Palliative care

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Palliative care has been developing since the 1960s as a form of caregiving that focuses on the relief of suffering when there is no prospect of a cure or when a patient is at the end of life. Originating in the UK and US, palliative care has been taken up by global institutions such as the World Health Organization (WHO), and implemented in various cultural and socioeconomic settings. Anthropological studies have long been highlighting the wide variety of experiences and needs in illness and dying and have problematised the supposedly universal ideas behind palliative care. After a brief discussion of the historical and institutional development of palliative care, this entry highlights the links between palliative care principles and notions of a good death. It then turns to the medicalisation of death and the primacy of choice in palliative care discourses. It elaborates on anthropological studies that have observed how palliative care comes to relate to existing end-of-life care practices and the diversity with which local practitioners and care recipients give shape to this new care paradigm. Finally, it discusses various cultural and moral attitudes towards disclosure and concealment of dying as a site of friction in palliative care.

Introduction

Palliative care is commonly understood as professional caregiving that focuses on the relief of suffering when there is no prospect of a cure or at the end of life. Its central aim is to provide comfort, by focusing on symptom management and pain relief, as well as psychosocial and spiritual care. The word 'palliative' stems from the Latin *pallium*, which translates as 'to cloak' and is associated with the aim of providing comfort and alleviation that is inherent in palliative care. While definitions of palliative care continue to be subject of debate, as will be outlined below, the most commonly cited is the 2002 World Health Organization (WHO) definition:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (84)

Derived from hospice care, palliative care has been developing since the late 1960s into a form of caregiving that is practiced in various care institutions as well as in home care settings. Palliative care has developed into an interdisciplinary field of expertise in and of its own, with prominent contributions from medical disciplines such as nursing, oncology, and geriatrics, as well as social work and social sciences, and its practical implementation is accompanied by a range of studies on best practices and the

development of palliative care tools and models.

While palliative care is considered to have originated in the UK and builds on preceding developments in care for the dying in Western Europe and the US (Clark 2016), it has since then been promoted and taken up in other parts of the world. However, it cannot be assumed that palliative care is developing across the globe in the same manner and with the same effect. Hence, anthropologists have begun to study palliative care as a particular mode of end-of-life care that comes with particular sets of values and norms, exposing how it comes to exist alongside, reform, or replace existing end-of-life care structures and practices across geographical and institutional settings.

From an anthropological perspective, palliative care is approached as emerging from, and embedded in, cultural contexts, where it forms one particular way of managing illness and dying. As such, it has grown into a topic of interest both to researchers who position their work in the anthropology of death and in medical anthropology. Through immersive fieldwork, anthropologists have shed light on the lived experiences of patients, caregivers, and their networks. Taking critical as well as constructive approaches towards the paradigm of palliative care, anthropologists have asked questions such as: How is palliative care used in organisations and embedded in health systems? And how is care negotiated and what values does it reflect? Recognising, further, that death is not the great equaliser it is sometimes portrayed to be, but rather that dying is characterised by inequalities and difference, anthropologists have been interested in how access to palliative care is distributed between people of different backgrounds and across the globe. Also, anthropologists are critically assessing the use of terms like 'dignity', 'quality of life', and 'comfort' which are central in palliative care and are reflected in the WHO definition, and taking up the empirical question of what such terms come to mean in their local context.

In the sections that follow, and drawing on a range of anthropological studies, this entry first discusses the historical and institutional development of palliative care. It proceeds with a discussion of the ideals underlying palliative care and its connections to notions of a 'good death'. It then turns to the medicalisation of death and the primacy of choice in palliative care discourses. Finally, reflecting on the uptake of palliative care in diverse cultural settings, it discusses various cultural and moral attitudes towards disclosure and concealment of dying as a site of friction in the palliative care paradigm.

Genealogy of palliative care

The development of palliative care can be traced back to the 1960s and 1970s. It emerged as a response to the then-dominant focus on curative practices in healthcare, while patients were increasingly living with chronic conditions for which no cure was available (Clark 2007). By contrast, palliative care focuses on improving the quality of life of people who are dying or who live with a chronic condition. Although it does not exclude curative treatment, one of the key aims of palliative care has been to relieve suffering,

including psychological, social, and emotional, as well as physical pain.

