15

AGENTIC DYING

The Global Imperative to Acknowledge Socio-Anthropological Aspects in Palliative Care Services for All

Carlos J. Moreno-Leguizamon, Marcela Tovar-Restrepo, and Ana María Medina Chavez

Introduction

In Reimagining Global Health, Farmer et al. (2013) called for social theory to enrich the action orientation of the health sciences. They argue that theoretical work can inform health services research and training, including diverse populations' dying processes. Palliative care would benefit from incorporating the humanities and social sciences to complement the biological aspects of dying processes, dominated by medical science (Moreno-Leguizamon et al., 2015). This chapter proposes three socio-anthropological arguments to be inbuilt into palliative care. First, pain is a biological condition and a social intersubjective relation (Das, 1995; Kleinman et al., 1997; Djordjevic, 2021). Saunders (2006) reimagined and reconceptualised this complexity as 'total pain'.

Second, modern hospices and homes are not the only locations where people may die. They can be places where dying is treated more humanely and sympathetically (Sallnow et al., 2022). Third, the concept of agentic dying, based on Castoriadis' idea of autonomy (1987; 1991; 1992; 1997), opens the space for self-reflection about dying processes with the facilitation of health professionals and institutions, which help reduce suffering. In turn, this enables us to critically reflect upon how, where, and with whom, we wish to die. The United Kingdom (UK) and Colombia are used to illustrate these issues.

The Global Need for Palliative Care for All

Palliative care is formally defined by the World Health Organization (WHO) as:

> …an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with a

DOI: 10.4324/9781003128373-15

> life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.
>
> *(WHO, 2020)*

Further, it is one of the latest-recognised medical specialisations globally. For example, it was recognised in 1987 in the UK, and 2008, in the United States of America (USA) (Moreno-Leguizamon et al., 2017). However, it lends itself to misinterpretation from health professionals and the public. It is commonly assumed to be the healthcare you receive when you are dying or the type of care provided in hospices, which are 'new' places where people die, at least in advanced economies.

In most advanced economies, palliative care, as a medical discipline, has progressed immensely in the last 50 years, to the extent that there is now a marked differentiation between 'palliative' and 'end-of-life' care in the UK. Palliative care is the care needed when facing a long-term chronic or severe disease, and end-of-life care occurs, when a person is facing the 'last year' of life (Moreno-Leguizamon et al., 2017). In contrast to advanced economies, in low- and middle-income countries, there is still a need to recognise palliative care, end-of-life care, hospices, or alternative places to die, besides hospitals. In Colombia, death is an event that occurs in hospitals (Colombian Palliative Care Observatory, 2020).

According to the World Health Organization (2020), the current global picture of palliative care shows insufficient access to this service. Of the people requiring this type of care globally, only 14% receive it. Similarly, of the estimated 40 million people who need it globally, 78% are in low- and middle-income countries. The overall need for palliative care for children in low- and middle-income countries could be up to 98% (WHO, 2020). Additionally, this need is greater in low-income countries, which are mainly situated in Africa. Nonetheless, independently of the needs of countries of different income levels, the ageing population is globally increasing demand for palliative care.

Furthermore, the World Health Organization (2020) states that the global barriers to overcoming the insufficiency of palliative care services mean addressing misconceptions and misunderstandings around it. For example, the lack of inclusion in health policies and systems; training for professionals; access to opioid pain relief; awareness among policy makers, professionals, and the public; and education and self-reflection about death and dying from a cultural and social perspective, are missing from current debates around palliative care. The social sciences and humanities can contribute to the socio-anthropological aspects related to pain and dying, that palliative care, as a new medical discipline, does not currently include.

