

What is the cultural value of dying in an era of assisted dying?

Naomi Richards , Marian Krawczyk

School of Interdisciplinary Studies, College of Social Sciences, University of Glasgow, Glasgow, UK

Correspondence to

Dr Naomi Richards, Interdisciplinary Studies, College of Social Sciences, University of Glasgow, Glasgow, UK; naomi.richards@glasgow.ac.uk

Accepted 23 April 2019

Published Online First

26 July 2019

ABSTRACT

Assisted dying is now a lawful and integral component of many societies' death system', orienting individual and collective encounters with death and dying. While only a very small number of people living with terminal illness in these societies will opt for an assisted death, the choice, nevertheless, exists for those who satisfy the legal criteria. Theoretically, in these jurisdictions, this turns dying into an optional part of the human life cycle; a final phase of life that, until now, seemed a universal feature of life except in instances of sudden death. As anthropologists specialising in death and dying, we pose the question of how the various cultural scripts that have sought to give meaning to dying in post-industrial Western societies since the mid-20th century might be affected by the advent of assisted dying. We begin by building on both medical and social science literature to construct a working definition of 'dying'. We then identify four dominant cultural scripts: psychological growth, preparation for death, the suffering experience and the caring experience. After outlining each script, we discuss how it may (or may not) be affected by the increase in assisted dying legislation. We propose that it is the 'caring' script; the notion of affective, intergenerational bonds created through the experience of caring for people specifically in the last few months or weeks of their life, which are likely to be most affected. However, we find that access to these cultural scripts is already limited because of the widespread reluctance to recognise and name 'dying', and the challenges of doing so. Consequently, the various cultural scripts we identify are negated not by the increase in assisted dying, but rather by a combination of medical advances and institutional orthodoxies which limit opportunity for people to experience themselves, or others, as 'dying'.

INTRODUCTION

For better or worse, the legalisation of assisted dying has become a significant part of cultural meaning making around death and dying in Western Europe and North America. While vociferous debates persist about the morality of allowing doctors to intentionally hasten the deaths of patients, more jurisdictions are voting to give their citizens the legal right to request help to die. Assisted dying is now an integral component of many societies' social expectations, rules, motives and symbols that orientate individual and collective encounters with death and dying—including the 'dying role'—all parts of what psychologist Robert Kastenbaum termed a culture's 'death system'.¹ All cultures, past and present, have death systems: affective systems constituted through the myriad social processes

that teach us what to think and feel about death and dying, and what to do about it.

In this article, we follow Lewis and use the term 'assisted dying' to denote medicalised assistance, in the form of a lethal injection or prescription, which is requested by a mentally competent individual who wants to end their own life and has a prognosis of less than 6 months to live (as in the various US states which have legalised the practice) or whose death is 'reasonably foreseeable' (as in Canada).²

The laws in these jurisdictions are the formal manifestation and legitimation of a cultural desire to shorten the dying phase—whether by days, weeks or months. Without discounting the 'national contexts in which deathways operate',³ we can discern certain Western cultural trends which give rise to assisted dying legislation. One of the most significant trends is the rise of individualism and loss of collectively shared meaning about, and valuing of, the very end of life. In part this may be due to our 'secular age' where there is no mutually agreed on deity to infuse meaning into our actions or to act as the final arbiter over life and death. In post-industrial Western societies, meaning making around key moments in our lives is primarily derived within a psychological framework, or alternatively, within new age forms of spirituality.⁴ In the context of serious chronic and/or life-limiting illness, the archetypal autonomous individual, acting in their own best interests or perceived best interests of others, has seemingly become the ultimate authority in determining the meaning of their life and when it is appropriate to bring it to an end.

While on the one hand, people in post-industrial Western societies are increasingly expressing a desire to have the option to intentionally hasten their own death, on the other hand, desires to extend life seemingly ad infinitum are also clearly in evidence. Life-extending procedures and technologies are now requested and used routinely and their application has become normalised at the end of life, such that they are considered part and parcel of 'ordinary medicine', even for the very old (90+).⁵ The desire to hasten death, then, could also be interpreted as the antithesis of widespread medical efforts to extend or prolong life.

These desires are not necessarily contradictory, however, and can be viewed as two sides of the same coin. Whether a person seeks to extend life or hasten death depends on whether the individual, and those around them, perceives a meaningless prolongation of dying or a meaningful prolongation of life. Both life-extending and death-hastening techniques can be understood as manifestations of a Western *denial of dying*. We use 'denial of dying'



© Author(s) (or their employer(s)) 2021. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Richards N, Krawczyk M. *Med Humanit* 2021;**47**:61–67.

as opposed to the more sociologically well-known concept of ‘death denial’,⁶ as the latter term does not encapsulate the embrace of death which an assisted death signifies. This tension between understanding a protracted end stage of dying as either a meaningful or meaningless stage or experience in the lifecourse is where we locate our argument.

As anthropologists working in the field of death and dying, we are interested in how the increasing incorporation of assisted dying within the various death systems of Western Europe and North America might influence the meaning that dying is seen to have in those cultures. Our interest lies not with the moral question of whether assisted dying is ‘right’ or ‘wrong’, on which there is a robust bioethical literature.^{7,8} Neither is it our intention to assert that the process of dying is an inherently meaningful nor culturally productive human activity that needs to be protected or preserved, as other anthropologists have.⁹ Rather, we consider what significance experiencing a socially recognised ‘dying time’ may hold for individuals and caregivers, as well as the larger cultures within which they are situated. We do this by identifying some of the key cultural scripts that give rise to the idea that dying *can* be a culturally significant or productive experience. Once identified, we aim to think through how these scripts might be affected with the advent of lawful assisted dying. The question we pose is this: what might happen to the meaning given to dying in a death system in which dying has become optional; that is, when it is possible, with medical assistance, to intentionally eclipse the very end stage of life, that period designated as ‘dying’?

WHAT IS DYING?

