



**QUEEN'S
UNIVERSITY
BELFAST**

Introduction: A 'totalizing' view of palliative care

Elsner, A., & Wilson, S. (2024). Introduction: A 'totalizing' view of palliative care. *Literature and Medicine*, 42(1), 55-64. <https://doi.org/10.1353/lm.2024.a935833>

Published in:
Literature and Medicine

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
[Link to publication record in Queen's University Belfast Research Portal](#)

Publisher rights

Copyright 2024 the authors.

This is an accepted manuscript distributed under a Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution and reproduction in any medium, provided the author and source are cited.

General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.

Open Access

This research has been made openly available by Queen's academics and its Open Research team. We would love to hear how access to this research benefits you. – Share your feedback with us: <http://go.qub.ac.uk/oa-feedback>

A ‘Totalizing’ View of Palliative Care

Anna M. Elsner & Steven Wilson

Mortality in its many guises, either as the abstract horizon of our lives constituted by death, or as the actual experience of dying – both of others and ourselves – has always been at the heart of literary texts. In recent years, autobiographies about dying, written by terminal patients, their families, and caregivers, have proliferated, and almost without exception dying is presented as a medicalized experience. Much less attention has been paid, however, to the pressures technological advances have put on the care of the terminally ill and the ways medical progress has begun to interact with evolving experiences and expanding conceptions of end-of-life care, particularly in palliative settings. Recognized as a medical subspecialty and first defined by the World Health Organization in 1990 as a holistic approach specific to cancer pain relief, palliative care has subsequently become the paradigmatic end-of-life care modality for advanced terminal diseases in Western medicine.¹ This theme issue contextualizes the meanings of “palliative” within literature and culture since the 1970s, when reports about the work of Cicely Saunders – the founder of modern palliative care – provided the impetus to reform how national healthcare systems approached terminal disease in Europe and beyond. Spanning a broad range of local and national contexts, the articles in this volume raise awareness about the specific histories and cultural contexts in which approaches to palliative care were developed.

This issue considers transnational narratives of illness and dying written since the 1970s, in a variety of languages, and that are torn between the idealization and devaluation of palliative care. It analyzes the representation of key concepts associated with palliative care, such as pain control, holistic care instead of cure, the integration of the family, an individually defined quality of life, and the role of spiritual and psychological support for the patient. It thereby engages with broader question of what constitutes “a good death,” a

concept which has been given ample attention in the social sciences in particular.² We posit that conceptions of palliative care also have much to gain by taking literary and cross-cultural perspectives on dying into account. By considering palliative care's reception in literature across languages and societies, the issue aims to provide a refined understanding of some of the challenges of modern palliative care and the philosophical and cultural assumptions about what constitutes a "good death." Three interconnected reasons highlight the particular relevance of this theme issue: First, by focusing on palliative care specifically, it maps hitherto unexplored thematic territory and enables innovative interpretations of contemporary literature and culture. Second, it redefines the interdisciplinary research agenda of the field of literature and medicine within the Medical/Health Humanities by highlighting the importance of studying literary accounts of terminal illness since the 1970s across languages and cultures. Third, it grapples with culturally complex understandings of end-of-life care and thereby constructs crucial bridges between theory and praxis.

Much contemporary scholarship focusing on narrative approaches to death and dying in the context of modern medicine comes from bioethics. An example is Lydia Dougale's edited volume *Dying in the Twenty-First Century* (2015), which includes contributions from physicians, philosophers, and theologians in order to articulate what dying well means in the twenty-first century; Dougale's book thereby seeks to construct an ethical framework for a secularized and contemporary *ars moriendi*. Dougale proposes that two components are key to this art of dying well, namely "clear recognition of finitude and a strong sense of community."³ Just as in this theme issue, topics such as human finitude, the role of palliative care, as well as philosophical discourses of autonomy versus care ethics take center stage in Dougale's analysis. Our issue engages with similar theoretical questions that the authors of Dougale's volume draw on. However, instead of focusing on philosophical, theological and legal scholarship pertaining to the role of palliative care in shaping modern dying, our

contributors concentrate on how literature across cultures turns into a powerful means to come to terms with mortality in the context of modern medicine. In the literary texts our contributors analyze, it is the personal and creative engagement with their own finitude or that of loved ones, which allows writers to establish Dougdale's "sense of community." Writing itself thereby turns into a relational practice, as part of which connections with healthcare professionals, families, as well as patient and wider intellectual communities are fostered and maintained.

