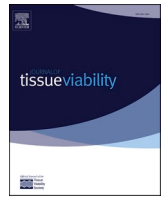




Contents lists available at ScienceDirect

Journal of Tissue Viability

journal homepage: www.elsevier.com/locate/jtv

Defining palliative wound care: A scoping review by European Association for Palliative Care wound care taskforce[☆]

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ARTICLE INFO

Keywords:

Concept
Definition
End of life wound care
Goal
Non-healing
Palliation
Palliative wound care
Principle
Terminal wound care

ABSTRACT

Background: Deciding whether to transition to wound palliation is challenging for health care professionals because there is no agreed definition or understanding of palliative wound care, including the goals, core elements and differences from general wound management.

Objectives: To conduct a scoping review with qualitative synthesis to define palliative wound care in terms of its conceptual framework, goals, principles, components, and differences from general wound management, and provide a new definition of palliative wound care based on this scoping review.

Eligibility criteria: Published literature that refers to the definitions, concept, goals and core elements of palliative wound care using any methodological approach, without any time limits, published in English.

Sources of evidence: The searches were conducted in CINAHL Complete via Ebsco, Medline via Ovid, Cochrane Library, Scopus, and Google Scholar.

Charting methods: A data extraction form was developed by the review team and used independently for data charting purposes. Braun and Clarke's six phases of thematic analysis guided the qualitative synthesis.

Results: A total of 133 publications met the inclusion criteria. Three main themes were developed to define palliative wound care and understand its differences from general wound management: 1- Healing potential of wounds and patient vulnerability, 2- Understanding the impact on individuals and family to address needs, 3- Towards new goals and perspectives in approach to care.

Conclusions: Palliative wound care focuses on symptom management, comfort, and dignity, but does not always target the healing of the wound, which is the goal of general wound care. The needs of the individual and their family must be addressed by clinicians through the provision of care and support that takes into account the true meaning of living and dying with a palliative wound.

Protocol registration: A review protocol was developed but not registered.

[☆] This work was completed as part of the European Association for Palliative Care wound care taskforce.

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<https://doi.org/10.1016/j.jtv.2023.07.002>

Received 7 March 2023; Received in revised form 30 June 2023; Accepted 18 July 2023

Available online 19 July 2023

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1. Background

Chronic wounds are defined as wounds where there is impaired healing [1] and a lack of normal wound progression to maintain physiological and structural integrity within 12 weeks [2]. The prevalence of chronic wounds is almost two per 1000 of the population [3], this makes information on their care essential for healthcare professionals and patients worldwide. Chronic wounds and their care have an impact not only on the person, their families and their quality of life but on the health service with increased service use and associated costs [4,5]. These include the cost of dressings, hours of nursing staff, hospital beds and the subsequent cost of treating possible infection [6].

Palliation of wounds is a recent approach which requires a different mindset than that of conventional wound care [7]. There are several types of wounds or conditions that could be determined to be palliative, such as malignant fungating wounds [8], terminal pressure ulcers [9], chronic limb-threatening ischaemia or critical limb ischaemia [10], non-healing wounds [11], and skin failure [12]. Some chronic wounds reach a stage where only palliation is possible; they are defined as palliative wounds on considering the background of the individual, such as a deteriorating general health status, frailty [10], whether they suffer from a long term or possible life-limiting illness [13] or from an acute illness [12] which compromises skin integrity [14]; p.653). The skin often fails along with other organs, when a person is actively dying, due to reduced oxygen availability and increased toxicity [15,16]. Skin failure may result in wounds that are untreatable due to the patient's high exposure to treatment and the unlikelihood of healing.

Non-healing wounds may require palliative wound care, which does not focus on the goal of healing as in standard wound care; a more person-specific approach is required to address the condition of the wound. Palliative wound care is generally reported in the literature as being similar to general palliative care, including wound-specific symptom management such as pain, bleeding, exudate, odour and infection, and ensuring comfort [17,18]. Palliative wound care focuses on the condition of a particular wound rather than the general condition of the patient.