Within medicine, there is no mutually agreed upon definition of dying, with most sources generalising it as a poorly understood physiological process of irreversible terminal decline characterised by certain biological markers and expected survival in terms of months or less.¹⁰ The importance of being able to medically identify this decline, and the challenges faced when attempting to do so, is evidenced in the ongoing proliferation of trajectory models and standardised screening tools designed to help clinicians identify patients who are ‘unavoidably dying’,¹¹ in the ‘last year of life’,¹² or with ‘months or less’ to live.¹³

Social scientists assume a broader focus in terms of how dying is defined, acknowledged or enacted through specific changes in both individual behaviour and social relations. Most famously, in the mid-1960s, the sociologists Glaser and Strauss defined dying as a ‘non-scheduled status passage’.¹⁴ This change in status from sick role¹⁵ to dying role^{16–18} can begin only once medical experts interpret the signs of bodily deterioration as terminal decline. Clinicians then become responsible for defining the temporal dimension of the various dying trajectories and timing announcements to all the different parties involved.¹⁹ Consequently, while ‘open awareness’ among all parties is the ideal dying context, it is only when authoritative others (healthcare providers) start behaving differently towards the person concerned that ‘dying’ officially occurs, regardless of whether or not the person or family publically acknowledges that they are dying.²⁰

In contrast, Kellehear, also a sociologist, argues that ‘dying’ can only happen when the person themselves is aware and accepts that death is approaching, emerging from ‘the personal expectation and acceptance of death as an imminent event’.²¹ In many social science accounts, both perspectives appear to overlap in that while a person can be undergoing a physiological process of irreversible terminal decline and be considered to be dying by healthcare providers, unless there is shared social

acknowledgement *among all parties*, the person themselves or their kin may never actually experience ‘dying’.

THE DYING ROLE

Given the above criteria, the conventional normative characteristics of the ‘dying role’ are that: (1) entry is established by experts once they interpret the signs of bodily deterioration as terminal decline, (2) it is a ‘liminal’ period of transition, which (3) occurs over time, (4) has a trajectory and (5) awareness and acceptance is shared by all parties. These aspects have been paramount in shaping the cultural scripts and social roles available to the dying and those caring for them. Ideally, once a limited prognosis has been given, a series of therapeutic encounters will take place with healthcare professionals generating a context of mutual open awareness and entry into the dying role.²² In this scenario, the dying individual indicates their acceptance of this role and she and her social network are able to engage in meaningful activities of closure that mark a life well lived and a good (even if unwelcome) death. In adhering to this social role, those who embrace it are re-inscribed as valuable members of society through their teaching-by-example of what it means to die well. In turn, this enactment ensures that the process and outcome of dying generates meaning and reinforces social bonds, thereby reducing individual and collective anxieties about non-existence. Dying is therefore best understood as a collective social process as much as an individual biomedical event.

In an era where lawful assisted dying is increasingly reconfiguring our understanding of the end of life, we believe it is of benefit to examine how the end of life and the dying role have been structured since the mid-20th century. Below, we identify four dominant cultural scripts within the predominantly secularised, biomedical death systems of Western Europe and North America that have imbued dying with individual and collective meaning during this era. These scripts are: psychological growth, preparation for death, the suffering experience and the caring experience. When considering each script, we discuss how it may (or may not) be affected by the increase in the permissibility of assisted dying. We identified these scripts through lengthy discussions between the authors drawing on our extensive knowledge of the social science literature as well as knowledge of broader cultural representations of death and dying, for example, in novels, pathographies, films, etc. We then presented our framework and arguments to academic and clinical colleagues in Canada and the UK and sought their feedback. An important result from these discussions and consultations was to clarify the distinction between two linked but separate considerations: the perceived cultural value of death and that of *dying*. Broadly, we employ a discourse analysis approach which has been particularly well established for exploring how socio-cultural contexts shape the ways we ‘story’ health and illness.^{23, 24}

FOUR CULTURAL SCRIPTS THAT AFFORD SHARED MEANING TO THE EXPERIENCE OF DYING

Psychological growth

The most established script promoting the benefits of a recognised dying period is that it can offer an individual a ‘final stage of growth’. The psychiatrist Elizabeth Kübler-Ross most famously promoted and popularised this script.²⁵ She championed the value of talking with dying people in order to learn from them, their state seemingly affording them more gravitas to communicate life lessons and ‘model the human condition’.⁹ According to the psychological growth script, the dying

themselves are also able to learn from their experiences through talking and being reflexive about their mortality—fulfilling what Wood termed the ‘expressive death.’²⁶ In a similar vein, Kellehear suggests that dying can offer ‘surprising insights, humour, positive changes, new and frequently enhanced relationships, the birth of other feelings or perspectives’ and can genuinely ‘reveal deeper and novel experiences in personal direction, positive purpose and social intimacy’ despite the difficult trials undergone.²¹ The influence of Freud is clearly evident here and his view that difficult experiences can be productive because they aid self-development.²⁷ This cultural script is also part of a broader ‘revival of death’, spearheaded by the hospice and death awareness movements, which promotes dying as an ‘emotionally satisfying’ experience and expressive of an authentic self.²⁸ In general, these transformative gains are expressed at the level of individual psyches enabling changes to self-identity, although enhancement of relationships can also be part of this. This script is evident in the bestselling book *Tuesdays with Morrie*,²⁹ and Professor Randy Pausch’s videotaped *Last Lecture*, with more than 14 million views.³⁰

