

ESSAY

Compassionate Care of the Dying Evokes Grace and Gratitude

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On 19 June 2019, the Victorian Voluntary Assisted Dying (VVAD) Act finally came into effect in Australia after protracted discussion for over two years in both houses of Parliament. Victorians who believe that they are at the end of life and who meet strict eligibility criteria could request access to voluntary assisted dying. By February 2020, eight months later, more than 130 extremely ill people had opted for voluntary euthanasia, what is known in other countries as medical assistance in dying.

Much interest and debate was generated during the passage of the Bill among community and health workers, doctors, churches, social scientists, and economists regarding the merits and demerits of allowing the intentional ending of lives of those who are chronically ill. Discussions in Parliament and across media often explored ways that could mitigate the suffering of seriously ill patients. Views were frequently exchanged on issues of cultural idiosyncrasies that affected care of long-term sufferers, institutional constraints in delivering care, community role in assuaging the desperation of the terminally ill, increased government investments in cultivating caring communities, social constructs, and religious tenets relevant to ending life intentionally.

Critics of the Bill regularly suggested that some of those seeking relief from their suffering through assisted dying feel a lack of genuine compassion in the care they receive. It appears that sloppy empathy for their severe medical condition and tactless engagement with their excruciating suffering may exacerbate the desperation of the critically ill, and provoke them to consider terminating their life.

Whether better compassionate care can reduce the desperation of excruciating suffering is a moot point. If tactless compassion is indeed the *agent provocateur* of heightened risks to terminate one's life, it might be relevant to contemplate the salutary effects of the possible nexus of suitable compassionate care with issues widely expressed during the passage of the Bill. The relevance of these focal issues to the delivery of care to the seriously ill has added gravitas because assisting life's termination is a disavowal of the Christian's fundamental belief that death is ordained only by *acts of God*. Any new thinking on engaging the care of the chronically ill may help keep dark thoughts away while assisting consideration of other faith traditions who have varying viewpoints on medical assistance in dying.

It appears that once it is legal to enable people in severe disability/discomfort to consider assisted suicide, society then absolves itself of extending a suitable helping hand to

alleviate their suffering. The gnawing concern of appropriate compassionate care becomes all the more pertinent in today's context when we can expect the raging Coronavirus to either kill or severely reduce the immune system of the elderly and bring on critical care needs for those severely affected by COVID19. It would be regrettable indeed if older COVID patients felt pressured to choose suicide over receiving care, or even believed that institutional compassionate care is not possible in a raging pandemic. Governments of all persuasions are expected through their actions to assuage such dark misgivings of the chronically suffering public, and play an active role in delivering compassionate hospice services. If a vaccine for the mutating Coronavirus is long in coming, physically distanced engagement will need to become the regulated behavior by which health workers provide their services. Such a protocol is likely to cause fear of inadvertently transgressing regulatory codes and create a degree of public anxiety and reluctance for care-givers to get involved in end-of-life care. Lack of genuine tactile exchange mitigates compassionate care. Anxiety of litigation on health and safety grounds is already often an inhibition for free-flowing compassion within Western society.

Cultural Connotations

It would indeed be unfortunate if care of the most fragile of humans were to be approached with anxiety that "over-reaching" kindness might draw opprobrium. Zaman et al. (2018) lament that, particularly in the developed world, free-flowing compassion is often withheld in an atmosphere of apprehension and fear. In his work on comparative cultural dimensions, Hofstede (1984) had similarly suggested that in low context societies of advanced economies there is a cultural abhorrence of relying on others to provide care, particularly in the most personal and intimate tasks of daily living. In such highly individualistic societies, where a high value is placed on autonomy, adult dependency is regarded as undignified, leading to a loss of self-esteem by those requiring care, no matter how willingly or lovingly administered. Unaccustomed to being assisted even when they are in dire need, these people, when critically ill, may feel extremely uncomfortable when cared for in what they might consider patronizing ways. On the other hand, in collective cultures, sufferers of acute pain and distress are more likely to be given free-flowing compassion by their care-givers and their kith and kin. However, even in collective cultures, the care of the chronically ill can vary widely between obligatory to privileged, though care is rarely outsourced.

Not surprisingly, even when care-givers in Western societies possess compassion or are trained in its components, it remains difficult for spontaneous compassion to flourish, whether in clinical settings or in communities. The sense of privacy in individualistic cultures is a particular, major barrier to the practice of free-flowing compassion. Although notions of privacy exist in any culture, these can take a heightened form in Western post-industrial societies, and therefore inhibit the development of "compassionate communities" for end-

of-life care. Third party involvement at the end of life means allowing an outsider into one's home, which makes it difficult to integrate free-flowing compassion within them.

Institutional Constraints

Booth (2016) is of the view that institutional constraints which limit the compassion care-givers can provide highlight the "production line" approach to health services. In this near mechanistic way of engaging patients, compassion within structural constraints is squeezed from routinised care, often resulting in a form of "institutionalized heartlessness." Motivated by arms-length efficiency in resource utilization, it is easy to see how economics is a significant driver in the move to legislate assisted dying, when compassion without pathos is given to people in the last five years of their life. The savings in the state's health care budget from achieving "dignified deaths" could then be applied to other valued objectives.

Community Role

According to Kellehear (2013), the starting point of end-of-life care is "everybody's business," and must not be abandoned to the health and social care system alone. His approach is rooted in a health-promoting orientation to end-of-life care. Kellehear (2013) believes that if compassion has to become the orienting principle for new public health approaches to end-of-life care in communities, there should be room for lay participation and engagement in giving free care to the infirm.