Another relevant title that speaks to the growing interest of Medical/Health Humanities scholarship in the analysis of death and dying in literature and culture is Brittany Pladek's *The Poetics of Palliation: Romantic Literary Therapy* (2019). Pladek builds her argument by opposing a point of view that has gained traction in the field, namely that literature has therapeutic qualities. She highlights that the Romantic period brims with examples of writers who think about the potentially healing effects of literature and actively seek conversations about it within their respective medical milieu. *The Poetics of Palliation* engages with these conversations and proposes that such multifaceted exchanges provide key contexts that are often ignored or over-simplified in the suggestion that the arts have healing properties. According to Pladek, Romantic medicine's curative uncertainty meant that the period's doctors understood their medical duty toward patients as the need to provide "palliation" rather than "cure;" Romantic writers, in turn, took up this palliative ethic to describe the therapeutic benefits of their own work. It is a subtle but powerful shift in wording, which suggests that all that medicine or literature can ever achieve is a temporary soothing and alleviating of suffering. Both domains can reduce but never erase pain. Pladek thereby urges us to recognize "the complexity of Romantic writers' relationship to literary therapy," highlighting that the kind of literary therapies apparent in writers like Keats, Wordsworth and Shelley are always "incomplete, fragmentary."⁴ Many writers considered in

this theme issue also engage with the palliative qualities of writing in the face of death, in that writing constitutes a dynamic process of pain alleviation which never fully materializes. As such, both Pladek's book and the contributions in this theme issue complement scholarship on what Emma Wilson has classified as "palliative art."⁵ Importantly, and unlike in Pladek's and Wilson's work, articles in this issue move beyond a largely metaphorical understanding of "palliative" in that they explicitly engage with – document, review, idealize, and criticize – the practice of palliative care as a medical subspecialty.

A direct literary and personal engagement with palliative care is at the heart of this theme issue. It is for that reason that physician writers, who have shaped narratives of death and dying in important ways at the end of the twentieth and the beginning of the twenty-first centuries, deserve to be mentioned. In his 1994 bestseller *How We Die: Reflections on Life's Final Chapter*, the surgeon and writer Sherwin B. Nuland sought to demythologize death by moving beyond euphemisms and taboos. Instead, he provided readers with a frontline view of how dying happens behind the closed doors of hospitals. "By and large, dying is a messy business," he remarked, and by relating his personal experience as a physician confronted with dying patients, he sought to make some of that messiness accessible against the sanitization of modern medicine.⁶ At the same time, his writing is also an outcry that formulates the need for a different kind of medicine and, as such, it is also reminiscent of texts like Ivan Illich's *Medical Nemesis* (1974). Given Nuland's own experience of illness and years of witnessing dying in the medical setting, it is unsurprising that he was on the founding board of the first hospice that opened in the United States in 1974 thanks to the initiative of the nurse Florence Wald, who had been inspired to reform the medical curriculum at Yale University to include end-of-life care after hearing a lecture by Cicely Saunders in 1964. Nuland's personal writing on death and dying is via this extended connection to Saunders also part of a local and transnational history of palliative care. This

applies to all contributions to this theme issue, namely that the diverse national healthcare contexts (US, UK, France, Germany, Italy, Switzerland), which are reflected in the literary texts on dying, all have their distinct histories of palliative care that are connected to the legacy of Cicely Saunders's work in unique ways.

Physicians and nurses, Nuland posited at the time of writing *How We Die*, experience the death of patients at close proximity, and yet they “rarely write about it.”⁷ But in recent years, a number of physician writers, many of whom are palliative care specialists, have followed in Nuland's footsteps: texts like Petra Anwar and John von Düffel's *Geschichten vom Sterben: Was am Ende wichtig ist* [Stories of Dying: What matters in the end] (2013), Atul Gawande's *Being Mortal: Illness, Medicine, and What Matters in the End* (2014), Seamus O'Mahony's *The Way We Die Now* (2016), Kathryn Mannix's *With the End in Mind* (2017) and Claude Debray and Régis Grange's *Le dernier souffle* [The last breath] (2023) are just some examples of the burgeoning genre of medical memoirs across languages and cultures that are concerned with how the twentieth-century medicalization of dying has transformed the way we die today. Thirty years after the publication of *How We Die*, this proliferation of memoirs about dying in and outside palliative care shows how the perspective of clinical doctors in the face of their patients' dying is increasingly accounted for in writing. This theme issue focuses on close encounters in relation to dying. Many of the individuals represented in the texts studied come into direct contact with palliative care as they experience death close up. These texts are written by doctors, patients, family members who have accompanied the terminally ill and writers who have turned into patients or who have spent time on palliative care wards for other reasons.