Evidence from the Netherlands suggests that many who request medical help to die do so when they are bedbound and very close to ‘natural’ death, thereby avoiding only a small part of the dying phase.³¹ In the USA, the requirement that people have a 6-month prognosis also ensures that those making use of the law are relatively near to ‘natural’ death. This means that people will continue to experience the earlier stages of dying, potentially a sufficient period of ‘dying’, that they can still access the psychological growth script. Indeed, we argue that the very end of life is unlikely to be the most psychologically productive time for an individual who will be physically weak and often heavily medicated. Further, we question the hegemony of psychological models of growth that can subtly demand certain normative behaviours from the dying person. Finally, the psychological growth ideal is predicated more generally on awareness of dying and a defined trajectory of decline. However, we live in an era marked by multimorbidity in later life, and end of life is increasingly defined by prognostic *uncertainty*, or what has been termed ‘ambiguous dying’.³² Consequently, even when irreversible terminal decline is identified, this is not always communicated by doctors or heard by patients.³³ Ironically, the psychological growth script therefore may not be available to people in conditions of ‘natural’ dying simply because they have not undergone the status passage required to be identified as ‘dying’. Yet, it *may* be available to people who opt for an assisted death who engage in self-reflexivity and self-expression before consuming or having the lethal dose administered. We therefore contend that lawful assisted dying does not necessarily negate the possibility of experiencing psychological growth and may even potentially enable it.

Preparation for death

An integral component accompanying the last stage of life is having the opportunity to prepare for one’s death in a practical and material sense. This is considered one of the central tenants of the ‘good death’ cross-culturally.³⁴ There are issues of estate and funeral planning to be addressed, as well as legacy work for surviving loved ones. A more recent development in this script is the ability to plan and control the very last phases of dying through engaging in advance care planning. Practical preparation of this kind is understood to facilitate anticipatory disentanglement or dissolution of the bonds that tie the now-dying person to their previous life and their web of

relations. Relationships are ordered and reordered to ensure social stability post-death.³⁵ In this script, the dying person’s interests and interactions with the outside world gradually diminish as they withdraw from the world and family and friends prepare for a future without the individual.

Assisted dying could potentially be aligned to this cultural script, although with certain caveats. On the one hand, practical and material preparation for death could become *more* focused in a context of assisted dying because the precise time of death—the precise hour of death even—is known in advance. Friends and family will have a definitive focus for their rallying and can assemble at the deathbed for the ultimate accompanied death, as illustrated in the images published in the New York Times of John Sheilds’s ‘choreographed’ assisted death in Canada.³⁶ On the other hand, sufficient time needs to be given for the family to make the social adjustments required so that the death of the individual is not experienced as a rupture in the social fabric. Social scientists have long recognised the importance of a transitional period between being alive and being dead. Research in the contexts of assisted dying,³¹ cardiopulmonary resuscitation³⁷ and intensive care³⁸ highlights that many of our medical routines at the end of life are often enacted with the intention of giving patients and their families a temporal space within which to adjust to the idea of death before it occurs. Intentionally creating or identifying a dying period, however short, marks an important ‘liminal’ phase between life and death, connecting and separating the two. While a good death is one without lingering, it is also not the sudden death. Without some kind of dying phase that marks a *transitional* status or stage between life and death, persons and relationships can become destabilised.

In the case of assisted dying, the medicobureaucratic process undergone before a wish to die early is acceded to can certainly take time, and sometimes delays are intentionally introduced into the process in the hope that a ‘natural’ death will occur first, or to allow for people to change their mind.^{31, 39} In this way, the person opting for an assisted death and their friends and family *can* experience a liminal or transitional phase despite an overall determination to curtail prolonged dying. However, the question remains as to whether or not a truncated dying phase complicates the ability to accept the status change between ‘living’ and ‘dead’. Yet, even in instances where this transition is not sudden and dying is fully acknowledged by all parties, loved ones may still experience a traumatic ‘rupture’ or become destabilised by the bereavement. So while we are confident that assisted dying holds the potential to enhance practical preparations, because an exact time of death is known to all, we are more conditional in our suggestion that a loss of recognised ‘dying time’ *could* make the transition between life and death too sudden for some of those accompanying.

The suffering experience

In the late 19th century, processes of secularisation and rationalisation in parts of the Western world challenged the notion that pain and suffering on the deathbed held sacred meaning.⁴⁰ With the decline in religious grand narratives, pain and suffering were no longer deemed necessary in order to redeem one’s sins and bring one closer to God in pursuit of entry to heaven. After World War II, suffering experienced at the end of life increasingly came under the domain of biomedicine, particularly the specialty of palliative care, which constructs it

as a complex affective experience often requiring targeted and multifaceted interventions to remedy it.

Despite the decline of religious meanings attributed to pain and suffering on the deathbed, there are secularised versions of the suffering script that continue to have some salience in Western death systems. The sociologist Clive Seale found that people who demonstrated ‘courage’ and ‘strong character’ in the face of pain and suffering during terminal illness retrospectively provided friends and family members with a narrative of a ‘heroic death’.⁴¹ Similarly, showing ‘endurance’ in the face of terminal illness is bestowed with value, evidenced through the use of military metaphors such as ‘battling’ with cancer.⁴² Another example of the cultural value of pain and suffering comes from Illich’s 1976 polemic *The Limits to Medicine*.⁴³ Illich argues that a person’s experiences of suffering help them to feel compassion for the suffering of others, and we should therefore resist the pain-killing technologies and drugs of modern medicine that are intent on ‘anaesthetising’ people to their own suffering. His argument could broadly be categorised as part of the ‘romantic’ tradition whereby suffering is seen to render a person more sensitive to the destructive elements of nature as well as to the pain and suffering of others, bringing greater wisdom and consciousness to the individual sufferer.⁴⁴ In other words, the pain and suffering that can be experienced while dying also paradoxically sews the seeds of their own resolution through engendering humility and acceptance of the impermanence of the self as part of the human condition.