Government Investments in Cultivating Compassionate Communities

While in past decades it has been mostly governments who built residential facilities for the aging, there is an increasing tendency for governments to contract the management of these residents to private enterprises who inevitably, being driven by profit motive, have little interest in incurring the cost of compassion. However, governments cannot absolve themselves from creating salutary measures that mitigate the sufferings of the terminally ill. The question to governments is how a compassionate health care system can be built that will actually help people achieve what is most important to them at the end of their lives—an attribute to be nurtured in the delivery of end-of-life care, a rallying call for community action and public health intervention. Governments ought to realize that certain types of social capital investments can help nurture compassionate cities and compassionate communities which convey ideas of reclaiming death and bringing it back to its appropriate setting—the home and community. This type of engagement seeks to nurture communities which are asset-based and have a social capital orientation which makes them more compassionate to human debilitations.

Capital widening efforts of governments which cultivate compassionate communities could include investments in geriatric health care, allowing for generous disability pensions, tax subsidies for care of the terminally ill, discounted medications, and providing support for community groups. Affirmative efforts to deepen social capital, for instance, could be to run civic campaigns that encourage communities to demonstrate greater compassion in engaging with those with significant debilitations, that legislate labor laws which give working hour flexibility to care-givers, that mandate school curriculums to include alleviation strategies for the chronically ill, and that institutionalize Good Samaritan awards for the general public as well as for health care workers.

Social Constructs

Affirmative policies and wide availability of resources inevitably encourage greater outreach efforts. It is reasonable for care-givers to feel less stressed and engage with genuine empathy for their seriously ill wards in a system that acknowledges their efforts and makes resources relatively easy to access. Work by Valdesolo et al. (2011) suggest that it is not unusual for the chronically ill to embrace and be grateful for honest compassionate care despite the outreach sometimes being out of character with cultural norms. The evocation and intensity of compassion and gratitude, unlike many other emotions, usually interact with one another. Compassion and gratitude also work together to build social equity, with compassion motivating the initial impulse to care for the chronically ill individual, and gratitude from that individual being the consequent recompense seeking more of the same.

Religious Tenets

The seriously ill who are grateful for tender loving care are probably more open to discourse on the Christian tenet that the time of one's mortality is ordained by God. Psalm 139:16 notes that, "The days allotted to me had all been recorded in your book, before any of them ever began." Those who select their time of mortality, according to Christian belief, are unwittingly getting ahead of themselves and are stepping out of the state of grace. Mathew 25:1-13 describes Jesus' teaching of the parable of the ten young women waiting for the bridegroom to come into the banquet room with them. This parable is commonly understood by Christians as a message of awaiting death's call at *an indeterminate time* with a trimmed wick kept ready in a lamp which has an assured supply of oil close to the wick, in order to always keep the flame alight. The groom, for whom the bridesmaids were waiting, was *long in coming*. Apparently, they were so fatigued with the wait that some of them dozed off. It appears however that the bridesmaids were resigned to the stress of the wait because they were looking forward to meeting the groom. When the bridegroom eventually arrives at death's knell, those with enough oil and a simmering flame could confidently proceed to meet the groom and enter the banquet with him. On the other hand, those without adequate supply of fuel and no light could not find their way to the groom.

The response the laggard bridesmaids got when they asked the others to share their oil, was a tongue-in-cheek “Go to the store and buy some for yourselves.” It is obvious that rear-guard efforts of acquiring the light were not helpful because these delinquent bridesmaids found themselves banging on a shut banquet door only to be rebuffed!

It is widely recognized by the Christian church that the supply of oil is necessary to sustain everyone all through their lives, no matter what their disposition is and the length of time they must wait for the bells to toll! While there is no suggestion in the parable that the anticipation of the laggard bridesmaids of the groom’s arrival at death knell was premature, it appears that these bridesmaids were compromised in their lifetime, and consequently, on their demise, found themselves short of oil. The metaphor of oil for grace is stark. Also, grace cannot be purchased! The forked language of the bridesmaids, who were sufficiently oil resourced, could well insinuate that grace is a celestial gift, freely available to all who participate in the Divine plan.

Conclusion

If compassionate care for those in extreme distress ferments within them a gratitude that can redeem their suffering, their misery is invariably able to take on refreshing meanings of life and immortality. Ben Patterson (2011), in his book *Muscular Faith: How to Strengthen One’s Heart, Mind, and Soul for the Only Test that Matters*, suggests that grace predicates gratitude. He quotes Karl Barth, the noted Swiss reformed pastor and well-known Christian thinker, as asking “How else can one be but profoundly grateful when such a thing as grace happens? It is grace that evokes gratitude like the voice of an echo. Gratitude follows grace like thunder does lightning.” Both grace and gratitude are related emotions and have the same original root. The Greek word *eucharistian* for gratitude is built on the word for grace, *charis*. The capacity to experience gratitude has been found to covary positively with life satisfaction, psychological well-being, and grace of coherence—a feeling that life is manageable, meaningful, and comprehensible (Wood et.al. 2010, Lambert et al. 2009).

Induced by tender loving care, the catharsis that can embrace the seriously ill, and epitomized by Paul in Acts 3:20 as “times refreshing may come from the presence of the Lord,” is the ultimate dividend of social capital invested in fostering compassionate care. The emotional relief felt from compassionate care is hardly likely to drive the critically ill to bang on Heaven’s door ahead of their natural calling.

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