January 2006 and December 2011	28
Hemington-Goose et al. (2011) United Kingdom	Paper notes and electronic records stored on Metavision™. 22 patients' deaths were included for analysis.	To assess the adherence to the Burn Modified Liverpool Care Pathway (BM-LCP) at the St Andrew's Centre for Burns.	No comparisons	BM-LCP allows highlighting areas where goals of care in end-of-life need to be attended. Patient comfort is increased while burden and families' bereavement levels tend to be lower.	Retrospective analyses of paper notes and electronic patient records	26

(Continued)

Table 2. (Continued.)

Authors (year) country	P: Participants	I: Intervention(s)	C: Comparison(s)	O: Outcome(s) related to our research objectives	D: Design	Quality assessment score following Hawker <i>et al.</i> (2002)
Ismail <i>et al.</i> (2011) United Kingdom	Notes from the West Midlands Regional Burn Service. 63 patients' records were included for analysis.	To review the withdrawal of life-sustaining treatment, the issuing of do-not-resuscitate orders and end-of-life care in burned patients' deaths.	No comparisons	End-of-life decisions in patients under 65 years of age were more often due to burns' severity. In those aged above 65 years, reasons were made late in the patient's admission and concerning comorbidities. In 34% of patients, end-of-life care was not comprehensively documented.	Retrospective review of case notes	25
Kallinen <i>et al.</i> (2012) Finland	Medico-legal autopsy reports and clinical data were collected during treatment from the Helsinki burn center. Of the 1,370 patients admitted, 74 died in the unit (5.4%). Only 71 had sufficient data to be included in the study.	To investigate the causes of death in patients with burns and to specify irreversible organ dysfunctions leading to death.	No comparisons	Of the assessed patients, 32 received comfort care after being considered to have no hope of survival within 24 h of the burn injury, considering the etiology, extent of the burn injury, age, and comorbid conditions. Multiple organ failure after burn was the leading cause of death ($n = 56$, 79%). In this group, lungs were affected in 18 patients, allowing the document of 2 types of injuries: acute respiratory distress syndrome ($n = 6$) and pneumonia ($n = 8$). Large burn injury was the direct cause of death for 28 patients. In this group, all patients received comfort care.	Retrospective analysis of 11 years of clinical data	28
Metaxa and Lavrentieva (2015) Several countries; not possible to specify	Burn intensive care physicians were randomly selected from the directories of the 45th annual meeting of the American Burn Association and the 15th European Burns Association Congresses. 41 participants were included.	To evaluate physicians' beliefs, values, considerations, and difficulties in end-of-life decisions in burn intensive care units.	No comparisons	Burn intensive care physicians make a clear distinction between withholding and withdrawing life-sustaining treatments, preferring to adopt the former in their clinical practice. Severity of burns, no response to treatment, and poor outcomes in quality of life are the main considerations for deaths.	Online survey study	25

(Continued)

Table 2. (Continued.)