Social scientists have agreed extensively that pain and dying are events that, far from being merely biological and individual, are emotional, psychological, and cultural processes, which involve various intersectional identity markers, such as gender, ethnicity, class, sexual orientation, disability, age, location, and religion

(Moreno-Leguizamon et al., 2017). For example, ethnic minorities in the UK and USA have less access to palliative care services, due to lack of information, resources, and limited linguistic skills (Moreno-Leguizamon et al., 2017). Also, among certain ethnic groups in the UK, British Punjabi women indicated a preference for dying in hospital, while men's preference was for dying at home, implicitly revealing the type of care expected. Women expected better care in hospitals, while men expected care at home, by their carer/wife/partner (Smith et al., 2015).

Using Castoriadis' philosophical concepts (1987; 1991; 1992; 1997), pain, death, and dying can be defined as social imaginary significations, which provide meaning, and sense to the individual's lives. Social imaginary significations constitute the web of meanings that permeate, orient, and direct social life, providing internal cohesion, and routinised means of behaviour and culture. They produce what we call 'reality' or 'rationality' in our social and psychical life. Therefore, social imaginary significations are socio-historical meanings that give society norms, values, procedures, and methods to understand and construct lived experience (Castoriadis, 1987). It is through these, that processes of pain and death, are represented and managed.

Consequently, the social imaginary significations give meaning and identity to social institutions, which are defined as sanctioned symbolic networks, which function among human collectives. The social construction of social institutions is continuously in a state of contingency by individuals and collective discourses and directed by human agency and intentions. Therefore, social institutions never exhaust the creations of their social and functional roles (Castoriadis, 1997). As social constructions, both the social imaginary significations, and its produced social institutions, are not fixed. They are historically and contextually informed and are constantly changing, through significations and resignifications. Gawande (2014), in his account of recent history of healthcare and hospitals as social institutions, to cope with death and dying processes, illustrates this fact. For him, recent dying practices developed in hospitals do not produce the most effective outcomes.

The socio-historical meanings of pain and death can be questioned and altered by individuals and collective institutions, which are capable of self-reflection, to redefine, and manage 'quality of life' and 'quality of dying'. A current illustrative example in the UK is the grassroots movement, 'My Death, My Decision', which seeks compassionate legislation for greater choice in assisting dying adults with sound minds, who are terminally ill, or suffering from pain to an intolerable point (My Death, My Decision, 2022). Saunders (2006), the founder of the modern hospice movement, in her reimagining of a more sympathetic signification around treatments for cancer patients in the 1970s, revolutionised biomedicine with (1) the reconceptualisation of pain as total pain; (2) the creation of the hospice as an alternative institutional space to die; and (3) the opening of debates about more compassionate and sympathetic choices for dying (Moreno-Leguizamon et al., 2017). This is elaborated below.

Total Pain and Dying as Social Imaginary Significations

Moreno-Leguizamon et al. (2017) argue that Saunders's construction of the concept of total pain witnessed the emergence of the social, cultural, psychological, and spiritual dimensions that were rarely conceptualised by conventional biomedicine. The fact that she initially studied philosophy, later nursing and social work, and finally medicine, probably assisted her in designating the comprehensive and intersectional conceptualisation of total pain (Moreno-Leguizamon et al., 2017). This critical philosophical concept animates the modern hospice movement. However, this resignification of pain has had a limited impact on other areas of biomedicine, in which the conceptualisation of pain is still constructed, as a biological event, for example, pain clinics.

Total pain can be seen as an intersubjective relationship, where different intersectional identity markers are at stake, in addition to its biological condition (Das, 1995; 1996; Kleinman et al., 1997; Djordjevic, 2021). As ethnographic research in different contexts has shown, pain talk (Djordjevic, 2021) is related, not only to knowledge (as a medical object), but it is also associated with recognition and acknowledgement, or the lack of it (as an intersubjective relation) of the others' experience of pain. No one can communicate or transmit the experience of pain but through pain talk (Djordjevic, 2021). Since one cannot experience another's sensations, one must comprehend and apprehend pain through a narration of it. For this reason, empathy and compassion become central to the way pain is experienced, expressed, and acknowledged by others (i.e., medical doctors, nurses, carers, and institutions). Thus, understanding and acknowledging pain, when dying, is an intersubjective experience, informed by cultural content, and intersectional positionality.