Together, the essays presented in this issue of *Literature and Medicine* propose that these literary texts are an untapped resource for understanding the practice of palliative care from different perspectives and across cultural and historical contexts. The literary examples

our contributors analyze speak to the changed role that care for the dying has played across cultures of medicine since the late twentieth century. They also highlight that these diverse contexts have reciprocally shaped the proliferating genre of what literary scholar Jeffrey Berman has called the “end-of-life memoir,” which he defines as “a story about death and dying, either one’s own story or that of a relative or friend.”⁸ Within scholarship on literature and medicine, this theme issue is the first to consider the multiple ways the two dynamic fields of literature and palliative care intertwine. It not only asks the question of how literature can help improve our response to and understanding of dying but, importantly, considers the other side of this relationship by enquiring: how does the experience of dying in a palliative care context transform literature and the literary form?

The timeliness of this theme issue is also significant. The global pandemic of Covid-19 brought the nature and function of palliative care back into focus. As a recent article in the *BMJ* reminded us, “the relief of suffering, through provision of holistic and compassionate care, is an essential component of care,” not just for those who are dying, but “for all patients with life threatening illness.” The article thus pointed to the urgent requirement for a more “palliative approach to the management of patients with severe Covid-19 in hospital and community settings, focusing on the management of distressing symptoms, planning ahead, communicating with patients and their families, and grief and bereavement.”⁹ Similarly, *The Lancet* has published an influential piece on “The key role of palliative care in response to the COVID-19 tsunami of suffering,” in which the authors suggest that patients, caregivers, health-care providers, and health systems could “benefit from the extensive knowledge of the palliative care community” as they dealt with the pandemic,¹⁰ while Marie Curie updated its website to include new sources of support for patients, healthcare professionals and carers at this time.¹¹ If Covid has – tragically – reasserted the need for fresh attention to be paid to

palliative care, the global pandemic of 2020-21 also prompted us to (re)consider health in an international and transcultural frame, which is precisely one of the aims of this volume.

One of the key features of the issue is therefore its concern to bring into productive dialogue representations of palliative care from different cultural, political and healthcare contexts. Offering diverse existential, religious and experiential perspectives on the end of life from a range of post-war contexts in the US, UK, France, Germany, Italy, and Switzerland, the overarching aim of this volume is to analyze the different ways literary texts present a more encompassing understanding of what it means to dying and be confronted with death. We might even term this approach, going back to one of the key terms used in the development of palliative care, a more *holistic* understanding of dying and death. When the *Lancet Commission on the Value of Death* was created in 2018, it proposed that in order to improve medicine's relationship with death, we needed to gain a better *cultural* understanding of how different societies think about death and dying.¹² With rapidly evolving socio-political and legal contexts for the end of life in many Western countries, such an understanding seems more urgent than ever. Literary accounts of dying which directly engage with palliative care provide privileged access to such understandings and yet, they remain largely unacknowledged.¹³

The essays collected here offer intriguing, and important, transnational literary perspectives on palliative care. They thereby reflect not so much on the medicalization of death and dying, which as historian Philippe Ariès has made clear, is the predominant mode of dying across Western countries at the end of the twentieth century. Rather, they take us one step further by engaging with accounts in which palliative care – set up as a reaction against the medicalization of dying – plays the paradoxical role of de-medicalizing dying from within medicine. The essays that follow engage with three approaches; taken together they underpin the issue's distinctiveness. Firstly, they adopt a resolutely interdisciplinary

methodology, in which literary and cultural representations of palliative care are selected for their engagement with medical, philosophical, sociological, theological, and ethical concerns. The approach is illustrated in the first article, in which Joe Woods argues that Cicely Saunders' development of the idea of "total pain" – the idea that it is to be understood and articulated within a constellation of emotional, spiritual, social as well as physical influences – did not only result from her personal experiences in a variety of healthcare roles during and after the Second World War, or from her devout Christianity, but from readings of literary, philosophical, and theological texts. Examining "total pain" in light of Saunders' reading thus gives an insight into the particular intellectual contexts from which palliative care emerged, offering new points of reference about its origins that recent accounts of the field have obscured.