Authors (year) country	P: Participants	I: Intervention(s)	C: Comparison(s)	O: Outcome(s) related to our research objectives	D: Design	Quality assessment score following Hawker et al. (2002)
Partain et al. (2016) United States of America	Electronic charts from all patients over 65 years of age, admitted to the Parkland burn center, who died within this episode. 57 patients were identified.	To investigate the impact of the timing of goals of care discussions on outcomes in geri-burn patients who did not survive their injury.	There is a comparison between an early discussion of goals of care group (within 24 h after admission) and a late discussion group (after 24 h of admission).	95% of the subjects had at least one documented discussion between a burn physician and the patient or surrogate, regarding code status and aggressiveness of the treatment plan. The severity of injuries appears to hasten burn surgeons' decision to initiate a family discussion regarding goals of care. The early nature of this discussion and the greater magnitudes of injury do not lead to care more quickly. However, these patients suffered significant fewer interventions and died more quickly as a consequence of their injury.	Retrospective review of charts from April 2009 to December 2014	29
Pham et al. (2012) United States of America	Medical charts from adult patients admitted to the University of Washington Regional Burn Center. 126 patients were considered for analyses.	To evaluate the frequency of early withdrawal and the impact of a stepwise protocol on end-of-life process of care in burn patients who died within 72 h of hospitalization.	Comparison between before and after using a protocol that emphasizes a stepwise approach to withdrawal of life-sustaining support.	The large majority of early burn deaths occurred via withdrawal of life support. Implementing a protocolized withdrawal has resulted in more consistent provision of analgesia and sedation without hastening death. Using a protocol for the withdrawal of life support should be considered by burn centers in order to improve consistency in end-of-life symptoms palliation.	Retrospective chart review of all adult patients admitted from January 1995 to December 2007	29
Swanson et al. (2013) United States of America	National Burn Repository database and regional burn center in Seattle, Washington. 6,212 records of patients were analyzed concerning injury and death characteristics.	To test the hypothesis that burn non-survivors will follow distinct temporal distributions and patterns of decline, parallel to the tri-modality of deaths previously described for trauma.	No comparisons	The majority of burn deaths follow a pattern of early and rapid decline or early organ failure manifested by death or critical illness. More than three-quarters of burn deaths are related to failure or significant decompensation in the beginning of the resuscitation phase.	Retrospective analysis of repository database	23
Weng et al. (2019) Taiwan	1,823 cases of burn injuries from the emergency service at a medical center.	To identify risk factors and quantify the disease burden following burn injury, including outcomes of fatality, length of hospitalization, and acute medical cost.	No comparisons	328 cases (18.0%) required further hospital admissions; 8 cases (0.4%) died within 30 days, and 17 cases (0.9%) died within 1 year.	Retrospective case reviews	Conference abstract from a poster presentation

(Continued)

Table 2. (Continued.)

Authors (year) country	P: Participants	I: Intervention(s)	C: Comparison(s)	O: Outcome(s) related to our research objectives	D: Design	Quality assessment score following Hawker <i>et al.</i> (2002)
Wessman <i>et al.</i> (2017) United States of America	The intervention was provided to nursing, ancillary staff, house staff, and attending physicians from a tertiary trauma intensive care unit. 122 participants responded to the pre-intervention and 101 to the postintervention survey.	To test the effect of a novel goal of care/end-of-life focused program providing a multidisciplinary communication approach for the critically ill burned patients' families.	Comparison between before and after applying the multidisciplinary teamwork, communication tools, and didactic sessions.	The developed program involved input from diverse critical care providers with a specific focus on improved education, improved family communication and support, improved order sets, and improved intensive care units' resources to support end-of-life care. Observed benefits include improving caregivers' perceptions regarding end-of-life/goals of care issues, lowering self-perceived work stress, and fostering critical care team growth. Improved perception and experience of the critical care provider were documented, as they helped both patients and their families' transition into the end-of-life spectrum of care.	A survey evaluation was completed between the years 2011 and 2013.	27
Zach-Williams <i>et al.</i> (2021) United Kingdom	Not applicable	Not applicable	Not applicable	This letter highlights that the decision to deliver comfort care for patients with major burns should be between senior and experienced burn professionals who have directly assessed the patient whenever possible. Even patients who may die within a few days of admission to a burn center will receive, where necessary, expert PC.	Letter to the Editor	Not applicable

Table 3. Overview of the experiences related to the end-of-life in burn intensive care units