While some continue to believe that pain and suffering experienced in the last few months, weeks and days of life have unique and potentially valuable characteristics,⁴⁵ others are increasingly less certain.⁴⁶ For example, Morris, a leading author on cultural interpretations of pain, describes how for his secular Jewish wife who was dying of Alzheimers’ disease, pain had ‘no redeeming qualities’, did not ‘constitute a trial of faith or a test of character’ and held ‘no redemptive power’, thus becoming a source of intense fear for her. In an empirical sense, any purpose or meaning in pain and suffering at the end of life remains phenomenally difficult to ascertain because the contemporary cultural imperative in post-industrial Western societies to ameliorate all forms of pain and suffering is so compelling. Consequently, the increase in lawful assisted dying is already a *result* of the growing cultural belief that pain and suffering at the end of life are meaningless, biographically disruptive, and therefore need to be eradicated. We continue to try to make sense of pain and suffering when we feel we have no choice to dispense with it, viewing responses to it as courageous or ‘heroic’ perhaps, or rationalising it as a test of our endurance. But given a choice, perhaps all sense of purposeful suffering would disappear. As research undertaken by one of the authors has shown, even among Christians, belief in the redemptive potential of suffering is no longer a given, and Christians as well as those of other faiths, also opt for assisted dying.⁴⁷ The option to lawfully end your life with assistance validates the view that there is no value in dying unless the suffering person says so. We therefore contend that lawful assisted dying will further highlight an evolving cultural script that constructs *any* form of pain and suffering at the end of life as meaningless and untenable, as well as fundamentally questioning the belief that suffering at the end of life yields *particular* forms of compassion and relations between people.

All three cultural scripts discussed so far are inextricably intertwined with ideas about, and the values associated with, care and caregiving at the end of life. We now move to consider

how assisted dying might affect cultural meaning around the value of caregiving and specifically about the care given and received in the last months or weeks of life.

The caring experience

Extreme physical vulnerability marks the last stages of life. Whether or not a person experiences pain and/or suffering, most will be heavily dependent on others and require care. Care can be defined both as affective concern (caring about) and practical action (caring for).⁴⁸ Caring as relational practice (rather than resource) can be generative for all involved.⁴⁹ Indeed, Kleinman encourages us to view it as a ‘moral practice...of empathic imagination, responsibility, witnessing and solidarity with those in great need’.⁵⁰ Through an anthropological lens, caregiving—whether familial or otherwise—entails relations of exchange that can be conceptualised as gift giving.^{49, 51, 52} Within families and other intensively affective social networks, gift giving is ideally premised on notions of reciprocity and establishes bonds of mutual obligation and sentiment. Over time, and indeed over generations, the ‘gift of care’ can be reciprocated when a former caregiver themselves requires care in the latter stages of dying. In the case of (mostly female) professional caregiving for the dying, ‘care, touch, stories and love’ are also given as gifts in a moral economy which Russ argues reciprocally supports the self-production of the caregivers themselves.⁵² The anthropologist Graeber has recently extended Mauss’s ideas about gift-giving in his theory of debt, arguing that societies are founded on debt; not just person-to-person debt, but a generalised reciprocal debt that cuts across the generations and sustains cultural ties.⁵³ It could be argued that caregiving at the end of life, when caring can be particularly intensive, is a debt which is accrued and serviced, but never settled, in a long line of dying humans.

This is not to argue that this form of care is easy. Terminally deteriorating bodies are often ‘uncontained’: leaky, smelly and fragmenting, challenging and even frightening both carers and those being cared for.⁵⁴ We also do not wish to diminish the personal, emotional, financial and physical costs that many family and friend caregivers pay in providing care at the end of life, particularly in conditions that unfold over years. However, if sustained, embodied care given in the last months or weeks of life is no longer required due to death being intentionally hastened through lawful assisted dying, then family members and professional caregivers will no longer be able to ‘gift’ this particular type of generative care. We need to ask what the social significance of this level of dependence is in terms of the emotional and social bonds engendered through both affective and practical forms of care. The extreme precarity that is inherent in this last stage of life represents a considerable challenge to the promise of modernity that our lives can be controlled up until the day we die, or what Castel calls ‘the rationalising dream of absolute control’.⁵⁵ Through experiencing a diminishment of capacity and control during the dying process, all parties are exposed to the vulnerability and precarity that are arguably at the heart of the human condition. To be denied exposure to this on a vast scale might jeopardise the reciprocal, debt-bearing relationships and entanglements that, according to Graeber, are the very fabric of a culture.

However, it has been argued that assisted dying does not wholly negate the opportunity to care, but instead alters the duration and type of care.⁵⁶ If we understand assisted dying to be a *refusal* to endure or even to enter into a state of precarity, then it could be understood to be a different type of ‘gift’ which can be caringly given; compassion by a different means. In this

framing, assisted dying may also be a gift that is willingly given by the *recipient*, in order to lessen the perceived or real burden of care. The consequences of a qualitative change in relations of care can only be assessed over the course of generations and future research might usefully examine the bereavement experiences and meaning of dying for people whose relative had an assisted death, compared with those who experienced 'natural' death. Regardless, in our view, it is the cultural script about the value of care at the very end of life which is the most likely to change in a situation where dying becomes optional.

DISCUSSION

How each of us understands the meaning and worth of the experience of dying is fundamentally shaped by our collective beliefs and cultural scripts about the purpose of this last stage of life. Social and legal sanctioning of assisted dying marks the establishment of new rituals for, and meaning about, dying; a different aesthetic of dying more in tune with individualised notions of the person.⁴⁷ In order to explore the potential impact of these changes, we examined four dominant cultural scripts about the value of dying which exist in those countries that have legalised a form of assisted dying: psychological growth, preparation for death, the suffering experience and the caring experience. Through this discussion, we suggest that lawful assisted dying: (1) does not necessarily negate access to the psychological growth script and may even potentially enable it; (2) holds the potential to enhance practical and material preparations although may not leave sufficient time for others to come to terms with the individual's status passage; (3) can be understood as *resulting from* the declining cultural salience of the suffering script and (4) is most likely to alter the cultural valuing of care or the perception of caregiving at the end of life as being uniquely generative.