Djordjevic (2021) has recently argued for a further conceptualisation that reimagines and recognises pain for its productivity, rather than a malfunction, to be eradicated from the body. For example, certain ethnic groups have rites of passage in which pain is inflicted to prove one can be regarded as an adult by others in the community; this illustrates that pain can be traded for belonging and coming of age (Djordjevic, 2021). Furthermore, he perceives in pain, political and transformative possibilities, such as in the recollection by Rev. Dr Martin Luther King Jr, of African Americans walking deliberately into fire hoses and vicious dogs during the 1950s–1960s, when the Civil Rights movement redefined politics in the USA. Hence, it is possible to observe how pain works as a symbol, which enables new and different expressions of identity, subjective content, and a sense of community.

Thus, concepts of pain and suffering, either as total pain or as productive pain, within palliative care for all, are strengthened, when partnered with the social sciences and humanities. Such acknowledgement will enable the development of the intersubjective, political, and productive dimensions of pain within the living-dying process, the place where we wish to die, and, finally, the concept that is proposed in this chapter: 'agentic dying'.

Hospices and Homes as Alternative Dying Institutions

Kakar (2014) has pointed out the intrinsic difficulty of admitting the complexity of dying as a multidimensional, inescapable human condition. As he points out, 'Death is not mysterious… yet the mystery of death lies everywhere' (Kakar, 2014: 17). Commonly, people only embrace death when it becomes imminent. This is due not only to the inherent emotional and psychical difficulties in accepting our finitude but also to the lack of social institutions, in most cultures, to prepare us to accept death. However, as this article attempts to demonstrate, the modern hospice, as reimagined by Saunders (2006), is a social institution, where people die, not only in an almost 'de-medicalised' way but also in a more compassionate and empathetic way (du Boulay, 2007).

'Home' was the oldest and most traditional location of death until its relocation, to mainly hospitals. However, when people use the word 'home', they seem to mean a familiar site (dwelling) rather than people's houses in the physical sense. Home as a familiar site has a long socio-cultural and historical history, in contrast to the hospital. As Gawande (2014) demonstrates, the hospital is a recent invention, or social imaginary signification, and one that is unlikely to be effective in terms of dying. Nonetheless, despite the similarities, the two locations operate differently. While hospices provide some minimum medical technology and facilities for daily care, such as symptom management and adapted facilities (beds, baths, and showers), homes can appear precarious or lack adequate infrastructure (Hoare et al., 2019). What seems clear is that these two institutions are serious alternatives to the traditional hospital, and its deficiencies, because of their new and radical approaches. Heubber and Sellschopp (2014: 215) note that Saunders stated: 'Hospice is not a place to go to die, but rather a concept of care based on the promise that when medical science can no longer add days to life, more life will be added to each day'.

In Colombia, for example, death at home may imply radically different meanings and symbols for various intersectional groups. For instance, for the poorest, it means a lack of essential public services, home adaptations for end-of-life care, and the presence of a caregiver, who is usually a woman. The general health system does not pay for direct and indirect costs to caregivers. Although Colombia is unique among non-industrialised economies with legislation regulating palliative care services, with the Law 1733 of 2014 (Congress of Colombia, 2014), the hospice has not become a recognised institution. Access to this type of care is limited and concentrated in urban centres (Hernández-Rico and Ballén-Vanegas, 2021).

