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Rethinking end of life care: attending to care, language and emotions

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Dying and the dead body have long been a focus of the social sciences, and increasingly there is an emphasis specifically on the 'end of life' and the care that is enacted, experience and envisioned during this period. In many countries, end of life care is a growing area of social and health policy concern (Economist Intelligence Unit 2015; Woodthorpe and Foster 2016), yet defining what 'end of life care' is and what it should entail varies. Cross-culturally there are different expectations about this, including how long the period of 'end of life' is, and to what extent professional services, such as palliative care or hospice, are involved. The authors in this special issue have encountered end of life care in different countries, including Canada, Australia and the UK, where end of life care is often provided to people who have advanced, progressive, incurable illness with the intention to enable them to live well until they die and experience a 'good death'.

The contributions in this special issues explicitly and implicitly draw on this longer social science interest in death, which is sometimes referred to as 'death studies'. Social scientists have used the importance of death within different societies and settings as a method to analyze larger social issues in a cultural context (Bauman 1992; Hertz 1960; Durkheim 1952; Turner 1977) and ethnographers have explored issues of dying and the dead body in various geographic areas (Block and Parry 1982, Bluebond Langer 1987; Catedra 1992; Danforth 1992; Huntington and Metcalf 1979; Lawton

1997; Lock 2002; Long 2005; Scheper-Hughes 1992; Seremetakis 1991; Sudnow 1967). These studies collectively serve to illustrate that even though death is often framed as a universal human experience, how it is experienced, understood, and the practices around death – such as care and funerary rites – have been immensely varied across and within cultures. Furthermore, researching issues surrounding death has enabled social scientists to provide theoretical concepts to the process of dying and death, illuminating that it is not merely a biological event (Fabian 1973. Hallam, Hockey, and Howarth 1999, Seale 1998). Focusing specifically on end of life care, social scientists have examined how it can be a liminal period or transition between living and being dead, and the various practices that are involved in this transition and period of time (Lawton 1998; Kellehear 2007; Kauffman 2005; Timmermans, 2010).

The authors in this special issue draw on this background of social science engagement with death to think through how people enact and envision care around the end of life, and to illustrate how this varies within a global context where end of life care is not universal even though death is. In doing so, the articles concern themselves with care – in multiple forms – at the end of life and enacted through interaction. Building on recent developments in anthropology and related disciplines about care practices (Mol, Moser, and Pols 2010), contemporary rituals around death (Boret, Long, and Kan 2017), and social aspects of dying (Das and Han 2016), this special issue adds to our current theorizing of human life. In different ways the contributors examine how people in different contexts demonstrate and think through care practices and languages of care to understand human life. In particular, this issue rethinks acts of care and how they may be negotiated. All of the papers place care and death in relation with each

other – not necessarily as naturally occurring or normative but exploring how they are configured in various contexts. The contributors theorise and employ these concepts in different ways, partly through the empirical material they are drawing on, and through theoretical perspectives surrounding issues that pertain to the end of life. On one level, the contributions illuminate what care around death is and can be. On another, the ethnographic analysis demonstrates how unstable care as a category is and how it is being negotiated, performed and value-laden. In this way, care therefore is neither neutral nor necessarily assumed ‘good’ (Mol, Moser and Pols 2010).

The central theme of planning or seeking a ‘good death’ is predominant, but not monothetic. Notions of location, acceptance, and professional ideas as to the condition of the body all surface and are critically engaged with via theoretical perspectives of place, affect, emotion and relationality. By attending to different linguistic registers, enactments and sites of care at the end of life, the contributors show how care is practiced in relation to others, and how it is reconfigured, contested and always emplaced in social worlds. Extending recent theorising on care (Hobart and Kneese, 2020) this volume exposes the co-option of care by neoliberal agendas of economic rationalisation and individual responsibility to care for the self. While recognising how an awareness of dying and its possible trajectories may present options for care givers, family, and the dying person (Das and Han 2015; Stillion and Attig 2014; Scarre 2007; Glaser and Strauss 1965; Rinker 2021), these articles also unsettle the imperative to anticipate and plan for ageing, illness and the end of life, and the ways in which this is talked about, both between clinicians themselves and between clinicians and patients and their families. The articles in this issue demonstrate how the focus on a planned or

'good death', as promoted in policy and practice guidelines, obscures the variant spatio-temporalities, emotional affects, and social contexts and complexities in which end of life care is configured.

In this sense the need to be aware of impending death can create an environment that affects the process in which it will occur, but it needs to be negotiated among all the participants. Themes that emanate from the essays highlight the social, material and emotional entanglements that emerge in end of life care. The emotions of the dying person, family, and caregivers affect care trajectories and are intimately interrelated with availability of resources and access to appropriate support and services.