As founder of the first modern hospice in 1967 in the UK, Cicely Saunders is considered a pioneer in the development of palliative care (Clark 2002, 2007, 2016; Seymour 2012). Her work in oncology as a nurse and hospital almoner, and later as a medical doctor, provided her with a unique perspective on patients' conditions. She observed a lack of pain control in cancer patients, and became concerned with what she called 'total pain': the suffering of patients that extends beyond physical pain and reaches to their entire being, including social, physical, mental, and emotional distress. Around the same time, Elisabeth Kübler-Ross, through her work in hospitals and as a lecturer in the US, advocated a novel focus on the needs of dying patients and support for families and is credited with opening up the possibility to discuss death in Western society (Blaylock 2005; Sisk and Baker 2019). Both Saunders and Kübler-Ross have been central figures in the development of palliative care.

From the 1980s onward, palliative care rapidly developed into an area of specialisation that has been incorporated across different disciplines, including oncology, nursing, and geriatrics. In practice, palliative care is usually provided by multidisciplinary teams, involving for instance medical doctors, social workers, psychologists, nurses, and spiritual advisers. Medical associations and dedicated journals have been established to delineate the field of palliative care. Hence, palliative care is both a field of knowledge and a professional practice. The European Association of Palliative Care (EAPC) was founded in 1988, the Latin American Association of Palliative Care (ALCP) in 2000, and the Asia Pacific Hospice Palliative Care Network (APHN) in 2001 (Clark 2007). Additionally, palliative care has gradually become, or is in many countries in the process of becoming, embedded in national health structures, as well as in global health programmes. While palliative care was initially focussed on oncology, this has gradually broadened to other (chronic) illnesses, including HIV/AIDS, and increasing attention has been paid to the potential benefits of palliative care for older people (Davies and Higginson 2004; Visser, Borgstrom and Holti 2020). While this reflects the 'holistic' character of palliative care, this also implies palliative care is subject to a wide variety of interpretations, approaches, and backgrounds.

Considerable discrepancies in approaches and definitions remain, and these continue to be the subject of debate among researchers and practitioners alike (Pastrana et al. 2008). The WHO published its first definition of palliative care in 1990 and revised it in 2002. The latter (cited above) continues to be commonly used, but has since then been reformulated, both by the WHO itself and other organisations such as the International Association for Hospice and Palliative Care (IAHPC) (Radbruch et al. 2020). Additionally, many organisations that provide palliative care in practice will describe it in their own terms (Hui et al. 2012). Often, these definitions reflect in one way or another Saunders' concept of 'total pain', as palliative care is described as holistic, person-centred, and provided by multidisciplinary teams, and is associated with meaning and dignity at the end of life.

However, anthropologists have shown that, within these broad characteristics, in practice the concept also remains unclear as some practitioners use the terms 'terminal care', 'end-of-life care', and 'palliative care' interchangeably (Lemos Dekker, Gysels and van der Steen 2017), while others explicitly differentiate them (Hui et al. 2012). Also, the use of 'hospice care' outside of hospice settings where others might use the term 'palliative care' indicates that the boundaries of the concept are not always clear.

Furthermore, the anthropological record has demonstrated that health systems and institutions are often unequally accessible, to which palliative care is no exception. The degree to which palliative care is accessible or integrated in health care systems varies widely between countries (Clark et al. 2020), and may further be influenced by a patient's positioning in terms of class, ethnicity, and gender (Richards 2022). Also, the often limited and unequally distributed availability of opiates, limitations in a patient's mobility, and institutional structures can challenge the accessibility of palliative care (Knaul et al. 2018).