A six-year research project attempted to understand the palliative and end-of-life care of black, Asian, and ethnic minorities in the Southeast of England through a Learning Alliance – LAPCEL (2019). Various groups of local stakeholders familiarised themselves with the hospice as an institution (Smith et al., 2015) through collaboration, training, public engagement, and dissemination of research findings through pictograms (LAPCEL, 2019). Overall, it was observed

that the hospice, as a provider of care at the end of life, was friendly and sympathetic. As Djordjevic (2021: 11) clarifies, 'etymologically the root of 'empathy' 'is to feel with', to enter into another's pain and inhabit it with [them]'. Thus, the need for both the public and health professionals to familiarise themselves with the hospice, as an alternative institution for dying is urgent, as is the 'reimagining' of the hospice, or its equivalent in middle- and low-income countries.

In the UK, hospices have lately developed the infrastructure to support people dying at home, and this could also be a positive development for middle- and low-income countries where resources are scarce. Posing the question about 'dying institutions' and provision of care, nonetheless, raises the urgent need to challenge the unpaid or underpaid care work that the dying process implies. Globally, this work is mainly done by women, ethnic minorities, and migrants. This is another socio-anthropological aspect which needs to be explored as studies of dying and palliative care develop. The social sciences and humanities can assist here to affect all the socio-cultural, social, and even economic aspects of these two alternative institutions. In the UK, comparative studies of the costs for people dying in a hospital, hospice, or home are emerging, and they illustrate their financial viability, from the perspectives of governments, and health authorities. The case of the My Death, My Decision movement in the UK, sheds light on the perspective of 'public choice'. It includes advocacy for a place to die, and for agentic dying, which refers to the right to make decisions about one's dying process.

Agentic Dying as a Self-Reflection on How to Die

Societies have traditionally remained closed to discussing the processes of death and dying as social imaginary significations. They seek to defend themselves from a fear or the abyss of uncertainty of dying (Tovar-Restrepo, 2012). However, contesting the prolongation of life for the sake of it, as in the case of some biomedical practices, is an issue which contemporary discussions are challenging, as in the case with euthanasia, too. Only a few countries have legislated for euthanasia, including, among high-income countries: Belgium, Luxembourg, Canada, New Zealand, Spain, the Netherlands, and some states in the USA. Among middle- and low-income countries, Colombia is the only one to do so (Moreno-Leguizamon et al., 2017).

The concept of death revolves around a circle of heteronomy (e.g., subjection to religion or science) and the idea that death and dying institutions are self-instituted by society is emerging in social sciences (Castoriadis, 1987; Tovar-Restrepo, 2012). Castoriadis (1997) asserts, that even though heteronomy is socially present, there will always be an openness, which is a creative power, called the instituting imaginary, which opposes heteronomy. Autonomy, according to him, is the appropriation of creative capacity, or the power of self-institution, to provide meaning and sense, to central social imaginary significations and institutions, such as in the cases of death and dying. This is the reflective capacity of

self-regulation and the deliberate actions and creation of our own laws, agency, and social significations, about death and dying practices. The concept of agentic dying proposed here is based on Castoriadis' notion of autonomy.

In practice, agentic dying requires the acknowledgment that the meanings, practices, understandings, institutional procedures, and regulatory frameworks of death and dying be collectively defined, to enable utmost autonomy for individuals, as opposed to prescriptive cultural or religious frameworks, such as 'intervention from God' (Tovar-Restrepo, 2012). The right to autonomously decide when to die, and how to die, lays at the centre of this discussion, as My Death, My Decision in the UK, illustrates. It also includes promoting and creating institutions that provide palliative care health services to plan (as much as possible) our individual deaths in ways that respect carers' and family members' rights. For example, this may include (1) death with dignity and autonomy, (2) identification of wishes and preferences of the dying individual (part of patient-centred care), and (3) decisions on the preferred site of death (Moreno-Leguizamon et al., 2017).

Recent debates on euthanasia have emerged globally, showing how important it is to collectively discuss it, especially within multicultural societies. The debate about legislation on euthanasia is also crucial to agentic dying as is death literacy (Sallnow et al., 2022). Agentic dying compels us to autonomously approach the psychical anxiety created by our human finitude, a human sentiment that we are more familiar with, than we might like to acknowledge. As unbearable as they might be, death and finitude are more frequent than one would like to accept, be conscious of, or be responsible for. Health professionals are only facilitators of the processes that are our responsibility and autonomy.