Preparing for the end-of-life	Provision of end-of-life care	Follow-up for families and/or professional caregivers
<p>Decision-making processes reflect the complexity of the clinical situations experienced in burn intensive care units (Bartley et al. 2019; Metaxa and Lavrentieva 2015; Partain et al. 2016).</p> <p>Patients' medical condition is used to support decisions (e.g., burn size/severity, comorbidities, and multi-organ failure) (Dokter et al. 2015; Ismail et al. 2011; Weng et al. 2019).</p> <p>Types of burn death trajectories (Partain et al. 2016; Swanson et al. 2013).</p> <p>Multiple organ failure is the most common cause of death in burned patients (Bloemsma et al. 2008; Dokter et al. 2015; Kallinen et al. 2012; Swanson et al. 2013).</p> <p>The end-of-life period in the burn unit is poorly defined coupled with prognostic uncertainty (Bayuo et al. 2021a, 2021b).</p> <p>Decisions are made by the burns multidisciplinary team (Hemington-Gorse et al. 2011; Ismail et al. 2011).</p> <p>Educational and intervention programs, such as quality improvement initiatives, may help to improve the work of the health-care team, softening the experience of transitioning into the end-of-life spectrum of care for both patients and their families (Carmichael et al. 2021a, 2021b; Wessman et al. 2017).</p>	<p>Clarifying the concept of forgoing (i.e., withholding and/or withdrawing) life-support treatments and do-not-attempt to resuscitate orders (Bartley et al. 2019; Metaxa and Lavrentieva 2015; Partain et al. 2016).</p> <p>The Burn Modified Liverpool Care Pathway (BM-LCP) provides an educational strategy for professionals' education related to terminal care (Hemington-Gorse et al. 2011).</p> <p>The BM-LCP conducts a pathway to symptomatic control, improving patients' comfort and decreasing experienced burden (Hemington-Gorse et al. 2011).</p> <p>More evidence is required to determine if the Liverpool Care Pathway improves end-of-life care, namely in Burn ICUs (Al-Benna 2013).</p> <p>Decisions to providing comfort care for patients with major burns should be made by senior and experienced burn professionals. Even patients who may die within a few days of admission to a burn center should receive, where necessary, expert palliative care (Zack-Williams et al. 2021).</p>	<p>Relatives' bereavement is lower when terminal patients are treated with palliative care principles (Hemington-Gorse et al. 2011).</p> <p>Structured pathways provide education and feedback to professionals involved in terminal care (Hemington-Gorse et al. 2011).</p> <p>Bereavement/post-bereavement support for family members was recommended. It should be tailored to the unique needs of family members and offered by the palliative care team (Bayuo et al. 2021b).</p>

for patients in Burn ICUs (Bartley et al. 2019; Kallinen et al. 2012; Swanson et al. 2013).

In one study, most burns (68%) were due to flames. The average total body surface burned area was 53% in patients under 65 years of age, compared to 17% in patients over 65 years. In total, 96% of the patients over 65 years had significant comorbidities, including diabetes mellitus, cardiovascular diseases, epilepsy, alcoholism, and chronic obstructive pulmonary disease (Ismail et al. 2011).

The Burn Modified Liverpool Care Pathway is a care model, with positive results for patients, their relatives, and teams (Hemington-Gorse et al. 2011). This pathway was easy to adhere to and well received. Training/educational programs with multiple inputs about end-of-life care are used to improve health care, order sets, and resources to support end-of-life care in Burn ICUs (Wessman et al. 2017).

Provision of care

Decision-making processes affect care. Swanson et al. (2013) suggested that efforts should concern 2 divergent aims: first, an early institution of comfort care, the most humane option in massive injuries, and a better understanding of decision-making rationales and high-quality end-of-life care; second, difficult resuscitations, encouraging developments that may improve early care, such as a better understanding of fluid creep, computer-assisted decision support for fluid resuscitation, and rescue therapies.

How professionals are organized in Burn ICUs may also play a relevant role in quality of care. A US survey found that more than 60% of the participating hospitals had a nurse–patients ratio of 1:2 or less, which was associated with reduced incidence of withholding/withdrawing treatment (Metaxa and Lavrentieva 2015). Structural aspects may also be identified. In one study, all surgeries were performed in the burn operating room, and burned

patients in the ICUs were cared for in a discrete area of the central unit. Two teams were involved in the process of care: the burns team (i.e., specialists in burn treatment) and the team of intensivists and anesthesiologists (Ismail et al. 2011). Multidisciplinary teams were composed of a surgeon, a burns anesthesiologist, a senior nursing staff, and a therapist (Hemington-Gorse et al. 2011). PC teams were not involved in the care of most of these patients.