As this entry will show, palliative care is embedded in diverse cultural contexts, and as such is interwoven with particular values, practices, and beliefs. Anthropological studies have underscored the wide variety of ways in which illness and dying are perceived and treated, as well as the variety of needs and expectations across social and cultural settings (Souza, Borgstrom and Zivkovic 2021; Zaman et al. 2017). This great diversity inherent in care means there is an important role for anthropologists in showing how palliative care is provided differently across cultural and institutional contexts; how people of different backgrounds, including professionals, patients, and families, each relate to it; and how they use and adapt palliative care's key principles to fit within their own work, lives, and networks (Samuels and Lemos Dekker 2023).

Palliative care and the good death

Anthropologists have generally taken a contemplative approach to palliative care, to shed light on its underlying values and its implications at a sociocultural level. In particular, this research has underscored that palliative care is informed by ideals that are associated with a 'good' death. Hence, palliative care has been suggested to form a specific, institutionalised approach to operationalising ideals of a good death and to bring these into medical practice (Hart, Sainsbury and Short 1998; McNamara 2004).

Anthropological studies have demonstrated that the good death forms a moral objective that underpins people's narratives, decisions, and actions (e.g. Hart, Sainsbury and Short 1998), whereby anthropologists have asked what a good death is to different individuals and groups, unravelling the social and cultural dynamics of how people experience, manage, and plan for the final stages of life and death (Long 2005; Seale and van der Geest 2004; Zaman et al. 2017). This body of literature has highlighted the variations as well as similarities between cultural groups with regard to their perceptions of what constitutes a good death, such as the commonly shared preference for a death without suffering. It has also shown the value

that is attributed to the place, timing, and social circumstances of death (Driessen, Borgstrom and Cohn 2021; Kaufman 2005; Lemos Dekker 2018; Stonington 2012). Taken together, the aspects that are attributed to a good death in a particular cultural context reflect what people commonly value at the end of life and the societal norms regarding death and dying, and provide directives for how the end of life should be managed. As such, the good death is taken as an ethnographic object by looking at the efforts that are put into its achievement.

Ideals of a good death can thus be understood to inform a wide range of palliative care practices, discourses, and experiences. This includes, in particular, its aim to provide comfort and to relieve suffering at the end of life in psychological, social and physical domains. However, in practice this ideal can be difficult to achieve as it is linked to experiences of (bodily) decline and notions of dignity. For example, Julia Lawton's (2000) ethnographic research in hospice wards in the UK underscores the fundamental importance of bodily deterioration, which, she suggests, has a 'non-negotiable' impact upon patients' sense of self (16). Lawton highlights significant disparities between the ideology of palliative care and what she calls the bodily realities of degeneration and dying. She shows that the dying process in many cases does not conform to normative goals of a calm, pain-free, and dignified 'good death', and suggests that the ideological underpinnings of palliative care may offer little room for deaths that do involve pain and distress.

Furthermore, as researchers in anthropology and related disciplines have demonstrated, the place of death plays an important role in the perception of a good death. In many cultures, the home is seen as the ideal place of death, while the clinical space of the hospital is often disfavoured. Nevertheless, it is quite common for people to be hospitalised as part of care provided at the end of life. Similarly, nursing homes and long-term care institutions may not be regarded as ideal places for dying, and yet are common places of death. Hence, a discrepancy may occur between the actual and preferred place of death (Kaufman 2005; Stonington 2020; Visser 2019). Addressing these concerns, palliative care institutions and staff, the ethnographic record shows, often put great effort into creating a 'homely' atmosphere, a place that is familiar to patients and their relatives (Pasveer 2020; Lemos Dekker and Pols 2020). For example, Annelieke Driessen, Erica Borgstrom, and Simon Cohn (2021) describe the efforts of palliative care teams in a UK hospital to create a familiar, personal, and meaningful space for the dying person in the institutional environment, in order to make it suitable for dying—a practice the authors call 'placing work'. Following Scott Stonington's (2012, 2020) research in northern Thailand, home and hospital may be understood as 'ethical locations', as each place may hold different ethical frameworks through which death and dying are managed and valued. Stonington discusses what he calls 'choreographing a good death,' which refers to the strategies through which people manage the end of life. This involves planning and improvisation so as to influence the place and timing of death, whereby families make use of, and navigate, biomedical systems as well as local and communal practices of approaching death. Stonington (2020: 1-8)

describes an instance of a dying person who was brought into the hospital so as to make sure they would receive all viable treatment, but was finally hurried back home to die to ensure their death would happen in the 'right place', reflecting ideas of the home as a moral space that would ensure the process of rebirth.

