End of life – Introduction

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This special issue brings together six ethnographic contributions examining end-of-life care across clinical, visual and methodological registers. Drawing on fieldwork in Britain, France, South Africa, Brazil, Indonesia and India, the articles explore how institutional frameworks – medical, bureaucratic and ethical – encounter the irreducible particularity of dying.

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End-of-life care is both universal and irreducibly particular. Everyone dies, but the institutional arrangements that govern dying – clinical protocols, care rhythms, pain management – vary enormously and repeatedly encounter forms of specificity they cannot accommodate. Ben Kasstan-Dabush recently watched his grandmother follow end-of-life processes (with and without care) in a residential home in the northwest of England, while Samuel Sami Everett returned to the cancer clinic in the southeast of France where close observant Jewish members of his family had died decades ago. These encounters exposed the political and economic conditioning of care at life's end as much as the way that non-Christian expression is marginalized in palliative pathways.

Societies with ageing populations contain disproportionately more people over the age of 65, which raises conceptual and practical questions of how to care for a growing number of individuals with life-limiting conditions. Anthropological approaches to palliative care can help to ensure that such conversations are grounded in the priorities of individual people as they live and die (Greenfield et al. 2025), in an understanding of how those priorities are shaped by where they live in the world (Samuels & Lemos Dekker 2023) and in how those priorities are represented through our intimately visual and material worlds.

A shift from treatable to palliative care can be viewed by medical professionals as a predictable progression, but is often experienced diachronically by the 'patient' or person as they adjust to new meanings of (life)time (Chattoo & Ahmad 2004). Concepts such as 'quality of life' forge a process where care teams, families and the dying continuously make decisions amidst fragility and uncertainty (Borgstrom & Visser 2025; Driessen et al. 2021). Ethnographies have explored where people and families want to be at the cusp of death (Stonington 2020) and have examined institutionalized care as a site to understand how residents and carers negotiate race, gender, sexuality and ageing in their relationships (Golomski 2024). Managing death is not merely a clinical phenomenon but a social process of caring for people, bodies, wishes and knowledge. Dying and death take place amidst broad conceptualizations of care within religious legal frameworks (Kasstan 2017), at times in contrast to a state ethos of secularism (Everett 2018) or the cultural and linguistic familiarity of minoritized and migrant worlds (Arkin 2020).

Anthropological conversations about caring for people with life-limiting conditions have increasingly transitioned to critique the ethics of assisting people to end their lives or manage endings more 'humanely', possibly to avoid the social stigma attached to states of dependency or needing support (Buchbinder 2018; Hannig 2019). Current proposals in England and Wales to give terminally ill people the legal right to assisted dying are presented as offering people choice, autonomy and dignity in death (see Sallnow et al. 2025). Deciding when (and how) to end human life remains a tense ethical and legal challenge in many countries, but it is compounded by the sheer inequity that shapes access to health and social care across Global North and global majority settings. Yet advancing laws on assisted dying by asserting rights and autonomy 'to choose' can obscure how 'quality of life' in the context of palliative care is conditioned by patchwork health and social welfare services, which configure dignity and ideas of a good death within a narrow (if not austere) political economy of care. Such realities remind us how the margins of life offer a profound positionality from which to understand and critique epistemic boundaries (Kaufman & Morgan 2005).

This special issue emerges from a workshop on Ethnographies of Endings held at Durham University in 2024, which charted how anthropologists are navigating end-of-life care across clinical pathways, social worlds and visual representation.[1] The six articles critically reflect on the overlap between ethnographic and palliative practices by discussing the processes anthropologists use to conceive what we are left with and what comes after an ending. This collection curates an anthropological analysis of end-of-life care as a stage of life that is universal but shaped by situated and evolving influences in clinical medicine and social relationships. It demonstrates that institutional frameworks for managing death – be they clinical protocols, ethical review or hospice ideology – repeatedly encounter forms of specificity they cannot accommodate, and that those involved, whether clinicians, families, researchers or patients, respond with pragmatic improvisation.

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Casey Golomski's guest editorial draws on ethnographic research in a South African care facility to explore grace as both an analytical concept and survival strategy in end-of-life settings, showing how staff and residents use temporary acceptance to navigate racial tensions, workplace adversity and ethical uncertainty without requiring affection or absolution.

Methods of healthcare at the end of life form the focus of two articles. Simon Cohn, Annelieke Driessen and Erica Borgstrom argue that two logics of end-of-life care in England's National Health Service rest on fundamentally different conceptualizations of life itself: life as a possession to be protected through intervention, versus life as a process to be sustained through accompaniment. David Ansari argues that enactments of belonging at the end of life require what one French palliative care doctor calls *bricolage*: piecing together financial, institutional and clinical resources across families, health professionals and community networks. The article's distinctive method is intimate ethnography, which brings the author's own family deliberations about his grandfather's last journey between Pakistan and the United States into conversation with professional accounts from Paris.

How the end-of-life stage and care are mediated through visual and material cultures is explored in two complementary articles. Gaudenz Metzger uses Cicely Saunders' historical photograph archive from St Christopher's Hospice as a dialogical instrument in workshops with current hospice staff, whose responses unsettle hospice ideology. The key findings concern complicated deaths that resist the 'good death' narrative, and marginalized deaths, including the erasure of HIV patients from early hospice visual memory. Samuel Sami Everett argues that Pistoletto's

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[1] This workshop was funded by a Durham University Global Engagement Grant awarded to Yulia Egorova.