Besides being difficult to make, end-of-life decisions may not have happened on time. Out of the 63 patients participating in one study, only 3 had an input from the PC team (Ismail et al. 2011).

Palliative care

PC was rarely involved in end-of-life care in Burn ICUs. Four studies highlighted the input of a PC team, but for a minority of patients (Carmichael et al. 2021a, 2021b; Dokter et al. 2015; Ismail et al. 2011). Qualitative studies with professionals and family members emphasized that PC should come alongside active treatment for severely burned (Bayuo et al. 2021a, 2021b), focusing on communication, symptom management, and post-bereavement support for relatives and staff (Bayuo et al. 2019, 2021a, 2021b). PC may have the benefit of attaining person and family-centered care at the end-of-life and needs to be integrated in Burn ICUs to ensure that persons whose injuries are deemed unsurvivable and their families receive adequate support (Bayuo et al. 2021b).

Discussion

This scoping review shows the paucity of studies focusing on end-of-life care in Burn ICUs. Included articles were heterogeneous and focused mostly on clinical records/databases or professionals' (physicians) perspectives. The main findings suggest the presence of different trajectories to death in patients with burn injuries. Most

Table 4. Synthesis of the key themes and subthemes about the end-of-life in burn intensive care units

Key themes ^a	Subthemes	Main findings
Characteristics of the end-of-life in burn intensive care units	End-of-life decisions	End-of-life decisions were reported, namely forgoing (i.e., withdrawing and/or withholding treatment) (Bartley et al. 2019; Metaxa and Lavrentieva 2015) and do-not-attempt to resuscitate (Ismail et al. 2011). Reluctance of burn intensive care physicians to forgo life-sustaining treatments was observed (Bartley et al. 2019; Metaxa and Lavrentieva 2015).
		Reasons to forgo (withhold/withdraw) treatments were described, namely severity of burns, no response to treatment, high probability of dying, expected poor outcome, age, previous and potential future quality of life, patient/family request (Bartley et al. 2019; Metaxa and Lavrentieva 2015; Pham et al. 2012), and likelihood of return to independent living (Pham et al. 2012).
		Age-related end-of-life decision-making was identified. For patients aged under 65 years, the main reason to make an end-of-life decision was burn size/severity; for patients aged 65 years and above, the main reason was the presence of comorbidities (Ismail et al. 2011).
		The severity of the injuries accelerated and improved the discussions about the goals of care, and the vast majority of deaths occur after that (Partain et al. 2016). These decisions were discussed with the family or next of kin when possible (Ismail et al. 2011; Partain et al. 2016).
		The observation that, despite maximal treatment, death was inevitable was made by the burns multidisciplinary team. This team was composed of the following members: consultant surgeon, consultant burns anesthetist, senior nursing staff, and therapists (Hemington-Gorse et al. 2011). The decision-making process would involve the intensive care medical team (Metaxa and Lavrentieva 2015). Nurses were rarely involved (Metaxa and Lavrentieva 2015).
	The end-of-life period in the burn unit is poorly defined coupled with prognostic uncertainty (Bayuo et al. 2021a).	
Main causes of death		The most common comorbidities of burned patients who died were circulatory and endocrine conditions (Dokter et al. 2015).
		Burn shock, sepsis, or multiple organ failure (Bloemsma et al. 2008; Dokter et al. 2015, Kallinen et al. 2012; Swanson et al. 2013).
		Female gender and increasing age were significantly associated with an increased odds of withdrawal of life support in the burn intensive care unit (Bartley et al. 2019).
End-of-life trajectories		Four end-of-life trajectories were identified: (i) early rapid decline (patients with the highest mean size burn); (ii) early organ failure; (iii) sudden death; and (iv) late terminal illness (Swanson et al. 2013).
		Mortality and acute burden were studied (Weng et al. 2019). Patients with more severe injuries had an early decision for comfort care, experienced a shorter time prior to death, and fewer interventions, including surgeries (Bartley et al. 2019; Partain et al. 2016).
		End-of-life trajectories in burn intensive care units are characterized by uncertainty (Bayuo et al. 2021a, 2021b).
Symptomatic control at the end-of-life in burn intensive care units	Patient comfort	Several references to comfort care without mentioning specific care interventions (Bartley et al. 2019; Swanson et al. 2013; Wessman et al. 2017; Zack-Williams et al. 2021).
		Symptom control and attending goals of care increased patients' comfort and reduced burden (i.e., pain free, not agitated, no breathlessness, mouth care, not troubled by secretions, no nausea or vomiting, adequate wound care, medication given as planned, pressure care, psychological support, and family support) (Hemington-Gorse et al. 2011).
		Implementing a protocolized withdrawal consistently improved the palliation of end-of-life symptoms without hastening death (Pham et al. 2012).
Concepts, models, and designs, of the care provision	Care approaches	A multidisciplinary program was implemented for health-care teams, with multiple inputs about end-of-life care and goals of care, improved education, family communication, and support. It also improved order sets, and intensive care units' resources to support end-of-life care (Wessman et al. 2017).
		Various instruments were used to assess the severity of the patient's condition, namely the Injury Severity Score (Wessman et al. 2017), the Abbreviated Burn Severity Score (Kallinen et al. 2012), and the Charlson Comorbidities Index (Bartley et al. 2019; Kallinen et al. 2012; Swanson et al. 2013).
	Provision of care	Using a care pathway (i.e., Burns Modified Liverpool Care Pathway) improved the quality of end-of-life care in burn intensive care units (Al-Benna 2013; Hemington-Gorse et al. 2011).
	Provision of care	Organizational factors may have played a relevant role in the care approaches, since a large majority of participant hospitals had a nurse-patient ratio of 1:2 or less, which was associated with reduced incidence of forgoing treatment decisions (Metaxa and Lavrentieva 2015).