Likewise, anthropologists have demonstrated that palliative care is concerned with the timing and duration of the dying process. In her seminal ethnography, *...And a time to die: how American hospitals shape the end of life* (2005), Sharon Kaufman discusses how the medical bureaucratic system of hospitals in the US has become increasingly focused on the timing of death. In particular, decision-making at the end of life, such as decisions to continue or withdraw treatment, are concerned with postponing or allowing death, and can thus be seen as an attempt at exerting control over when death occurs. While her focus is on dying in hospitals in general, she notes that palliative care is integrated into hospitals as one form of end-of-life medical practice through which such questions of timing are negotiated. Although the moment of death is in many cases very difficult to predict, palliative care seeks to understand and gain control of time at the end of life. Accordingly, advance care planning (ACP) is, especially in Western contexts, often an explicit aspect of palliative care. ACP is often used in institutional care settings as a process through which patients, often in consultation with medical professionals and family members, establish their wishes and preferences to inform caregiving at later stages. While ACP in palliative care usually involves directives regarding dying and death, it may also include medical as well as psychosocial preferences in long-term care more generally. Palliative care, then, through its various tools and ACP, operates along the idea that anticipating care needs, and preparing for illness trajectories, will improve caregiving. More fundamentally, with this focus on timing, palliative care further channels the idea that an anticipated death is a controlled, and thus 'good', death.

This striving towards a good death is both implicitly and explicitly incorporated in the various models, tools, and practices of palliative care. Anthropological inquiry into such tools has shown that they may seek to coordinate caregiving and to transfer palliative care values in a standardised manner. Together with Erica Borgstrom, my work (Borgstrom and Lemos Dekker 2022) examines the Liverpool Care Pathway (LCP) as a tool that seeks to shape the dying process in accordance with ideals of what a good death is. The LCP is a document that is used to mark the onset of the 'palliative phase' and to communicate between care professionals that caregiving should shift to a focus on comfort and the management of specific symptoms. We draw on ethnographic research in care institutions in the UK and the Netherlands, to show that the tool is used to impart moral values, to standardise practices, and to demonstrate a sense of professionalism. Moreover, this ethnographic comparison shows that the use of such tools in practice can be expected to differ significantly from their intended use, and varies between geographic and institutional settings since they require interpretation and adaptation.

Choice and medicalisation

Palliative care continues to be promoted by some as an alternative to the hegemony of biomedicine, as it shifts attention from life-prolonging treatment to well-being and comfort. Anthropological work has investigated this seeming discrepancy between care and cure. Kaufman's (2005) research on death and dying in hospitals in the US underscores that palliative care, with its focus on comfort, is at odds with the curative focus of hospitals. This plays out in negotiations over what kinds of 'treatment' are recognised and funded within the hospital system, whereby Kaufman suggests that even though most people die in hospitals, these institutions were generally unable to provide the kind of death that people would prefer. Related to this, and based on fieldwork with palliative care staff in the UK, Erica Borgstrom, Simon Cohn, and Annelieke Driessen (2020) have signalled that when palliative care is framed in contradiction to curative care, patients, families, and even medical professionals may perceive it as 'doing nothing'. The authors show that what is seen as intervention or non-intervention depends on what practices are valued in care relations, whereby 'palliative care becomes "nothing" when a cure is posited to be the only form of success' (2020: 209). Accordingly, a key challenge in palliative care is to convey that withholding curative treatment is no longer taken to be a medical failure, but rather reframed as viable care at the end of life.