Secondly, the essays probe shifting understandings of what it means to experience a "good death." In this way, they problematize the complexity of a concept that has often been framed by cultural assumptions and partial realities. Contemporary literature has nonetheless begun to challenge the moral values implied hitherto in the concept of a "good death," by providing access to the de-idealized domain of the taboo, the unsaid, and the unsayable. Katja Herges, in her analysis of two collaboratively written memoirs in contemporary German popular culture, examines how relationality and affectivity in women's end-of-life narratives might influence the philosophies and politics of palliative care and the associated concept of a "good death." Herges shows how affective aesthetics may lead to the creation of an intimate public sphere of palliation that transgresses traditional approaches to dying in health care while also shaping sentimental notions of family care and of the self-determined and autonomous death. Marc Keller, focusing on cultural narratives of assisted dying in Germany, Switzerland, and France, extends the theme issue's enquiry into how relationality provokes new understandings of a "good death" by addressing the effect of illness on relationships

between partners. In Keller's analysis, the imminent or experienced loss of an ill partner can provoke an onset of "existential suffering" in the healthy partner, who refuses to outlive the other, recalling the long literary tradition of the "Liebestod." While the idea of a "Liebestod" is repeatedly portrayed as a "good death," it is also linked to a defensive one, consisting of the rejection of a medicalized end of life. Julia Pröll, in her article, returns to the etymology of "palliative" (derived from the latin *palliare*) and suggests, through a reading of two contemporary French novels, that the idealistic aim to "cloak" or "cover" pain and suffering in order to achieve the goal of a "good death," obscures the often-neglected perspective of caregivers and relatives. These individuals are frequently confronted with conflicting feelings as they navigate a path that requires presence and self-preserving distance in relation to the terminally ill.

Thirdly, we assert the crucial role that literature has to play in representations of and responses to palliative care. From presenting reflections on palliative care to offering comfort, the polyvalent status of writing serves, we suggest, as an activity that not only prompts individual therapy, but creates a space for the emergence of new subjectivities. Research on palliative care has emphasized the role of narratives in the encounter with suffering and dying patients because we need to hear and learn from the dying in order to improve our care for them.¹⁴ In her article, Franziska Gygax considers the literary practice of autothanatography, arguing that the process of writing about the last stage of life constitutes a palliative narrative praxis because the narrative act itself is comforting and alleviates suffering. Jordan McCullough, in his analysis of Philippe Forest's first novel, *L'Enfant éternel* (*The Eternal Child*), also understands literature as palliative in its own right, but in this case, he points out that the text written about a dying daughter also allows for the incorporation of the father, as writer, into the dynamics of palliative care. Our theme issue concludes with the question of form, by asking how the multifarious characteristics of textual

production contribute to the more holistic understanding of writing as palliative praxis considered by Gygax and McCullough. Specifically, Maria Vaccarella explores the representation of terminal brain cancer from the point of view of family carers in two contemporary texts: Marion Coutts's memoir *The Iceberg* (2014) on her husband's illness and death, and Marco Peano's autofiction *L'invenzione della madre* [The Invention of the Mother] (2015), about a son who cares for his mother during her final days. What characterizes both texts is a remarkable pervasiveness of visual culture, as references to images, the visual arts, and cinema provide a language that helps both carers (an aspiring film director and an established artist) make sense of the end of life and contrast the worst excesses of biomedical interventionism.

In both function and form, the array of texts and cultures considered in this issue embrace the potential and the urgent need for more diverse, multi-layered, and richly complex understandings of palliative care. Relationality – the fostering of relationships and communities – transcends this volume as a thematic and a methodological concept. The relational dynamics explored include not only patients, their families and healthcare professionals, but also the various influences and interconnections that destabilize an orthodox understanding of what “literature” is and does. As the contributions in this theme issue highlight, references to the visual arts, exchanges with digital communities, and discourses from within medicine and philosophy all demonstrate the capacity of literature to serve as a nexus for multiple perspectives on the complex human experience of mortality.

By bringing together transnational, transcultural, and multilingual viewpoints, we also hope to set a precedent for fostering a more inclusive discourse about palliative care itself. Especially in the context of increasingly multicultural settings and amidst shifting political frameworks for end-of-life care, the implications of this theme issue reach beyond interdisciplinary scholarship in that they question the actual needs of individuals facing end-

of-life care choices within various cultural backgrounds and healthcare systems. This widened perspective on palliative care thereby takes us back to the idea of a “totalizing” view that Cicely Saunders had in mind when thinking about how to approach a patient’s suffering at the end of life. As we hope this theme issue makes clear, literary accounts of palliative care have a key role to play in enhancing that picture.