The existing literature highlights that palliative wound care is known to focus on maintaining or improving the person's quality of life and preventing suffering and is applicable when curative treatment is not working or can no longer be endured by the person [19,20]. It also emphasises the maintenance of the persons' spiritual and psychological health through the care provided [21]. Despite the variety of literature available, there is a lack of a comprehensive definition for palliative wound care. Nonetheless, the differences between general wound management and palliative wound care, including the transition to a palliative wound care approach, remain uncertain [22,23]. Therefore, this scoping review was conducted to collect, evaluate, analyse, and synthesise the data published on palliative wound care in relation to its conceptual framework, goals, principles, components, and differences from general wound management, and provide a new definition of palliative wound care based on this scoping review.

2. Methods

A scoping review was conducted to address the following review questions:

- How palliative wound care has been defined in terms of concept, goals, principles, and components?
- How is palliative wound care differentiated from general wound management?

The review was conducted following the meta-aggregative approach [24–26], which guided researchers to pool, compare and summarise data to understand the definitions and concepts of palliative wound care in the published literature. Meta-aggregation is a form of qualitative

synthesis [27], and involves gathering of information from the sources as they were originally reported, without interpretation [28]. The following steps were followed to implement meta-aggregation in this review: 1- development of the review question and search strategy, 2- literature searches, screening, and data extraction, 3- pooling of all the extracted data and mapping of main and sub-categories, and 4-further data synthesis [28]. The review aimed to devise a comprehensive definition of palliative wound care; however, all relevant phrases and quotations addressing the definition, concepts, goals, principles, elements, or components of palliative wound care were identified and included in the dataset.

3. Protocol and registration

A review protocol was agreed by the researchers; however, it was not registered. Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist guided the reporting process [29].

4. Eligibility criteria

Literature that refers to the definition, concept, goals, principles, components, or elements of palliative wound care reported as a primary or secondary source; evidence (including grey literature) that follow any methodology and design; published any time (no year limits); published in English were considered for inclusion.

5. Information sources

The following databases were searched: CINAHL (Cumulative Index to Nursing and Allied Health Literature) Complete via Ebsco, Medline via Ovid, Cochrane Library, and Scopus. Google Scholar was also searched to identify additional reports.

6. Search

The full search strategy for each database has been provided in [Appendix 1](#). Examples of the search terms used, combining the Boolean operators (AND or OR) include “palliative wound care, end of life wound care, terminal wound care, palliation, palliative, non-healing, definition, concept, component, principle, or goal”. The search strategy was piloted, and the final searches were conducted on 27th of May 2021.

7. Selection of sources of evidence

All titles and abstracts of the records were screened by at least two independent reviewers from a team of seven. Conflicts were resolved by discussions by a pair of reviewers, and with involvement of a third member of the team where needed to reach consensus. Full-text screening was also performed with a team of seven reviewers. Any conflicts were resolved following the same approach.

8. Data charting process and data items

Upon completion of the full text screening, data were extracted by seven researchers independently, using a data extraction form developed and piloted by the research team with the following headings: Author; title; year; country; design; clinician reported; aetiology/type of wound; duration if recorded; key conclusions as reported; definition or concept of palliative wound care as reported by the authors; primary or secondary source; other notes. Only available data were extracted, and the authors were not contacted for further information.

9. Synthesis of results

Braun and Clarke's six phases of thematic analysis were applied to

define palliative wound care [30]. Overall, an inductive analysis approach was followed. Four researchers were involved in the initial data analysis, and then the theme drafts were reviewed by the wider team. For phase one, familiarisation, four researchers read their allocated data extracted from the literature searches with agreed keywords and inclusion and exclusion criteria. Phase two, coding, included the generation of initial codes (open coding, initially semantic and then latent) using the comments function in Microsoft Word (2022). Reflexive notes were added. The codes were then collated to support the researchers' search for themes (phase three). A conceptual map was developed during phase four, reviewing themes. This was part of the meta-aggregation process since this map provided the categorisation of the coded extracts to reflect their meaning and contributed to the development of themes. The wider research team's input was warranted at this stage. Following team discussions, the themes were further defined and named (phase five). For the final phase, reporting, relevant extracts were selected as examples to support each theme and sub-theme as part of the final reporting process.