At the same time, palliative care is not wholly antagonistic to the medicalisation of death—that is, the process through which death is framed as a medical concern and which reflects the idea that death can be managed and controlled through medical knowledge and technological possibilities (Green 2008; Howarth 2007; Kaufman 2005, 2006). Asking how hospital medicine shapes the conditions for death, Kaufman (2005) further shows that the end of life is characterised by planning and decision-making, whereby patients and their families, in consultation with medical professionals, become responsible for often difficult choices, for instance of whether or not to continue life-prolonging treatment. As such, Kaufman writes, 'death has entered the domain of choice' (Kaufman 2005: 326). However, in practice, patients and their families may lack the specialised knowledge necessary to make informed decisions and may be unable to oversee the illness trajectory ahead or the consequences of (advance) decisions (Kaufman 2005). In her ethnographic study of end-of-life care in England, Borgstrom (2015) unpacks the rhetoric of choice, showing that this is intimately linked to neoliberal understandings of individual autonomy. She gives an example of a man who, despite the insistence of care professionals, refused to write down whether he preferred to be cared for at home or in an institution, because he considered this to be dependent on how his wife would cope with his care. In this case, advanced decision making did not resonate well with the uncertainty of changing care needs. Problematising the notion of choice, Borgstrom thus shows that it fails to address 'the relational, and often subtly negotiated, nature of care' (Borgstrom 2015: 709). Devin Flaherty (2018) also sheds light on the limitations of choice by discussing a case in the US Virgin Islands, where older adults have turned to hospice care due to lacking possibilities of receiving curative treatment. Hence, she demonstrates that the 'choice' to enter hospice care may be less based on an acceptance of death, than on how different forms of care are covered within the health care system. While palliative care thus incorporates a responsibility to make the right choices or establish preferences in advance, as well as

ideals of individual autonomy, these studies show that such notions are not always clear-cut.

Moreover, anthropologists have demonstrated that patients may be sceptical towards decision-making, as this may invoke the fear of being unable to undo decisions or of relinquishing control (Borgstrom 2015; Zivkovic 2018). For Beverly McNamara (2004), the increased emphasis on patient autonomy and choice is at odds with the original conception of a good death in hospice and palliative care, which is based on open communication and acceptance of death. In her ethnographic research among Australian palliative care practitioners, she shows that the wishes of patients, which may be to extend curative treatment despite efficacy, were at times prioritised over palliative care principles. Accordingly, she suggests, palliative care in practice became reduced to medical symptom management, and puritan notions of a good death were replaced with a 'good enough death'. In a similar manner, Marian Krawczyk (2021) has explored the experiences of palliative specialists in Canadian hospitals. She focuses on the affective labour of these professionals and shows how they organise patients' dying trajectories, not only in terms of their biomedical and physical needs, but also with the aim of defining and ordering 'appropriate' emotional responses. In so doing, she argues that hospital palliative care can be seen as an affective economy in which ambiguity, negotiation, and conflict are not failures, but rather constitutive components of the institutional and professional employment of palliative care principles. Anthropologists have thus shown how ideology and practice merge, clash, and change over time, and how palliative care pushes against biomedical frameworks yet continues to operate within the limits and affordances of a medicalised system.

(Non-)disclosure at the end of life

A key contribution of anthropologists to the field of palliative care has been to demonstrate how seemingly universal principles and definitions are being understood, taken up, and challenged in local, sociocultural contexts, and to look in detail at how palliative care is being provided in and beyond care institutions such as hospitals and nursing homes, as well as at home (Samuels and Lemos Dekker 2023). Stonington (2020), in his work on end-of-life care in Thailand, shows that palliative care was conceived of as a new concept and discussed only in its English terminology in an otherwise Thai linguistic context, showing a glimpse of the friction in the cultural adaptation of palliative care between globally circulating discourses and locally rooted practices. This conception of palliative care, as a new way of understanding and providing care at the end of life that comes to be in dialogue with pre-existing discourses and practices, further reveals some of the normative aspects of palliative care. Anthropologists have been calling this normativity into question, viewing palliative care alongside other resources and care practices (Stonington 2020; Zaman et al. 2017).