Death is shaped by shifting intersections of gender, class, religion, ethnicity, ability and individual biography. Variant assemblages produce different ways of dying and they require different responses and responsibilities to care. The papers articulate the limitations to uniform approaches to policy and practice, and they show how care at the end of life is negotiated in local contexts, how it is adapted and tinkered with to meet the needs of the dying and their families at this critical time. In a global world with transnational movement and increased social and economic inequalities, there is an ever greater need to provide access to diverse pathways of care. The articles in this volume seek to understand how cultural and clinical assumptions interrelate and are coordinated in different end of life settings. They offer practical suggestions to reorient care at the end of life to be more sensitive to social diversity, and less stressful and fraught with tension. However, they do not reduce care's complexities. On the contrary,

the authors aim to contextualise and communicate the often messy, relational and emergent repertoires of care in ethically responsive ways.

Krawczyk situates her article in two acute care hospitals in Canada focusing on palliative care in these institutions. She underscores the competing issues in this context between a curative and end of life trajectory. She articulates the components as an affective economy in this setting. Using a social constructionist approach, she cites that their work is at the micro, meso and macro levels. She notes that the work needs to be both compassionate and efficient. Her in-depth analysis recognizes the ambiguity, conflict and negotiation that is evident. In conclusion she provides a model not as a prescription, but rather to provide some insights in ways to provide care to dying persons and to deal with the mandates situated in the acute hospital setting. She concludes that the work is critical to provide appropriate end of life care and the work of clinicians in this context need to recognize and respond to the changing trajectory of the hospitalized patient's condition.

Carter, Mohammed, Upshur, and Kontos underscore the importance of clinicians' recognition of the trajectory of illness. They focus on the concept of malleable versus senescent elderly bodies. Reviewing the literature regarding end of life conversations they note the lacuna regarding the screening for medical frailty that limits the conversations regarding advance directives and end of life care. Using the concept of biomedicalization, they highlight the imperative to treat with perhaps undesired interventions, but they also recognize the impact of these interventions and their intersection with race, gender, and class. Their article demonstrates how dominant

discourses of successful aging and frailty mandate intervention for the elderly, thereby surfacing the power relation of medical authority.

Zivkovic's research highlights the issues of Chinese aging migrants in Australia concerning advance care planning and decision making at end of life. She uses the concept of (*mianzi*) 'face' not in Goffman's theoretical approach as an individual autonomous actor, but as it is understood and embedded in Chinese relationships. From her participant observation and interviews with Chinese elderly migrants and their families, she provides data and an analysis of 'saving face' when an elderly person requires nursing home care or is nearing death. The complexity of how care is provided and by whom is inherent in cultural norms and embedded in concepts of "saving face." Immigration, socio-economic status and the one child policy affect how face can be lost or what tactics can be employed to restore face within the larger context of interpersonal relationships. This is a valuable contribution given how policy discourses about advance care planning often focus on the dying individual and their autonomy, rather than recognising the familiar and relational elements that Zivkovic illuminates.

Driessen, Borgstrom and Cohn problematize how the concept of place is enacted in palliative care practice towards the end of life by focusing on the 'placing work' palliative care professionals do. Through ethnographic research in London, they illustrate how palliative care professionals are driven by end of life care policy to record dying people's preferred place of death and the work, and tensions, that such a policy requires. They highlight the attention palliative carers provide to ensure safety, stability, control and a 'sense of home' when navigating the end of life and often the changing conditions of patients and their social situations. By foregrounding practices and

processes they do not focus on choice, which the rhetoric around preferred place of death does, but rather the fact that by defining 'where' solely in terms of making a singular decision about location fails to take into account the nature of a place as an environment for living, and dying.

Olson, Smith, Good, Neate, Hughes and Hardy engage with the issue of how to communicate in the context of palliative and end of life care. They note that clinicians face a tension between direct, open communication (e.g. explicitly saying someone is dying) and patients' and families' diverse, and sometimes differing, preferences for information and awareness about the situation. Using data from interviews with clinicians in a range of medical career stages, they illustrate how clinicians working within palliative care in Australia communicate in an emotionally reflexive manner. Rather than use the same language within clinical settings and with patients and their families, the clinicians rely on emotional and cultural cues to consequently tailor their communication. This adds to a growing literature that encourages nuanced communication about the end of life, which acknowledges diversity, rather than support blanket protocols about language use.

Kirby, Broom, MacArtney, Lewis and Good examine family meetings with palliative care teams in Australia to examine hope as a desire for a possible outcome. They acknowledge that hope can be alluring for those facing the end of life, and even those supporting or caring for them. Their analysis attends to hoping for something and living with hope to illustrate what 'hope' does in the context of palliative care. Whilst family meetings may generally be perceived by palliative care professionals as opportunities to share information and develop consensus on care planning, their

accounts in their article show how difficult it can be to shift goals of care and the role hope can play in this. They point to how hopefulness can be a way of doing dying, and we'd extend this further as an example of doing care in the contexts they describe, albeit with tensions about how 'caring' hope can be when mortality is on the horizon.

Collectively, these articles problematise often taken-for-granted approaches and practices in end of life care that point to the tensions in what 'care' is and can be when someone is dying. Across the articles, ideals and expectations of care are present in policy, palliative care, biomedical, and familial and individual notions of what should happen at the end of life and why. Whilst these may at times be explicitly articulated, the illustrations in these articles often reveal how they can be known tacitly through the practices and interactions that are between people. These articles therefore encourage us to think about the intersections between these different elements and challenge potential foregone conclusions about what care and dying should look like.

