

## Nurses and End-of-Life Care Pathways: A Review of the Literature

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### Abstract

*This review explores the evolving landscape of end-of-life care (EOLC) pathways and their connection to nursing practice. The paper clarifies distinctions between EOLC and palliative care, highlighting the importance of high-quality EOLC. It then examines the definition, goals, and benefits of EOLC pathways, acknowledging the current lack of robust evidence for their effectiveness. A significant focus is placed on the multifaceted role of nurses. Nurses act as facilitators, project leads, and educational facilitators during EOLC pathway implementation. The review explores various educational strategies employed, emphasizing the need for a cohesive framework and effective inter-professional education. The paper concludes by acknowledging knowledge gaps regarding the long-term impact of educational interventions and the overall effectiveness of EOLC pathways. By addressing these gaps, EOLC pathways can be further optimized to ensure compassionate and dignified care for patients nearing the end of life.*

**Key words:** end-of-life care (EOLC), nurses.

### Introduction

In the realm of healthcare for terminally ill patients, the terms "end-of-life care" (EOLC) and "palliative care" are frequently used interchangeably (1). This, however, can lead to confusion as these terms represent distinct phases within a patient's journey (2). The importance of high-quality EOLC has gained significant traction in recent years, reflected in the health policies of various governments around the world (UK Department of Health, 2008; Welsh Assembly Government, 2008; Australian Government, 2009) (3). In Canada, this focus has translated into numerous initiatives aimed at improving EOLC across public

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and private sectors. One key approach gaining momentum is the implementation of integrated EOLC pathways (4).

These pathways function as blueprints for navigating the complex transition from the palliative care phase through the dying process and ultimately, bereavement. They aim to ensure consistent delivery of high-quality, individualized comfort care regardless of the setting, ultimately striving for a peaceful and dignified death (5). The UK government and healthcare bodies recognize the value of EOLC pathways, endorsing them as best practice templates and essential tools for guaranteeing minimum care standards for those nearing the end of life (National Institute for Clinical Excellence, 2004; UK Department of Health, 2005, 2008; Welsh Assembly Government, 2008) (6).

In the Middle East; EOLC is a developing field navigating the tension between honoring cultural and religious values while providing quality care. Limited access to palliative care and discomfort with open communication about death pose challenges. Nurses play a critical role in EOLC by managing symptoms, facilitating communication, advocating for patient wishes, and supporting families. As EOLC pathways become more standardized, further research is needed to explore patient and family preferences within the Middle Eastern context. This will inform culturally sensitive care models and educational programs for nurses, ultimately improving the quality of EOLC in the region (7).

### Purpose

Quality management and improvement are fundamental aspects of nurse manager responsibilities (8). Their leadership positions make them uniquely qualified to significantly impact the implementation and utilization of EOLC pathways (9). To address this critical need, this paper aims to provide a current resource for nurse managers in both public and private healthcare sectors. Through a comprehensive review of the literature, this work will identify the current state of knowledge regarding EOLC pathways and their connection to nursing practice. This analysis will equip nurse managers with the necessary information to effectively champion the adoption and successful implementation of these pathways, ultimately ensuring high-quality, and compassionate care for patients nearing the end of life.

### Defining EOLC Pathways

This paper adopts a specific definition of EOLC pathways, drawing upon the works of Rotter et al. and Chan and Webster (10, 11). Here, an EOLC pathway is defined as a structured, multidisciplinary, and evidence-based document. It functions as a roadmap, outlining crucial care interventions for patients and their families during the final days and hours of life, extending support through the immediate bereavement period (12).

The pathway is initiated upon reaching a consensus that the patient has entered the dying phase. Its purpose is to guide clinical decision-making, replacing the need for all other documentation (13). These pathways typically comprise three distinct sections: initial assessment, ongoing assessment, and care following death. Additionally, sections may be included for recording deviations from the planned care and providing resources for both families and healthcare professionals. Medication guidance may also be incorporated (5).

### Goals within EOLC Pathways

Each section of a structured EOLC pathway outlines specific goals (10, 11). These goals encompass a holistic approach, addressing physical, psychological, social, and spiritual needs of both the patient and their family. However, the two assessment sections prioritize physical comfort care. This focus translates into practices such as:

- Anticipatory prescribing: Proactively providing medications to manage potential or ongoing distressing symptoms.

- Discontinuation of futile interventions: Withdrawing treatments that offer minimal benefit but cause discomfort.
- Continuous monitoring of patient comfort: Regularly evaluating and addressing the patient's physical well-being.

In contrast, the goals following death within the pathway primarily address standard procedures and legal requirements. This includes tasks like verifying and certifying death, and potentially contacting the coroner's office if necessary.

#### The Rise of EOLC Pathways

The development of EOLC pathways emerged from the critical need to address shortcomings in care for the terminally ill and their families, particularly within acute care settings (12, 14, 15). Many EOLC pathways were inspired by the groundbreaking Liverpool Care Pathway (LCPs) (15). This innovative approach aimed to strengthen education for healthcare professionals and translate the hospice model of care into an evidence-based framework. The LCP's focus was on optimizing EOLC for patients with cancer in acute care settings.