In trying to establish how cultural scripts might change as a result of the introduction of a new mode of transitioning between life and death, it is all too easy to perceive rupture and categorical distinctions between the existing dying 'situations'⁵⁷ and a new situation (assisted dying), especially when that situation is so ethically controversial and divisive. Throughout our article, we have made reference to 'natural' dying. We use quotation marks to indicate that in fact there is no such thing as natural dying, as 'irreversible terminal decline' is constantly subject to human interventions of one kind or another, and death is often 'timed' through medical decision-making.⁵ We surmise that while the advent of assisted dying legislation is leading to new social rituals, meanings and relations of care, any of the cultural changes we discuss here would be incremental and debated rather than dramatic and linear. Further, instead of perceiving a negation or an impoverishment of cultural scripts for the dying, we find a certain degree of continuity within existing death systems in the countries which have legalised the practice. As Karsoho *et al* identified, assisted dying only succeeds in becoming lawful in the first place when proponents are successful in attaching cultural scripts about the virtues of assisted dying to pre-existing, already socially accepted cultural scripts about the postmodern 'good death'.⁵⁸

In posing the question of how the cultural meanings attributed to dying or the dying role might be affected when dying becomes optional, we find that our attention has been drawn to the existing ways in which dying is denied. The challenge and reluctance to recognise and name dying within the institutions where people die means that in many cultures in the post-industrial Western world already have 'death with as little dying as possible' or a case of 'disappearing dying'.^{9, 57} In many cases,

the cultural scripts which valorise the experience of dying for all those involved are negated not by the advent of assisted dying legislation, but rather by a combination of medical advances and institutional orthodoxies which mean there is limited opportunity for people to experience themselves as 'dying' and therefore to gain access to the various cultural scripts we have identified.

CONCLUSION

Since the historical moment when death could be foreseen and a discernable dying period emerged, it appears that humans have striven to do one of two things: sacralise or erase it. At the beginning of this article, we suggested that both extreme life-extending measures and assisted dying involve a denial of dying. Since the mid-20th century, we have engaged primarily in erasure through a biomedical model aimed at prolonging life and staving off dying. Even palliative care has increasingly become directed by the mantra 'helping you live as well as possible until you die', minimising any mention of the liminal stage of dying or indeed any benefits which may accrue or meaning which may be derived from this stage in the lifecycle. Assisted dying has emerged as another legitimate script through which dying can be erased.

The bodily transformations undergone from living to dying, and through dying unto death, are increasingly viewed by people in post-industrial Western societies as a redundant or vestigial stage of life. It is this sentiment that has given rise to the desire to eclipse the dying process through intentionally hastened death. What we do not yet know is what the larger social impact will be when the transition from life to death no longer needs to take time nor requires sustained relations of obligation. There may well be psychological adjustments which need to occur, caring which needs to be done, and observations to be gleaned about the value and meaning of life which cannot be conjured up or condensed into the earlier stages of an illness. In particular, there may be relations of care specific to the very end of life, when people are extremely physically vulnerable, that are uniquely constitutive of intergenerational relations and cultural 'webs of significance'. While this may indeed be so, it also needs to be acknowledged that the various cultural scripts which support our death systems are being modified or co-opted with the advent of lawful assisted dying, scripts which are more utilitarian (viewing assisted dying as a 'rational' choice) and engage different notions of care and of intergenerational solidarity. These scripts are part adaptation of postmodern revivalist sentiments about the 'expressive death', and part rejection of those same scripts, criticised for valorising or romanticising embodied dying situations.

We initially posed the question of what might happen to the various cultural scripts that attribute meaning to dying when assisted dying is legalised and dying becomes an optional part of the lifecycle. In doing this, we aimed to shed light on some possible longer-term cultural effects of incorporating assisted dying into an existing death system. We found that while there are cultural scripts that ostensibly value 'dying time', and which may be impacted on to a greater or lesser extent by the legalisation of assisted dying, they are situated within death systems already shaped by a deeply entrenched denial of dying. Thus, the conclusion we arrive at is that assisted dying is not so much a cause but rather a symptom of a cultural loss of meaning in the human experience of dying.

Twitter @DrNaomiRichards, @MTKrawczyk_42

Acknowledgements The authors are grateful for the opportunity to present an earlier version of this argument at the Solway Seminar Series in the School

of Interdisciplinary Studies, University of Glasgow, and to colleagues at McGill Palliative Care, Montreal, Canada. The authors would also like to thank members of the Glasgow End of Life Studies Group who commented on earlier drafts and the anonymous peer reviewers for their feedback.

Contributors NR and MR co-conceived the theoretical ideas outlined in the article and wrote and co-edited the article.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement There are no data in this work.