(Continued)

Table 4. (Continued.)

Key themes ^a	Subthemes	Main findings
		Care was mostly provided by burn teams in combination with intensivists and anesthetists (Ismail et al. 2011).
	Palliative care	Palliative care was rarely involved in end-of-life care provision in burn intensive care units. The input of palliative care was mentioned, but only for a minority of burned patients (Carmichael et al. 2021a, 2021b; Dokter et al. 2015; Ismail et al. 2011).
		A collaborative model of practice and further training were recognized as being required to support the integration of palliative care in the burn unit (Bayuo et al. 2021a).

^aStep (iv) in Arksey and O'Malley's framework, as reported in Table 1.

deaths in Burn ICUs are preceded by end-of-life decisions. The complexity of making end-of-life decisions and inherent decision-making processes is also explored. It seems that symptom control in critically ill burned patients facing the end-of-life in Burn ICUs has received little attention. Specialist PC was rarely involved in end-of-life care in these units.

Deaths in Burn ICUs are often preceded by end-of-life decisions, namely forgoing treatment and do-not-attempt to resuscitate. Nevertheless, there is a need to further improve decision-making processes, increasing the discussion about the goals of care with patients, family members, and even with other team members (e.g., nurses), and managing uncertainty.

End-of-life care is a major step in the care provided to critically ill burned patients in Burn ICUs and their families. It requires a specific set of competencies to enable improved quality of life, comfort, and optimum family support. Still, end-of-life care in Burn ICUs is often neglected, and there is a scarcity of studies on this specific topic.

Communication with critically ill burned patients and their families is difficult for professionals working in Burn ICUs. Often, professionals feel unprepared to face end-of-life situations. Communication obstacles are mostly related to family engagement, information exchange, process transparency, and standardization for both clinicians and family members in Burn ICUs (Fanning et al. 2017). There is a long way still to improve communication, particularly for patients to express their end-of-life wishes. Among teams, roles need to be better clarified, and guidelines should be developed alongside competencies and changes in the organizational and physical environment (Bernacki et al. 2014; Bergenholtz et al. 2019).