Conclusion

To conclude, following Farmer et al. (2013), this article has presented three critical socio-anthropological issues which underpin the recently founded science of palliative care. This paper discussed the need to complement the approach reimagined by Saunders with perspectives from the social sciences and humanities, which will enable the creation of social imaginary significations, and institutions around pain, death, and dying, and that will provide autonomy and responsibility, as suggested by Castoriadis (1987; 1991; 1992; 1997). This is called agentic dying. This chapter illustrated cases in the UK and Colombia where additional aspects related to palliative care are being discussed. It showed that pain, death, and dying can be resignified. Saunders reimagined these aspects: (1) the re-conceptualisation of pain as total pain; (2) the creation of hospices as alternative institutional spaces for dying; and (3) the opening of debates about more compassionate and sympathetic choices regarding the processes of dying (Moreno-Leguizamon et al., 2017). With the risk of more pandemic threats like COVID-19, climate and environmental disasters, structural violence, and health inequalities, we are being challenged to reflect on our dying processes and, by default, about quality of life and dying.

As this article was being submitted for publication on the 31st of January 2022, the Lancet Commission launched a report that validates the socio-anthropological arguments raised in this article. To quote from the report, this calls for:

> …radically reimagining a better system for death and dying, the Lancet Commission on the Value of Death has set out the five principles of a realistic utopia: a new vision of how death and dying could be. The five principles are: the social determinants of death, dying, and grieving are tackled; dying is understood to be a relational and spiritual process rather than simply a physiological event; networks of care lead support for people dying, caring, and grieving; conversations and stories about everyday death, dying, and grief become common; and death is recognised as having value'.
>
> *Sallnow et al., 2022:1*

Research Points and Reflective Exercise

With reference to the discussions in this chapter, begin to reflect upon the following:

- How far do concepts of total pain and dying need to be researched further by social and health scientists?
- Is the concept of 'agentic dying' useful in thinking about dying processes?
- How far are debates around euthanasia relevant in middle- and low-income countries?

Further Resources and Reading

Sallnow, L. Smith, R., Ahmedzai, S. H., Bhadelia, A., Chamberlain, C. et al. (2022). "Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life". *The Lancet*, 31 January 2022. (London, England), S0140–6736(21)02314-X. Advance online publication. https://doi.org/10.1016/S0140-6736(21)02314-X

References

Castoriadis, C. (1987). *The Imaginary Institution of Society.* Cambridge: The MIT Press.

Castoriadis, C. (1991). *Philosophy, Politics, Autonomy: Essays in Political Philosophy.* Oxford: Oxford University Press.

Castoriadis, C. (1992). "Logic, Imagination, Reflection". *American Imago*, 49 (1): 3–33.

Castoriadis, C. (1997). "Radical Imagination and the Social Instituting Imaginary". In. D. Curtis (ed). *The Castoriadis Reader.* Oxford: Blackwell Publishers, 319–338.

Colombian Palliative Care Observatory. (2020). "Educación". Available at: https://occp.com.co/dominios/educacion/ (Accessed: 23 February 2022).

Congress of the Republic of Colombia, Law 1733 of 2014". (2014). Available at: http://www.secretariasenado.gov.co/senado/basedoc/ley_1733_2014.html (Accessed: 4 January 2022)

Das, V. (1995). *Critical Events: An Anthropological Perspective on Contemporary India*. Delhi: Oxford University Press.

Das, V. (1996). "Language and the Body: Transactions in the Construction of Pain". *Daedalus,* 125 (1): 67–91.

du Boulay, S. (2007). *Cicely Saunders: The Founder of the Modern Hospice Movement*. London: Society for Promoting Christian Knowledge.