10. Results

10.1. Selection of sources of evidence

A total of 2694 records were identified for title and abstract screening. A flow diagram detailing this process was created (Fig. 1) [31]. The full texts of 196 reports were read in detail, and 133 were included in the data synthesis.

10.2. Characteristics of sources of evidence

10.2.1. Country, type of evidence, and setting

Most of the included publications were reports from or led by authors from the United States (n = 55), United Kingdom (n = 24), and Canada (n = 10), followed by other European countries (n = 18). A table summarising the characteristics of the included publications is available in Appendix 2. A majority of the evidence was either reviews, systematic reviews, editorials or commentaries (n = 69), while the remaining were book chapters (n = 11), case reports or case series (n = 9), consensus statements (n = 6), prospective and observational studies including cohorts (n = 6), conference abstracts including posters (n = 5), descriptive quantitative studies including surveys (n = 5), qualitative studies (n = 5), retrospective studies (n = 3), theses (n = 3), and other (n

= 11). Many (n = 70) did not specify the setting, others reported from hospice and or palliative care settings (n = 31), home or community settings (n = 7), hospital and or oncology settings (n = 13), and others such as educational centres or development units (n = 14).

10.2.2. Reporting professionals and wound aetiology

Many of the included papers were reports from nurses (n = 57), while the remainder were from interdisciplinary teams (n = 33), physicians (n = 22), where the professional backgrounds of the authors were unspecified in the remaining reports (n = 21). The included literature reported a wide range of wounds with mixed aetiologies (n = 53), fungal or malignant fungal wounds (n = 26), malignant wounds including Kennedy Terminal Ulcer (n = 13), pressure injuries (n = 16), diabetic foot ulcers (n = 3) and peripheral arterial disease (n = 3), and major burns (n = 2). In general, the location and duration of the wound were not reported.

10.2.3. Results of individual sources of evidence

The characteristics of the included publications are presented in Appendix 2 with the data extracted in relation to definition, concepts, goals, principles, elements or components of palliative wound care as individually reported by each included source of evidence.

10.2.4. Synthesis of results

The data synthesis resulted in development of three themes. A cloud map visualising the mostly repeated phrases within the extracted data is presented in Fig. 2.

A limited number of included reports presented an explicit definition of palliative wound care. Ferris et al. [32]; p.37) defined it as "Palliative wound care is the evolving body of knowledge and skills that takes a holistic approach to relieving suffering and improving quality of life for patients and families living with chronic wounds, whether the wound is healable, or not". Ferris et al. [32]; p.38) also cited that "Palliative wound care is an extension of both palliative care and wound care" while Grocott and Gray [33]; p.41) mentioned "Palliative wound care comprises palliative treatment of underlying causes of skin and wound problems wherever possible, symptom management, local wound management together with supportive patient and family care." They also reported that "Palliative wound care involves the care of patients who have long-term potentially life-limiting, single or multiple illnesses of any aetiology which may result in the development of altered skin such as pressure ulcers, leg ulcers, cellulitis or wound infection. In this context, the term life-limiting may mean weeks, months or