Whilst the contributors have been engaging with their research over many years, we acknowledge that we are bringing them together at the precipice of a pandemic. The juncture between life and death and healthcare landscapes that they are writing about has to some extent been drastically changed – perhaps momentarily, and perhaps longer – because the “percussive – immediate, disruptive and urgent – effects” of COVID-19 will ring loudly for many years to come (Manderson 2020).

The virus also has provided a new focus on public health and the pharmaceutical industry. The long term effects of this renewed focus needs to be researched. However, these articles provide an historic concept of how palliative care and hospice prior to the pandemic and the issues that surface. They provide models of past practice that could

be a foundation upon which to learn and build the process as we move forward in a post pandemic world. They do not provide answers, but rather reveal ways in which past practice has been applied and utilized. In this way it can serve as a point of reference as new models and practices evolve.,

## References

Bauman, Z., 1992. *Mortality, Immortality and Other Life Strategies*. Polity Press, Oxford, UK.

Bloch, M., Parry, J., eds. 1982. *Death & the Regeneration of Life*. Cambridge University Press, Cambridge UK.

Bluebond-Langer, M., 1978. *The Private World of Dying Children*. Routledge, London.

Boret, S.P., Long, S.O., Kan, S., eds. 2017. *Death in the Early Twenty-first Century: Authority, Innovation, and Mortuary Rites*. Springer, Cham Switzerland.

Catedra, M., 1992. *This World, Other World. Sickness, Suicide, Death and the Afterlife among the Vaqueriros de Alzada of Spain*. University of Chicago Press, Chicago.

Danforth, L, M., 1982. *The Death rituals of Rural Greece*. Princeton University Press, Princeton.

Das, V., Han, C., 2015. *Living and Dying in the Contemporary World: A Compendium*. University of California Press, Oakland California.

Durkheim, E., 2002 [1897]. *Suicide: A Study in Sociology*. Routledge, London.

Economic Intelligence Unit. 2015. *The 2015 Quality of Death Index: Ranking palliative care across the world*. *The Economist Intelligence Unit 15*, London

Fabian, J. 1973. "How Others Die – Reflections on the Anthropology of Death.". In *Death in American Experience*. Ed. By Mack. 177-201. Schocken, New York.

Glaser, B., Strauss, A., 1965. *Awareness of Dying*. Aldine, Chicago.

Hallam, E., Hockey., J., Howarth, G., 1999. *Beyond the Body: Death and Social Identity*. Routledge, London.

- Hertz, R., 1960 [1909]. *Death and the Right Hand*. Cohen and West, London.
- Hobart, H.J.K., and Kneese T., 2020. *Radical Care: Survival Strategies for Uncertain Times*. *Social Text*. 38 (142), 1-16.
- Kaufman, S., 2005. *And a Time to Die: How American Hospitals Shape the End of Life*. Scribner, New York.
- Kellehear, A., 2007. *A Social History of Dying*. Cambridge University Press, Cambridge, UK.
- Lawton, J., 2000. *The Dying Process: Patients' Experiences of Palliative Care*. Routledge, London.
- Lock, M., 2002. *Twice Dead: Organ Transplants and the Reinvention of Death*. University of California Press, Berkeley, CA.
- Long, S.O., 2005. *Final Days: Japanese Culture and Choice at the End of Life*. University of Hawaii Press, Honolulu.
- Manderson, L., 2020. The Percussive Effects of Pandemics and Disaster: Introduction. *Medical Anthropology*, 39(5), 365-366.
- Mol, A., Moser, I., Pols., 2010. *Care in Practice: On Tinkering in Clinics, Homes and Farms*. Transcript Verlag, Bielefeld.
- Huntington, R., Metcalf. P., 1979. *Celebrations of Death. The Anthropology of Mortuary Ritual*. University of Cambridge Press, Cambridge UK.
- Rinker, C.H., 2021. *Actively Dying: The Creation of Muslim Identities Through End-of-life Care in the United States*. Routledge, London.
- Scarre, G., 2007. *Death*. Acumen, Stocksfield.
- Scheper-Hughes, N., 1992. *Death without Weeping: The Violence of Everyday Life in Brazil*, University of California Press, Berkeley, CA.
- Seale, Clive 1998. *Constructing Death*. Cambridge University Press, Cambridge UK.
- Seremetakis, Nadia. 1991. *The Last Word: Women, Death, and Divination in Inner Mani*. University of Chicago Press, Chicago.
- Stillion, J.M., Attig, T., eds., 2014. *Death, Dying, and Bereavement: Contemporary Perspectives, Institutions, and Practices*. Springer, New York.

Sudnow, D., 1967. *Passing On: The Social Organisation of Dying*. Prentice Hall, Englewood Cliffs NJ.

Timmermans, S., 2010. *Sudden Death and the Myth of CPR*. Temple University Press, Philadelphia, PA.

Turner, V., 1977. *The Ritual Process*. Cornell University Press, Ithaca, NY.

Woodthorpe, K., Foster, K., eds. 2016. *Death and Social Policy in Challenging Times*. Palgrave, Basingstoke.

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