Communication is a key element to manage decisions, particularly those surrounded by uncertainty (Bayuo et al. 2021b, 2019). These decisions are based on clinical knowledge, previous experiences, and personal beliefs (Ismail et al. 2011). Improving end-of-life care is part of high-quality intensive care (Curtis et al. 2001; Gramling et al. 2015), particularly in Burn ICUs. Patient-centered care approaches with shared decision-making processes (Elwyn et al. 2014) featured, for example, by family conferences can improve the quality of communication between family members and teams (Curtis et al. 2001). Family satisfaction increases when they are involved in the process associated with the withdrawal of life support (Gries et al. 2008).

End-of-life decision-making is particularly challenging (Emanuel and Scandrett 2010). Specifically, decisions to forgo (i.e., withhold/withdraw) life-sustaining treatments in ICUs are difficult. A large heterogeneity is observed worldwide with respect to making decisions to forgo life-sustaining treatments in ICUs (Lobo et al. 2017; Sprung et al. 2019). Declining to provide a treatment that is medically inappropriate or futile is ethically

sound (Botti and Vaccari 2019; Wilkinson and Savulescu 2011). Despite the expectation that patients would die sooner if invasive interventions were forgone, no such association was found (Ramazzotti et al. 2019).

Early comfort care may be the most humane option for massive burn injuries, requiring a better understanding of both decision-making rationales and processes, and ways to promote high-quality end-of-life care (Bartley et al. 2019; Swanson et al. 2013; Wessman et al. 2017). It is paramount to ensure person-centered care approaches, involving multidisciplinary teams in end-of-life decision-making processes.

A large proportion of patients in Burn ICUs had no comprehensive documentation of the care they received at the end-of-life (Ismail et al. 2011). Indeed, only one study reported effective symptom control at the end-of-life (Hemington-Gorse et al. 2011). Interventions to manage pain, agitation, breathlessness, mouth problems, secretions, nausea, vomiting, wound care, adequate use of medication, psychological support, and family support are core elements and should be implemented to ensure comfort for critically ill burned patients at the end-of-life.

Based on this review, it seems that PC is suboptimal in Burn ICUs. Only 4 studies referred to the involvement of PC in end-of-life care provided to a very small number of severely burned dying patients (Carmichael et al. 2021a, 2021b; Dokter et al. 2015; Ismail et al. 2011). Most of these studies were quality improvement initiatives. Studies show that PC teams are still not involved in clinical decisions, definition of goals, and end-of-life care in Burn ICUs (Ismail et al. 2011). Although PC is applicable in burn care, its current role is mostly confined to the end-of-life, suggesting that it is not fully integrated in the care process (Bayuo et al. 2019). PC specialists and burn surgeons perceive that end-of-life discussions, particularly those concerning goals of care, should occur within the first 72 h of admission (Carmichael et al. 2021a, 2021b; Cunningham et al. 2018). This shows the need for an early identification of PC needs, timely PC referrals, and identification and standardization of triggers for PC referrals.

Well-developed guidelines and protocols exist to promote the appropriate integration of PC in other specialties, including intensive care (Ismail et al. 2011). Yet, they do not directly transfer to the unique needs of critically burned patients and, therefore, are difficult to implement in Burn ICUs. Identifying, clarifying, and prioritizing patients' goals are paramount to develop patient-centered care processes and can provide the rationale for timely PC referral (Gramling et al. 2015), as suggested for other health-care settings (Hui et al. 2018, 2022). Evidence shows that PC consultation teams help to meet patients' goals of care, wishes, and preferences (Quill et al. 2006). The early integration of PC is associated with improved quality of life and survival (Mittmann et al. 2020). Nevertheless, although the integration of PC in Burn ICUs

was mostly implemented to improve end-of-life care, no distinction was made concerning early and late deaths in Burn ICUs. As pinpointed by Hui *et al.* (2018, 2022) in the context of cancer care, more than focusing on “early PC integration” it is paramount to ensure “timely PC,” which is a systematic process to identify patients with high supportive care needs and to refer these individuals to specialist PC in a timely manner based on standardized referral criteria.