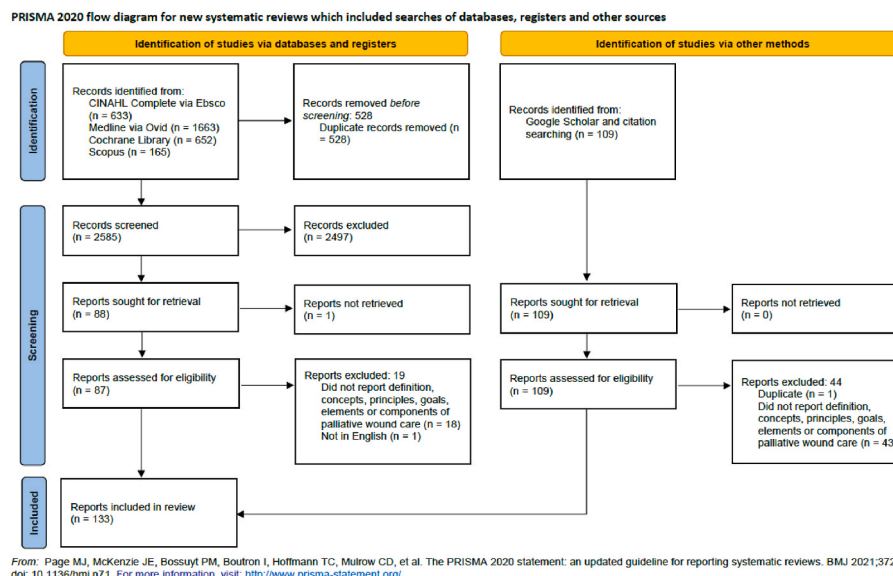


Fig. 1. The Preferred Reporting Items for Systematic reviews and Meta-Analyses flow diagram including searches of databases, registers, and other sources.

10.5.1. Goals of palliative wound care: Symptom management and beyond

The goals of palliative wound care mainly focused on symptom management such as prevention of pain, controlling the exudate and odour, maintaining the current state of the wound, minimising burden and discomfort and increasing quality of life. This was discussed as a feasible option for patients who need palliative wound care, as stated by Alvarez et al. [35]; p. 1161) “Palliative wound care should be centred on symptom management and is a viable option for patients whose chronic wounds do not respond to standard interventions, or when the demands of treatment are beyond the patient’s tolerance of stamina.” Alvarez et al. [35] and Liao and Arnold [52] discussed strategies to prioritise managing symptoms and improving the wound but not healing whereas Artico et al. [53]; p.23) added that “In the palliative care setting, the ultimate goal is injury healing, but equally important is wound maintenance, wound palliation (wound-related pain and symptom management), and primary and secondary wound prevention.”

Treatment of the reasons for the symptoms was recommended but the focus of this was suggested to be “tempered” rather than aggressive. Many of the included papers concluded that the potential impact of the interventions must be considered before they are implemented. As Hotaling and Black [40]; p.16) mentioned “Once the goals of care are established, aggressive treatments may be indicated for symptom management.” The importance of appropriate assessment of individuals’ needs in symptom management was emphasised by Naylor [41] “The cornerstone of effective symptom management is accurate assessment”.

10.5.2. Shifting perspectives in principles of palliative wound care in terms of healing

The principles of palliative wound care emphasised a shift from traditional, healing-focused wound care to a comfort and dignity-focused care approach. This was stated by Langemo [54]; p.24) as “Palliative care is focused on holistically supporting the individual for comfort rather than to cure or heal the wound, while improving the quality of living and dying”. Similarly, Annesley [55]; p. 293) discussed the complicated nature of caring for a dying person and emphasise focusing on dignity and comfort: “... shutting down’ of the peripheral circulation means that no intervention will promote wound healing and so nursing care is directed toward patient comfort and dignity.” However, in some publications [8,40], the healing did not always solely refer to wound healing: “Proper wound care provides healing for not only the body, but for the whole person” [40]; p16).

An interdisciplinary approach was mentioned as the general principle to provide holistic and person-centred care. Person-centredness generally referred to being connected with the patient and their families, and having mutual goals in care [45,56]. As Den Hollander et al. [57]; p.258) mentioned “The aims of terminal wound care are to relieve suffering, and to avoid the family’s last memories of the patient as soaking in foul smelling exudate.” This also includes allowing more time for care. The principle of “not to cure but to alleviate” was referred to in most reports, which is in line with the goals of palliative wound care. [45]; p.26) concluded that “Learning to incorporate a palliative approach to wound care means dispelling one last myth-that palliative wound care is a ‘do-nothing’ approach.”