ORCID iD

Naomi Richards <http://orcid.org/0000-0002-3029-5132>

NOTES

- Robert Kastenbaum (1977), *Death, Society, and Human Experience* (St. Louis, MO: C. V. Mosby), 77.
- Penney Lewis (2007), *Assisted Dying and Legal Change*, (Oxford, UK: Oxford University Press).
- Tony Walter (2012), "Why Different Countries Manage Death Differently: A Comparative Analysis of Modern Urban Societies," *The British Journal of Sociology* 63, no.1:125.
- Tony Walter (1993), "Death in the New Age," *Religion* 23, no. 2: 127–145, doi:10.1006/reli.1993.1012.
- Sharon Kaufman (2015), *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line* (London: Duke University Press).
- Ernest Becker (1973), *The Denial of Death* (New York: Simon & Schuster).
- Emily Jackson and John Keown (2001), *Debating Euthanasia* (London: Hart, 2001).
- Michael Cholbi and Jukka Varelius (2015), *New Directions in the Ethics of Assisted Suicide and Euthanasia* (London: Springer).
- Helen Stanton Chapple (2018), "The Disappearance of Dying and Why it Matters," in *A Companion to the Anthropology of Death*, ed. Antonius C.G.M. Robben (Oxford, UK: Wiley, Blackwell), 434.
- David Hui et al. (2014), "Concepts and Definitions for "Actively Dying," "End of Life," "Terminally Ill," "Terminal Care," and "Transition of Care": A Systematic Review" *Journal of Pain and Symptom Management* 47, no. 1: 77–89, doi:10.1016/j.jpainsymman.2013.02.021.
- Magnolia Cardona-Morrell and Ken Hillman (2015), "Development of a Tool for Defining and Identifying the Dying Patient in Hospital: Criteria for Screening and Triaging to Appropriate ALternative Care (CRISTAL)," *BMJ Supportive & Palliative Care* 5, no. 1:78–90, doi: 10.1136/bmjspcare-2014-000770.
- Anne O'Callaghan et al. (2014). "Can We Predict Which Hospitalised Patients Are in Their Last Year of Life? A Prospective Cross-Sectional Study of the Gold Standards Framework Prognostic Indicator Guidance as a Screening Tool in the Acute Hospital Setting," *Palliative Medicine* 28, no. 8:1046–1052, <https://doi.org/10.1177/0269216314536089>.
- Health Improvement Scotland (2018), "Palliative Care Identification Tool Comparator," Ihub, accessed November 8, 2018, <https://ihub.scot/media/3559/palliative-care-identification-tools-comparator.pdf>
- Barney Glaser and Anselm L. Strauss (1965), "Temporal Aspects of Dying as a Non-Scheduled Status Passage," *American Journal of Sociology* 71, no. 1: 48–59.
- Talcott Parsons (1951), *Social System* (London: Routledge).
- Marian Krawczyk (2015), "Negotiated Practices: Understanding Hospital Palliative Care as an Affective Economy" (PhD diss., Simon Fraser University).
- Anssi Perakyla (1991), "Hope Work in the Care of Seriously Ill Patients," *Qualitative Health Research* 1, no. 4: 407–433.
- Stefan Timmermans (2005), "Death Brokering: Constructing Culturally Appropriate Deaths," *Sociology of Health & Illness* 27, no. 7: 993–1013.
- Anselm Strauss and Barney Glaser (1970), "Patterns of Dying," in *The Dying Patient*, ed. Orville G. Grim, Jr., Howard E. Freeman, Sol Levine and Norman A. Scotch (New York: Russell Sage Foundation), 129–155.
- Barney Glaser and Anselm Strauss (1965), *Awareness of Dying* (Chicago: Aldine).
- Alan Kellehear (2015), *The Inner Life of the Dying Person* (New York: Columbia University Press), 9.
- Carl May (1992), "Individual Care? Power and Subjectivity In Therapeutic Relationships," *Sociology*, 26: 589–602.
- Cecil Helman (2007), *Culture, Health and Illness* (Hoboken: CRC Press).
- Deborah Lupton (2012), *Medicine as Culture: Illness, Disease and the Body* (London: Sage).
- Elizabeth Kubler-Ross (1975), *Death: The Final Stage of Growth* (New York: Touchstone; Simon & Schuster).
- Juanita Wood (1977), "Expressive Death – The Current Death Work Paradigm" (PhD diss., University of California at Davies).
- Sigmund Freud (1910), *Five Lectures on Psychoanalysis, Leonardo Da Vinci and Other Works* (London: Vintage, 2001).
- Tony Walter (1994), *The Revival of Death* (London and New York: Routledge).
- Mitch Albom (1997), *Tuesdays with Morrie: An Old Man, a Young Man and Life's Greatest Lesson* (New York: Doubleday).
- Randy Pauch (2018), "Last Lecture," Carnegie Mellon University, accessed November 8 2018, <https://www.cmu.edu/randyslecture/>.
- Robert Pool (2000), *Negotiating a Good Death: Euthanasia in the Netherlands* (Binghamton: Hawthorn Press).
- Mercedes Bern-Klug and M. Bern-Klug (2004), "The Ambiguous Dying Syndrome," *Health Social Work* 29, no. 1: 55–65.
- Ann-Mei The et al. (2010), "Collusion in Doctor-Patient Communication About Imminent Death: An Ethnographic Study," *BMJ*, no. 321 (7273) (Dec 2010): 1376–1381.
- Maurice Bloch and Jonathan Parry (1982), "Introduction: death and the regeneration of life," in *Death and the Regeneration of Life*, ed. Maurice Bloch and Jonathan Parry, (Cambridge University Press), 1–44.
- Clive Seale (1998), *Constructing Death: The Sociology of Dying and Bereavement*. (Cambridge: Cambridge University Press)
- Catherine Porter (2017), "At His Own Wake, Celebrating Life and the Gift of Death," *The New York Times*, May 25, 2017, <https://www.nytimes.com/2017/05/25/world/canada/euthanasia-bill-john-shields-death.html>.
- Stefan Timmermans (1999), *Sudden Death and the Myth of CPR* (Philadelphia: Temple University Press).
- Jane Seymour (2001), *Critical Moments – Death And Dying In Intensive Care* (Milton Keynes, UK: Open University Press).
- Frances Norwood (2007), "Nothing More to Do: Euthanasia, General Practice, and End-of-life Discourse in the Netherlands," *Medical Anthropology* 26, no. 2:139–174.
- Shai Lavi (2005), *The Modern Art of Dying: A History of Euthanasia in the United States* (Princeton, NJ: Princeton University Press).
- Clive Seale (1995) "Heroic Death," *Sociology* 29, no. 4: 597–613.
- Susan Sontag (1978), *Illness as Metaphor* (McGraw-Hill: Toronto, Canada).
- Ivan Illich (1976), *The Limits to Medicine. Medical Nemesis: The Expropriation of Health* (London UK: Calder & Boyers).
- James Davies (2011), "Positive and Negative Models of Suffering: An Anthropology of Our Shifting Cultural Consciousness of Emotional Discontent," *Anthropology of Consciousness* 22, no. 2: 188–208, <https://doi.org/10.1111/j.1556-3537.2011.01049.x>.
- R. George (2009), "Suffering and Healing – Our Core Business," *Palliative Medicine* 23: 385–387, <https://doi.org/10.1177/0269216309106099>.
- Jennifer Corns (2018), "Collaboration on Suffering and Autonomy at the End of Life," Glasgow End of Life Studies Blog, accessed November 8, 2018, <http://endoflifestudies.academicblogs.co.uk/collaboration-on-suffering-and-autonomy-at-the-end-of-life/>.
- Naomi Richards (2017), "Assisted Suicide as a Remedy for Suffering? The End-of-Life Preferences of British Suicide Tourists" *Medical Anthropology: Cross-Cultural Studies in Health and Illness* 36, no. 4: 248–362.
- Elana D. Buch (2015), "Anthropology of Aging and Care," *Annual Review of Anthropology* 44: 277–293, <https://doi.org/10.1146/annurev-anthro-102214-014254.p.279>.
- Linda R. Phillips and Pamela G. Reed (2010), "End-of-Life Caregiver's Perspectives on their Role: Generative Caregiving," *The Gerontologist* 50, no. 2:204–214, <https://doi.org/10.1093/geront/gnp116>.
- Arthur Kleinman (2009), "Caregiving: The Odyssey of Becoming More Human," *Lancet* 373: 293.
- Marcel Mauss (1954), *The Gift. The Form and Reason for Exchange in Archaic Societies*, (Routledge: London, 2002).
- Ann Julienne Russ (2005), "Love's Labor Paid for: Gift and Commodity at the Threshold of Death," *Cultural Anthropology* 20, no. 1: 128–155, <https://doi.org/10.1525/can.2005.20.1.128>.
- David Graeber (2011), *Debt: The First 5000 Years* (Brooklyn, NY: Melville House Printing)
- Julia Lawton (2000), *The Dying Process: Patients' Experiences of Palliative Care* (London, UK: Routledge).