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culture of failure (eds) D. Jeevendrampillai. London: Bloomsbury.
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Sallnow, L. et al. 2025. Assisted dying, complex systems and global inequity in palliative care. *The Lancet* 405(10473): 103-105.
Samuels, A. & N. Lemos Dekker 2023. Palliative care practices and policies in diverse socio-cultural contexts. *Palliative Care and Social Practice* 17:1-9.
Stonington, S. 2020. *The spirit ambulance.* Berkeley: University of California Press.

Mètre cube d'infini installation in a Marseille cancer clinic materializes what he calls 'medical Mediterraneanisms': pragmatic negotiations between secular governance and embodied ritual practice grounded in Mediterranean patterns of pluralism rather than abstract multicultural frameworks.

Two articles consider the methodological politics of disclosure at the end of life. Carolyn Sargent and Kimberly Arkin juxtapose clinical contexts in France to argue for epistemological modesty in end-of-life care. Their core finding is that biomedical truth-telling, far from being a universal good, can be experienced as a form of violence by patients whose frameworks for understanding death are shaped by religious conviction, migration and structural inequality. The article covers Roma families and Maghrebi patients alongside West African women. Natashe Lemos Dekker, Hanum Atikasari, Syeda Shajeela Shawkat and Annemarie Samuels present three fieldwork encounters in Brazil, Indonesia and India where researchers faced dilemmas about sharing or withholding diagnostic knowledge when death was near. Their distinctive contribution is an argument for collective, team-based ethical deliberation as an ongoing practice during and after fieldwork rather than relying solely on pre-fieldwork ethical reviews.

Taken together, these articles suggest that the distance between how institutions provide a space for dying and what people experience or hope for offers a productive but painful tension for anthropologists to grapple with. Ethnography's contribution is to stay close to that distance – to show what improvisation looks like from the inside, what is lost when institutional frameworks cannot bend in the ways that people and practitioners might want, and what forms of care, relationships and harm emerge in the gaps. ●

Processes and partitions

Two logics of end-of-life care

Simon Cohn, Annelieke Driessen & Erica Borgstrom

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This article describes two logics through which end-of-life care is framed in biomedicine: the first is a logic of intervention, while the second is one that emphasizes support. We call them logics not only because this refers to different 'ways of dealing with' a health concern, but more specifically because associated practices enact different aspects into being (Mol 2008). Although the two logics regularly coexist, they sometimes clash, especially when the specific circumstances of a patient precipitate discussion about what actions might be taken. Such end-of-life situations frequently bring differing, and often conflicting, values to the fore, making them visible for anthropological enquiry through the various practices medics and others perform.

Interventionist medicine – even if not a coherent whole in itself (Berg & Mol 1998) – rests on the positivist assumption of a universal material body that is measurable, knowable and controllable (Lock 1993). Its central norms are rooted in Enlightenment thought and a mechanistic cosmology, including the belief in universal reason, linear and technical progress and human mastery over the natural and social world. These norms travelled well beyond the Global North where they emerged. Livingston's ethnography of oncology care in Gaborone, Botswana, for example, describes a clash between biomedical treatment imperatives and local realities of failing equipment and bed scarcity, foregrounding improvisation as a defining feature of everyday cancer care (Livingston 2012).

We extend these arguments by showing how approaches to medical intervention are invariably tied to ideas about what exactly biomedical staff can act upon. Specifically, our argument is that the very idea of an intervention – both in health research and biomedical practice – is informed not only by a certain temporal conceptualization but also by the notion of an amenable body that responds predictably to a clinical procedure. Here, the potentiality of medical practice is premised on its ability to come to know a disease entity, take action to rectify its effects and thereby postpone death (Taussig et al. 2013). As such, it imagines the body, disease and the patient in specific ways that make them 'intervenable'.

This notion of the body, or indeed a part of the body, however, is never entirely secure; a wound may not respond to medication as expected, tissue may remain obstinately infected or an organ may not repair itself as expected. These counter instances tend to be tolerated or simply regarded as anomalies to usual clinical practice; reasons may be proposed as to just why, in this particular instance, a drug did not have the predicted effect or a patient's skin did not heal as anticipated. In doing so, explanations are directed to idiosyncrasies of the particular site of the intervention or the match between intervention and a specific patient, rather than questioning the value of an intervention itself.

Dying in anthropological perspective

End-of-life care within biomedicine has been a significant focus in medical anthropology for a number of decades (Kaufman & Morgan 2005). Many early studies explored how hospital routines and healthcare systems influenced the provision of care – who received it, when and under what circumstances. These works also examined the complexities surrounding the determination of death and who holds the authority to decide (see, for example, Kaufman et al. 2006; Lock 2002). More recently, anthropologists have explored the issue of 'decision-making' (see, for example, Fortin et al. 2022), critically questioning the centrality of individual autonomy in bioethics in studies that highlight more relational and cultural dynamics (Zivkovic 2019). Some also delve into legal dilemmas which clash with accepted processes (Banerjee 2022). The assumption that end-of-life care should promote a 'good death', which is a common mantra in end-of-life studies, has also been questioned in work that looks at the detail of how care is adapted, resisted or reinterpreted in different contexts (Borgstrom & Lemos Dekker 2022; Samuels & Lemos Dekker 2023; Zaman et al. 2017).

While much of this work implicitly contrasts the perspectives and practices of the Global North with the Global South, a deeper analysis reveals that many questions about care for those who are dying are shaped by a range of fundamental cultural concerns. These often include conceptions of personhood, the relationship between the individual and others, ideas of suffering in this world and beyond, as well as the nature of care and how it should be provided. Critical approaches also highlight how the end of life is shaped by power dynamics (Borgstrom & Visser 2025), including the lasting impacts of colonialism and racism (Golomski 2024).

Based on an ethnographic project conducted with palliative care teams in the UK's National Health Service (NHS),