¹ World Health Organization (1990) Cancer pain relief and palliative care. *Report of a WHO Expert Committee (WHO Technical Report Series, No. 804)*. World Health Organization, Geneva.

² For an overview of social science definitions of a “good death” see Steinhauser and Tulsky, “Defining a ‘good’ death”.

³ Dougdale, *Dying*, 174.

⁴ Pladek, *Poetics*, 28

⁵ See Wilson, “Museum Spaces in Palliative Art: Mariana Otero’s *Histoire d’un secret*,” 112. For a longer exploration of the concept see the introduction of Wilson, *Love, Mortality, and The Moving Image*.

⁶ Nuland, *How We Die*, 142.

⁷ Nuland, *How We Die*, 8.

⁸ Berman, *Dying in Character*, 11.

⁹ Ruth Ting et al., “Palliative Care for Patients with Severe Covid-19,” *BMJ*, 2020; 370. DOI: <https://doi.org/10.1136/bmj.m2710> (Published 14 July 2020).

¹⁰ Lukas Radbruch et al., “The Key Role of Palliative Care in Response to the COVID-19 Tsunami of Suffering,” 1467

¹¹ See <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/covid-19>

¹² Smith, “*Lancet* Commission on the Value of Death,” 1293.

¹³ The French-language volume *Les soins palliatifs à travers les humanités médicales* by Martyna Tomczyk et al. is the only volume to our knowledge that engages with palliative care from a medical humanities perspective. The volume brings together several disciplines from the humanities and social sciences, with the exception of literature.

¹⁴ See Stanley, P. and Hurst, M. (2011).

BIBLIOGRAPHY

- Anwar, Petra and John von Düffel. *Geschichten vom Sterben: Was am Ende wichtig ist* [Stories of Dying: What Matters in The End]. Munich: Piper. 2013.
- Ariès, Philippe. *Western Attitudes Toward Death: From the Middle Ages to the Present*. Translated by Patricia M. Ranum. Baltimore: Johns Hopkins University Press, 1975.
- Berman, Jeffrey. *Dying in Character: Memoirs on the End of Life*. Amherst and Boston: University of Massachusetts Press, 2012.
- Debray, Claude and Régis Grange. *Le dernier souffle* [The last breath]. Paris: Gallimard. 2023.
- Dougdale, Lydia. *Dying in the Twenty-First Century: Toward A New Ethical Framework for The Art of Dying Well*. Cambridge, Massachusetts: The MIT Press, 2015.
- Gawande, Atul *Being Mortal: Illness, Medicine, and What Matters in the End* (2014),

-
- Nuland, Sherwin B. *How We Die: Reflections on Life's Final Chapter*. New York: Vintage, 1994.
- O'Mahony, Seamus. *The Way We Die Now: The View from Medicine's Frontline*. London: Head of Zeus. 2016.
- Kathryn Mannix. *With the End in Mind: How to Live and Die Well*. London: HarperCollins. 2017.
- Pladek, Brittany. *The Poetics of Palliation: Romantic Literary Therapy, 1790-1850*. Liverpool: Liverpool University Press, 2019.
- Lukas Radbruch et al. "The Key Role of Palliative Care in Response to the COVID-19 Tsunami of Suffering." *The Lancet*, 395, 10235 (2020): 1467-1469. DOI: [https://doi.org/10.1016/S0140-6736\(20\)30964-8](https://doi.org/10.1016/S0140-6736(20)30964-8).
- Stanley, Patricia and Hurst, M. "Narrative Palliative Care: A Method for Building Empathy." *Journal of Social Work in End-of-Life and Palliative Care* 7, no. 1 (2011) :39-55.
- Smith, Richard. "Lancet Commission on the Value of Death." *The Lancet*, 392, 10155 (2018):1291-1293.
- Steinhauser, Karen E. and James A. Tulsky, "Defining a 'good' death" in *Oxford Textbook of Palliative Medicine*, 5th edn, ed. by Nathan Cherny. Oxford: Oxford University Press, 2015: 77-83.
- Tomczyk, Martyna et al., eds. *Les soins palliatifs à travers les humanités médicales : Au confluent des disciplines, des approches et des pratiques cliniques*. Chêne Bourg: Georg Editeur. 2023.
- Wilson, Emma. "Museum Spaces in Palliative Art: Mariana Otero's *Histoire d'un secret*." *L'Esprit Créateur*, 51, 1(2011), 112- 124.
- Wilson, Emma. *Love, Mortality and The Moving Image*. London: Palgrave Macmillan, 2012.