55. Robert Castel (1991), "From Dangerousness to Risk," in *The Foucault Effect: Studies in Governmentality*, ed. Graham Burchill, Colin Gordon and Peter Miller, (London: Harvester Wheatsheaf), 289.
56. Mara Buchbinder (2018), "Choreographing Death: A Social Phenomenology of Medical Aid-in-dying in the United States," *Medical Anthropology Quarterly*, Online first, doi: 10.1111/maq.12468.
57. Helen Stanton Chapple (2010), *No Place for Dying: Hospitals and the Ideology of Rescue* (Walnut Creek, CA: Left Coast Press).
58. Hadi Karsoho et al. (2017), "Constructing Physician-Assisted Dying: The Politics of Evidence From Permissive Jurisdictions in Carter v. Canada," *Mortality* 22, no. 1: 45–59.
- ## BIBLIOGRAPHY
- Albom, Mitch. *Tuesdays with Morrie: An Old Man, a Young Man and Life's Greatest Lesson*. New York: Doubleday, 1997.
- Becker, Ernest. *The Denial of Death*. New York: Simon & Schuster, 1973.
- Bern-Klug, Mercedes, Bern-Klug, M.. "The ambiguous dying syndrome." *Health & Social Work* 29, no. 1 (2004): 55–65.
- Bloch, Maurice, and Jonathan Parry, eds., "Introduction: death and the regeneration of life" *Death and the regeneration of life*, 1–44. Melbourne, Australia: Cambridge University Press, 1982.
- Buch, Elana D. "Anthropology of aging and care." *Annual Review of Anthropology* 44, no. 1 (2015): 277–93.
- Buchbinder, Mara. "Choreographing death: a social phenomenology of medical Aid-in-dying in the United States." *Medical Anthropology Quarterly* 32, no. 4 (2018): 481–97.
- Cardona-Morrell, Magnolia, and Ken Hillman. "Development of a tool for defining and identifying the dying patient in hospital: criteria for screening and triaging to appropriate alternative care (CriSTAL)." *BMJ Supportive & Palliative Care* 5, no. 1 (2015): 78–90.
- Castel, Robert. "From Dangerousness to Risk." In *The Foucault Effect: Studies in Governmentality*, edited by G. Burchill, C. Gordon, and P. Miller, 281–385. London: Harvester Wheatsheaf, 1991.
- Chapple, Helen Stanton. *No Place for Dying: Hospitals and the Ideology of Rescue*. Walnut Creek, CA: Left Coast Press, 2010.
- . "The Disappearance of Dying and Why it Matters." In *A Companion to the Anthropology of Death*, edited by A. C. G. M, Robben, 429–45. Oxford, UK: Wiley, Blackwell, 2018.
- Cholbi, Michael, and Jukka Varelius. *New Directions in the Ethics of Assisted Suicide and Euthanasia*. London: Springer, 2015.
- Corns, Jennifer. "Collaboration on Suffering and Autonomy at the End of Life." Glasgow End of Life Studies Blog., 2018. Accessed 8 Nov 2018. <http://endoflifestudies.academicblogs.co.uk/collaboration-on-suffering-and-autonomy-at-the-end-of-life/>.
- Davies, James. "Positive and negative models of suffering: an anthropology of our shifting cultural consciousness of emotional discontent." *Anthropology of Consciousness* 22, no. 2 (2011): 188–208.
- Freud, Sigmund. *Five Lectures on Psychoanalysis, Leonardo Da Vinci and Other Works*, vol. 2001. London: Vintage, 1910.
- George, R. "Suffering and healing—our core business." *Palliative Medicine* 23, no. 5 (2009): 385–7.
- Glaser, Barney, and Anselm L Strauss. "Temporal aspects of dying as a Non-Scheduled status passage." *American Journal of Sociology* 71, no. 1 (1965): 48–59.
- , and Anselm L Strauss. *Awareness of Dying*. Chicago: Aldine, 1965.
- Graeber, David. *Debt: The First 5000 Years*. Brooklyn, NY: Melville House Printing, 2011.
- Health Improvement Scotland. "Palliative Care Identification Tool Comparator." Ihub, 2018. Accessed 8 Nov 2018. <https://ihub.scot/media/3559/palliative-care-identification-tools-comparator.pdf>.
- Helman, Cecil. *Culture, Health and Illness*: CRC press, 2007.
- Hui, David, Zohra Nooruddin, Neha Didwaniya, Rony Dev, Maxine De La Cruz, Sun Hyun Kim, Jung Hye Kwon, Ronald Hutchins, Christiana Liem, and Eduardo Bruera. "Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": a systematic review." *Journal of Pain and Symptom Management* 47, no. 1 (2014): 77–89.
- Illich, Ivan. *The Limits to Medicine. Medical Nemesis: The Expropriation of Health*. Calder. London UK: Boyers, 1976.
- Jackson, Emily, and John Keown. *Debating Euthanasia*. London: Hart, 2001.
- Karsoho, Hadi, David Kenneth Wright, Mary Ellen Macdonald, and Jennifer R. Fishman. "Constructing physician-assisted dying: the politics of evidence from permissive jurisdictions in Carter v. Canada." *Mortality* 22, no. 1 (2017): 45–59.