Based on the themes and sub-themes discussed above, a new definition of palliative wound care has been proposed by the review team, which is provided in Table 1.

Table 1

A new definition of palliative care based on the results of this scoping review.

Palliative wound care can be defined as “person and family centred, holistic and interdisciplinary care of wounds that may heal, or not, or may be too onerous to treat; including but not limited to symptom control and management, for individuals who are often vulnerable and have impaired quality of life”.

10.6. Outstanding needs

While the review team focused on defining palliative wound care, the emphasis on the outstanding needs in the palliative care approach were reported repeatedly, therefore, they will be briefly mentioned here. These were staff training, proper assessment tools, having the culture and understanding of setting realistic goals with the person and their families. Graves and Sun [22] suggested that “palliative nurses practicing in all settings should have the basic knowledge necessary to manage palliative wounds”. The impact and meaning of living with a wound requiring palliative care must be reflected in the care plan [58]. “Careful communication” with patients and families about palliative wound care was mentioned, for which adequate knowledge and clear understanding of palliative wound care are needed. Letizia [59]; p.279) recommends that “providers are encouraged to avoid inaccurate statements such as ‘there is nothing more we can do for you’”. Some reports referred to cost-effectiveness when considering treatments not with the purpose of healing but providing comfort, and this was also emphasised to avoid financial burden.

11. Discussion

This review explored definitions and the concept of palliative wound care in the existing literature and identified a significant number of reports referring to palliative wound care. These included examples of palliative wounds and the patient population with different wound aetiologies. Most of the included publications referred to palliative wound care as symptom management, wound maintenance, maximising and protecting dignity and comfort as well as person-centred approach with involvement of family members and the interdisciplinary members of the care teams. Outstanding needs to deliver palliative wound care were also briefly mentioned.

Three existing definitions of palliative wound care were identified. One defined it in relation to an evolving body of knowledge and skills taking a holistic approach to relieving suffering and improving quality of life for patients with healable or non-healable chronic wounds [32]. This definition referred to palliative wound care as an integration of palliative care and wound care. Another defined palliative wound care as palliative treatment of underlying causes of skin and wound problems with symptom management, local wound management and supportive patient and family care. Palliative wound care is seen to involve patients with life-limiting, single or multiple illness of any aetiology, which gives rise to altered skin and wounds [33,34]. A third defined palliative wound care as a holistic integrated approach of care that addresses symptom management, is multidisciplinary and driven by patient and family goals, and addresses a patient’s psychosocial well-being [23]. A common feature in all these definitions is their focus on symptom management and holistic supportive care. The review team suggests that a comprehensive definition of palliative wound care should focus on the “person” or “individual” rather than “patient” at the centre of care. Palliative wound care should address the experiences and expectations of persons living with a palliative wound as well as their families and informal carers.

The author team identified gaps in the descriptions of palliative wounds reported in the literature. Instead of reporting certain types of wounds as palliative, the review team suggests that the focus must be on a comprehensive assessment of the wound and the person’s background. The patient population with palliative wounds should be addressed more comprehensively as the review team’s interpretation of this is age, comorbidities, lifestyle and social background, trauma, physical disabilities and other factors that may contribute to palliative wounds. Some other issues were identified such as reference to palliative wounds as “too costly to heal” or “not feasible to heal”. Not all wounds are non-healable, but for some, the knowledge and skills of the staff are limited. Strategic use of costly treatments or advanced-technology care devices could be meaningful, in line with individuals’ wishes and shared care

goals. Value-based wound care from a palliative perspective should be considered as a focus for proactively treating palliative wound symptoms in a person-centred manner. Value-based healthcare is about achieving the best possible health outcomes with available resources in a sustainable way keeping in mind that “the lowest cost dressing is not necessarily the one which adds most value” [60]; p.42).