Integrating PC in Burn ICUs is challenging but has shown to benefit patients, families, and professionals. It is paramount to ensure that decisions concerning the goals of care meet patients’ physical, psychological, social, existential, and spiritual needs, enabling the best outcomes for patients, families, and teams, regardless of survival rates (Bayuo *et al.* 2019, 2021a, 2021b; Berlin 2017; Hemington-Gorse *et al.* 2011). Health-care systems need to invest as much effort on quality and integrated end-of-life care as they do in maintaining the population alive and free from prominent, alarming diseases (Mitchell 2017).

Although there is no worldwide consensus on the definition of PC (De Lima and Radbruch 2018; Knaul *et al.* 2018), it is recognized that PC can contribute to ensure the best quality of life for patients and their families, particularly at the end-of-life (Berlin 2017; Mittmann *et al.* 2020; Payne *et al.* 2022). As most of the deaths in Burn ICUs are preceded by a decision to forgo life-sustaining treatments, thus resulting in short periods of time survival, attending Burn ICU professionals might perceive it as impossible to timely refer these patients to PC. Another potential reason could be that professionals working in Burn ICUs consider that they already provide adequate comfort measures and care to dying burned patients, therefore not requiring any additional support from specialized PC teams. Indeed, evidence shows that specialized PC is not initiated in almost half of the people for whom it could be beneficial, most frequently because physicians deem regular caregivers to be sufficiently skilled in addressing PC needs (Beernaert *et al.* 2015).

Predefining trajectories in dying and death for patients in Burn ICUs might be crucial to anticipate and better identify patients and families’ needs. Swanson *et al.* (2013) present 4 death trajectories in patients with burn injuries. Despite the perceived uncertainty of end-of-life trajectories in Burn ICUs (Bayuo *et al.* 2019, 2021a), this is of relevance. Understanding burns’ physiopathology may help to better identify triggers for PC referral, integrating PC in these patients’ care pathways. Further research should focus on the identification of these triggers for PC referral and admission, and on the outcomes resulting from integrating PC in the care processes and decisions of severely burned patients.

Strengths and limitations

The main strength of this review is its novelty. To the best of our knowledge, this is the first scoping review addressing end-of-life care and decisions in Burn ICUs. The systematic approach and methodological framework of this scoping review bring robustness to the findings. Nevertheless, our review is not without limitations. Due to the limited number of available studies on this topic and heterogeneity of the information provided (10 articles were based on patients’ records, 2 were on online surveys with professionals, 2 were quality improvement initiatives, 2 were qualitative interview studies, 2 were letters to the editor commenting on previous studies), caution is needed in the interpretation of our findings. Although we thoroughly followed the steps defined by Arksey and O’Malley (2005), we did not perform the consultation exercise.

This is an additional optional and parallel step involving key stakeholders to inform and validate study findings. As this review is part of a larger study on the integration of PC in Burn ICUs, this step will be undertaken when conducting interviews and focus groups with relevant stakeholders.

Conclusions

End-of-life care is paramount in the care provided to critically ill burned patients who are dying and their families. It requires specific competencies to enable improved quality of life, comfort, and family support. Nonetheless, end-of-life care in Burn ICUs is rarely studied and characterized by complexity and uncertainty. This review suggests that deaths in Burn ICUs are often preceded by end-of-life decisions, namely forgoing treatment and do-not-attempt to resuscitate. Different trajectories to death were identified and can be considered to develop triggers for timely PC referrals in Burn ICUs. Symptom control was not described in detail. PC was rarely involved in end-of-life care and decision-making processes.

Our work highlights the need for the early integration of PC and high-quality end-of-life care in the trajectories of critically burned patients. It also leads to a better understanding of dying and death in Burn ICUs. In fact, professionals and guidelines should consistently claim quality end-of-life care to be as important as life-sustaining care.

Further research is needed to (i) complete the additional optional step of this scoping review and involve key stakeholders to inform and validate study findings, (ii) identify triggers for PC referral in Burn ICUs, and (iii) study the best way to foster the timely integration of PC in the care provided to burned patients dying in Burn ICUs.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951522001389>.

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