Djordjevic, C. (2021). 'The Politics In/Of Pain". *Philosophy and Social Criticism*, 47 (3): 362–388. https://doi.org/10.1177/0191453720912291

Farmer, P., Kim, J. Y., Kleinman, A. and Basilico, M. (2013). *Reimagining Global Health: An Introduction (Vol. 26)*. Berkeley: University of California Press.

Gawande, A. (2014). *Being Mortal: Mortal: Medicine and What Matters in the End*. New York: Picador, Metropolitan Books, Henry Holt and Company.

Hoare, S., Kelly, M. P. and Barclay, S. (2019). "Home Care and End-of-Life Hospital Admissions: A Retrospective Interview Study in English Primary and Secondary Care". *British Journal of General Practice*, 69 (685): 561–569. https://doi.org/10.3399/bjgp19X704561

Hernández-Rico, A. N. and Ballén-Vanegas, M. A. (2021). "Palliative Care in Colombia: Home Care Services, Access Barriers and Progress in the Implementation of these Programs during the COVID-19 Pandemic". *Revista de la Facultad de Medicina*, 70 (4). https://doi.org/10.15446/revfacmed.v70n4.95147

Heubber, P. and Sellschopp, A. (2014). "Adding Life to the Dying: Palliative Care and Psycho-Oncology" In. S. Kakar (ed.) *Death and Dying*. New Delhi: Penguin India, 213–222.

Kakar, S. (2014). *Death and Dying*. New Delhi: Penguin India.

Kleinman, A., Das, V., Lock, M. and Lock, M.M. (1997). *Social Suffering*. Berkeley: University of California Press.

Learning Alliance for Palliative and End of Life Care (LAPCEL). (2019). "Palliative Care and End of Life Practises". Available at: https://www.diversityhouse.org.uk/portfolio-items/palliative-care-end-of-life-practises-among-black-minority-ethnic-bme-groups/ (Accessed: 5 February 2022).

Moreno-Leguizamon, C. J., Patterson, J. J. and Gómez Rivadeneira, A. (2015). "Incorporation of Social Sciences and Humanities in the Training of Health Professionals and Practitioners in Other Ways of Knowing". *Research and Humanities in Medical Education*, 2: 18–23. https://doaj.org/article/711d3e763d4a4592911958a27f54de75

Moreno-Leguizamon C., Smith. D. and Spigner. C. (2017). "Positive Aging, Positive Dying: Intersectional and Daily Communicational Issues Surrounding Palliative and End of Life Care Services in Minority Groups". In. R. Docking and J. Stock J (eds.) *International Handbook of Positive Aging*. London: Routledge, 21–37.

My Death, My Decision. (2022). "What We Stand For". Available at: https://www.mydeath-mydecision.org.uk/ (Accessed: 5 February 2022).

Sallnow, L. Smith, R., Ahmedzai, S. H., Bhadelia, A., Chamberlain, C. et al. (2022). "Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life". *The Lancet,* 31 January 2022. (London, England), S0140–6736(21)02314-X. Advance online publication. https://doi.org/10.1016/S0140-6736(21)02314-X

Saunders, D. C. M. (2006). *Cicely Saunders: Selected Writings 1958–2004*. Oxford: Oxford University Press.

Smith, D., Moreno-Leguizamon, C., Grohmann, S. (2015). "End of Life Practices and Palliative Care among Black and Minority Ethnic Groups (BME). Health Education Kent Surrey and Sussex Vision". Available at: http://www.diversityhouse.org.uk/

wp-content/uploads/2017/07/REPORT-End-of-Life-BME-Groups-101115-submitted.pdf (Accessed: 21 February 2022).

Tovar-Restrepo, M. (2012). *Castoriadis, Foucault and Autonomy: New Approaches to Subjectivity, Society and Social Change*. London: Continuum Press.

World Health Organisation (WHO). (2020). "WHO Definition of Palliative Care". Available at: http://www.who.int/cancer/palliative/definition/en/ (Accessed: 11 May. 2020).