- Kastenbaum, Robert. *Death, Society, and Human Experience*, 77. St. Louis, MO: C. V. Mosby, 1977.
- Kaufman, Sharon. *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line*. London: Duke University Press, 2015.
- Kellehear, Alan. *The Inner Life of the Dying Person*, 9. New York: Columbia University Press, 2015.
- Kleinman, Arthur. "Caregiving: the odyssey of becoming more human." *The Lancet* 373, no. 9660 (2009): 292–3.
- Krawczyk, Marian. "Negotiated Practices: Understanding Hospital Palliative Care as an Affective Economy. PhD.", 2015, Dissertation. <http://summit.sfu.ca/item/15570>.
- Kubler-Ross, Elizabeth. *Death: The Final Stage of Growth*. New York: Touchstone; Simon & Schuster, 1975.
- Lavi, Shai. *The Modern Art of Dying: A History of Euthanasia in the United States*. Princeton University Press: Princeton, NJ, 2005.
- Lawton, Julia. *The Dying Process: Patients' Experiences of Palliative Care*. London, UK: Routledge, 2000.
- Lewis, Penney. *Assisted Dying and Legal Change*. Oxford, UK: Oxford University Press, 2007.
- Lupton, Deborah. *Medicine as culture: illness, disease and the body*. London: Sage, 2012.
- Mauss, Marcel. *The Gift. The Form and Reason for Exchange in Archaic Societies*, vol. 2002. London: Routledge, 1954.
- May, Carl. "Individual care? Power and subjectivity in therapeutic relationships." *Sociology* 26, no. 4 (1992): 589–602.
- Norwood, Frances. "Nothing more to do: euthanasia, general practice, and end-of-life discourse in the Netherlands." *Medical Anthropology* 26, no. 2 (2007): 139–74.
- O'Callaghan, Anne, George Laking, Rosemary Frey, Jackie Robinson, and Merryn Gott. "Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the gold standards framework prognostic indicator guidance as a screening tool in the acute hospital setting." *Palliative Medicine* 28, no. 8 (2014): 1046–52.
- Parsons, Talcott. *Social System*. London: Routledge, 1951.
- Pauch, Randy. "Last Lecture." Carnegie Mellon University." Accessed 8 Nov 2018. <https://www.cmu.edu/randyslecture/>.
- Perakyla, Anssi. "Hope work in the care of seriously ill patients." *Qualitative Health Research* 1, no. 4 (1991): 407–33.
- Phillips, Linda R, and Pamela G Reed. "End-of-life caregiver's perspectives on their role: generative caregiving." *The Gerontologist* 50, no. 2 (2010): 204–14.
- Pool, Robert. *Negotiating a Good Death: Euthanasia in the Netherlands*. Binghampton: Hawthorn Press, 2000.
- Porter, Catherine. *At his own wake, celebrating life and the gift of death*: The New York Times, 2017.
- Richards, Naomi. "Assisted Suicide as a Remedy for Suffering? The End-of-Life Preferences of British "Suicide Tourists"." *Medical Anthropology* 36, no. 4 (2017): 348–62.
- Russ, Ann Julienne. "Love's labor paid for: gift and commodity at the threshold of death." *Cultural Anthropology* 20, no. 1 (2005): 128–55.
- Seale, Clive. "Heroic death." *Sociology* 29, no. 4 (1995): 597–613.
- . *Constructing Death: The Sociology of Dying and Bereavement*. Cambridge: Cambridge University Press, 1998.
- Seymour, Jane. *Critical Moments - Death And Dying In Intensive Care*. Milton Keynes, UK: Open University Press, 2001.
- Sontag, Susan. *Illness as Metaphor*. TO, Canada: McGraw-Hill, 1978.
- Strauss, Anselm, and Barney Glaser. "'Patterns of Dying.'" In *The Dying Patient*, edited by O. G. Brim, Jr, E. Howard, S. L. Freeman, and N. A. Scotch, 129–55. New York: Russell Sage Foundation, 1970.
- The, Ann-Mei, Tony Hak, Gerard Koeter, and Gerrit van der Wal. "Collusion in doctor-patient communication about imminent death: an ethnographic study." *BMJ* 321, no. 7273 (2010): 1376–81.
- Timmermans, Stefan. *Sudden Death and the Myth of CPR*: Temple University Press, 1999.
- . "Death brokering: constructing culturally appropriate deaths." *Sociology of Health and Illness* 27, no. 7 (2005): 993–1013.
- Walter, Tony. "Death in the new age." *Religion* 23, no. 2 (1993): 127–45.
- . *The Revival of Death*. London and New York: Routledge, 1994.
- . "Why different countries manage death differently: a comparative analysis of modern urban societies." *The British Journal of Sociology* 63, no. 1 (2012): 123–45.
- Wood, Juanita. *Expressive death – the current death work paradigm*: University of California at Davies, 1977.