The experience of living with palliative wounds from the perspective of individuals and the people around them was discussed in the included papers. Social isolation and stigma due to the “unacceptable appearance” and symptoms of the wound were mentioned [58]; however, further details about the intimacy of having a “difficult” wound during dying process was not addressed adequately. Lawton [61] explored the embodiment during dying process and the ‘unbounded body and dirty dying’ in their research where they discuss selfhood being lost, which becomes evident when person loses the bodily autonomy due to their symptoms. The “self” dissociating from the body [62] may lead to an emotional or spiritual death before the actual physical death. In palliative wound care contexts [8], interviewed patients with malignant fungating breast wounds and reported that palliative wound care skills are needed among carers to support patients as they struggle to maintain the boundedness of their body due to the symptoms they experience. Further studies about the process of death with a palliative wound are needed, since this topic was rarely discussed in the publications that were included in this review, and it would be helpful to researchers and clinicians. The author team also investigated the meaning of living with a palliative wound and how individuals defined quality of life from their own perspective; however, this level of discussion was also not available in the existing literature. Similarly, the value of connecting with the patient when describing person-centredness was not widely discussed. More focus from clinicians in this area is warranted to understand the reality of living with a palliative wound and plan strategies to meet individual and family needs.

The care approach reported in the included literature evidence mainly focused on symptom management and prevention of discomfort, which is in line with general palliative care [63]. Symptoms associated with wounds should be addressed with an individualised approach and in a dignified way. We believe this could be extended to address restoring ‘wholeness’ during the life course. While treatment of palliative wounds was recommended in the literature to manage symptoms and provide comfort, we suggest that impact versus interventions can be presented to the patients and people around them in a weighted way. An understanding of realistic goals and quality of life improvement should be weighed against the burdens associated with these more invasive procedures [35]. The patients and the families must be informed that even if they agree to advanced treatment, despite all the efforts, healing may not be possible as individual response determines this. There is a need for specialised, resource-intensive efforts and clinicians should use them if this could make a difference for the individuals affected. To assist these clinical decisions, staff training co-designed with persons and families in palliative wound care is essential. Training should be accessible to all levels of the healthcare workforce with specific resources for patients, families and carers. Contradictory interventions due to lack of understanding are “costly” to the patient in different ways. Palliative wound care approach requires a teamwork and high level of collaboration. Interdisciplinary decisions must be negotiated and agreed with the person and their family or support persons.

11.1. Limitations

Although the review captured a broad range of in-depth evidence on the topic, it might have missed some relevant reports due to limitations with the search strategy. For example, we only included literature that was published in English, which may have resulted in limited data. We also omitted keywords about ulcers, and some search combinations might have further limited the search results. Moreover, it was challenging to differentiate the first and secondary sources of information for

definitions in the included pieces of literature. Since a content analysis approach was not followed, the number of citations for each theme or sub-theme was not counted. Instead, the meaning of these themes was explored within the data available.

12. Conclusions

This scoping review provided a synthesis of reports available on the definition, concepts, and principles of palliative wound care, and addressed the experience of persons and families living with palliative wounds. While a few existing definitions were identified, the majority of the publications reviewed provided “segments” of descriptions that led to a refined definition of palliative wound care following a comprehensive synthesis approach. Our reported themes highlight the differences between palliative wound care and general wound care. The new definition implies that palliative wound care may not always target wound healing but mostly focuses on protecting comfort and dignity. The main outstanding needs in this area were identified as increased training of formal carers (especially for care approaches and communication) and culture and understanding of setting realistic goals in care. Better understanding of the impact of living with a palliative wound on individuals and knowledge of palliative wound care by care providers could help align care to the needs and expectations of patients and families.

Funding sources

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Declaration of competing interest

None.

Acknowledgements

This work was completed as part of the European Association for Palliative Care wound care taskforce.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jtv.2023.07.002>.

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