A clear example of how principles of palliative care may clash with existing care practices is the way in which people do, or do not, talk about death and dying. Palliative care, as indicated above, involves a focus on anticipating a patient's disease trajectory and the process of dying. A common principle is that talking openly about the end of life between patients, families, and professionals improves decision making,

whereby the patient's knowledge that they are dying is thought to foster their autonomy. Stonington's work in Thailand shows that, in the process of choreographing death, medical professionals and family members sought to maintain the moral spirit of the dying person and maintain hope by *not* disclosing diagnosis and prognosis. Similarly, McNamara (2004) demonstrated in the Australian context that the ideal of open discussion and acceptance of death may not resonate with a patient's wishes. Along these lines, several anthropologists have demonstrated that cultures of end-of-life talk vary widely, and that letting a patient know they are dying is far from being a universally accepted good practice. To the contrary, in many cases discretion—not sharing a diagnosis or prognosis with either the patient themselves or with outsiders—has been argued to be perceived as a form of care and ethical practice (Banerjee 2020; Livingston 2012; Stonington 2020). Already in 1965, and based on fieldwork in US hospitals, sociologists Barney Glaser and Anselm Strauss published their volume *Awareness of dying*, in which they described interactions between staff, family, and dying patients, asking who knew about the terminal nature of the patient's condition, and what each suspected the other to know. Through the concept of 'awareness contexts', they showed the nuanced ways in which forms of disclosure and concealment of dying may intersect, and that whether, how, and when to talk about dying is a moral question that involves professional ethics as well as personal values and experiences.

Dwaipayan Banerjee (2020) discusses similar dynamics of speech and concealment, or disclosure and discretion, as crucial aspects of the social relations that are formed and reshaped around life-threatening illness in his ethnographic research with an NGO that provides palliative care to cancer patients in Delhi. Giving a prognosis and a diagnosis of, in this case, cancer, can open up certain possibilities, including access to palliative care. However, it can also foreclose others, as it may result in stigmatisation and a loss of livelihood. In one example, Banerjee describes how the NGO deliberately parked their vans at a distance from the home of the patients they visited so they would not be seen by neighbours, with the aim of preventing stigmatisation of the patient. Such an exercise of discretion reflects a broader set of practices, in which patients, families, and professionals would avoid explicitly talking about cancer, the ineffectiveness of further treatment, or the prognosis of dying. Banerjee suggests that 'knowing what not to say allowed for them to continue to live in the present, without compromising all hope of the future' (2020: 41), thus showing the potentiality and ethical concern that may be enveloped in acts of non-disclosure.

Conclusion

Since its early development in the UK and US, palliative care has been taken up by global institutions such as the WHO and has been implemented in various cultural and socioeconomic settings. Hence, anthropologists have observed how palliative care comes to relate to existing end-of-life care practices, showing the diversity with which local practitioners and care recipients give shape to this new care paradigm. From these studies, palliative care emerges as a field of knowledge and practice that draws

attention to the needs of dying and chronically ill patients and their networks. Often through the efforts of staff, palliative care has been carving a space for a particular focus on the relief of suffering within hospitals and care institutions. Palliative care, then, is not a single, clearly bounded idea, but a concept that is on the move. In many places, palliative care is relatively new, being advocated by a diverse group of medical professionals, and only gradually being embedded in health care policies. By looking in detail at how medical professionals communicate with patients and families about illness and the end of life, and the ways in which families among themselves do, or do not speak about this, anthropologists have been able to demonstrate that there are different ways of dealing with diagnosis and prognosis, and that what people find important at the end of life differs across cultural contexts. Accordingly, not only do care practices change in dialogue with this new approach, but also the concept itself is bound to be adapted.

Acknowledgements

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[1] Within the field of palliative care, increasing attention is paid to diversity and inclusion. For example, the theme of the 2023 EAPC World Congress was "Equity and Diversity". https://eapccongress.eu/2023/. Accessed 29 September 2023.

[2] World Health Organization. 2020. "Palliative care." https://www.who.int/news-room/fact-sheets/detail/palliative-care. Accessed 2 November 2021.