Over time, the LCP has been adopted, translated, and adapted for global use (16-18). This customization has ensured the pathways reflect local guidelines and protocols, addressing the specific needs of patients dying from various conditions beyond cancer. Examples include adaptations for advanced chronic renal failure (19, 20), stroke (5), heart failure (13), and even burns (21). These adaptations allow for the widespread application of EOLC pathways across diverse public and private healthcare settings.

#### The Global Spread of EOLC Pathways: Evidence and Implementation Challenges

Despite their growing international adoption, EOLC pathways currently lack robust evidence demonstrating their impact on patients, families, and healthcare professionals. Reviews by Chan and Webster and Phillips et al. concluded there's insufficient "sound evidence" (Chan & Webster, p. 7) or the evidence is of "low level" (Phillips et al., p. 951) to definitively support their use (11, 12).

This lack of conclusive evidence is partly rooted in the traditional hierarchy of evidence, where randomized controlled trials (RCTs) are considered the gold standard (5). However, conducting RCTs with terminally ill patients presents significant ethical and methodological challenges (22). Critics argue that the positivist epistemology underlying RCTs may not adequately capture the complexities of the end-of-life experience (23).

Nurses play a pivotal role in caring for patients and families nearing death across various healthcare settings (24-26). While EOLC pathways have been embraced in some clinical areas (27), concerns remain regarding their purpose, initiation, and use, particularly in generalist settings (28). This highlights the need for a deeper understanding of EOLC pathways to facilitate their effective implementation and address potential roadblocks.

#### Implementing EOLC pathways

Successful implementation of EOLC pathways hinges on a strategic approach driven by practitioners themselves. This means creating a supportive environment where the voices of those who will use the pathways are heard and valued (28).

A review of the literature reveals numerous international studies, audits, and anecdotal accounts detailing EOLC pathway implementation across diverse settings and patient conditions (29, 30). Notably, quality improvement methodologies are frequently advocated and utilized to facilitate this process (13). This approach aligns with best practices for successful change management (31, 32).

The long-term acceptance and sustainability of EOLC pathways depend on healthcare professionals feeling a sense of ownership, inclusion, and a clear understanding of the

pathway's purpose and scope. The literature suggests that as healthcare professionals use the pathway, it may evolve over time (5).

#### Nurses at the Forefront: The Role of Facilitation

The literature highlights the prominent role of nurses in EOLC pathway implementation, acting as project leads or facilitators (33-35).

#### Facilitative Leadership vs. Didactic Instruction

The facilitator's role and approach in EOLC pathway implementation are multifaceted (35). While Mellor et al. (2004) describe a senior nurse acting as a clinical facilitator educating hospital staff about the LCP, a closer look reveals a more didactic approach relying on expert knowledge rather than empowering and acknowledging existing healthcare professional expertise (34)

While ongoing support is crucial for sustained implementation (36), Mellor et al. (2004) suggest a point where the facilitator can withdraw (34). This contrasts with the findings of Hockley et al. (2005) (37). Their action research describes a range of facilitative approaches, including reflection and collaborative learning that empowered nursing home staff to confidently care for dying residents and their families. Hockley et al.'s work provides valuable insights into the process of successful EOLC pathway implementation, emphasizing the importance of collaborative leadership that builds upon existing knowledge and fosters ownership among healthcare professionals (37).

#### Educational Strategies for EOLC Pathway Implementation: Bridging the Gap

Quality improvement methodologies emphasize the importance of educational strategies to promote and sustain EOLC pathway implementation (34, 38). However, a critical review of the literature reveals a gap in understanding the underlying educational philosophy and the effectiveness of various approaches.

#### The Need for a Cohesive Framework

Current educational strategies often lack a strong philosophical foundation. Additionally, significant variations exist in the design, content, and target groups (38, 39). These discrepancies highlight the need for a more cohesive framework that considers philosophical underpinnings and tailors strategies to specific learner needs.

#### Pedagogical Diversity: Strengths and Challenges

A wide range of pedagogical approaches are employed, including both independent learning (formal/informal teaching, training-the-trainer) and collaborative methods (learning groups, reflection on practice). While educational content generally focuses on EOLC principles (symptom control, communication, bereavement), and the pathway itself, significant variability exists across settings (40). This inconsistency can present challenges for ensuring all healthcare professionals possess the necessary knowledge and skills. Lhussier et al. (2007) highlight the difficulties in simultaneously educating diverse healthcare professionals with varied needs. This suggests a potential lack of understanding or insufficient preparation for interprofessional education, which emphasizes learning "with, from, and about each other" (Watts, 2010, p. 43).

Studies indicate that some healthcare professionals feel unprepared to utilize EOLC pathways effectively (19, 39). Furthermore, with the exception of work conducted in Australia (Department of Health, State of Western Australia, 2009), there is a lack of evaluation on the long-term impact of educational interventions on practice and sustaining change.

## Conclusion

EOLC pathways hold promise for improving the quality of care for terminally ill patients and their families. Nurses play a pivotal role in facilitating their implementation and ensuring their effectiveness. However, further research is needed to address the gaps in knowledge regarding the impact of these pathways and to develop robust educational strategies that empower healthcare professionals to utilize them effectively. By addressing these challenges, EOLC pathways can become a cornerstone of compassionate and dignified care for those nearing the end of life.

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