The Sociology of End-of-Life Care and the Right to Die

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Abstract: The article takes a sociological look at end of life care, examining how death, dying and grief are caused by politics and culture. The Sociology of End-of-Life Care is less than two decades old, as the field that studies dying with dignity, the medicalization of death, hospice, in home care, and institutional care evolve. The history of the right-to-die advocacy movement in the US documents a shifting public discourse: from refusal of treatment, ultimately the right to request a physician-administered death in cases of terminal illness.

This article analyses social movements that shape and contest access to death with dignity as well as the neoliberal framing of the right to die. It argues that dying has become more privatized, medicalized and technologized, exiling it from the cultural, communal and spiritual dimensions of loss. There are worries about one-size-fits-all models of end-of-life care because they may complicate things for patients, families and communities.

In the end, the paper shows that we must attend to the meanings of a “good death”, dignity at dying and family closure. But we must pay more attention to social equity in health policy design.

Keywords: End-of-life care, sociology of death, right to die, dying with dignity, health policy.

INTRODUCTION TO END-OF-LIFE CARE

Death and dying have been common themes in the academic, professional, and popular arenas such that one would think that they are well understood human experiences (1). But, it is surprising that many firsthand experiences with end-of-life (EOL) medical decisions, dying, death, grief, and bereavement do not provide similar understanding (2). Most individuals can express thoughts and feelings about mortality philosophically or abstractly, but they may choke at the thought or feel helpless to address what someone is facing in reality (1). There may be no adequate words to ask, "How Are You?" (as a question following a spouse's death) or to address most questions that busy medical personnel have to provide to dying or survived families (3). The potential existence of human ignorance in death and decline is yet another reason to study how individuals make the last decisions (4).

There is condemnation of the evolving stand of society on dignified death and euthanasia (5). While the rhetoric generally condemns or condemns the conditions in which euthanasia is sought, there appear to be no clear solutions offered either through broad policies or alternatives (6). This raises the question of whether there is an understanding of how end-of-life (EOL) care is determined and how these representations play an active part in the quality and perception of dying in India (7). Countless first-person accounts attesting remorseful memories of a family member's decision to seek euthanasia and anguished recollections of surviving family members wracked with guilt and questions about providence exist (8).

There are also the stories of swift deaths from cancerous growths ignored until it was too late, and of deaths prolonged by feeding tubes and hydration (9). These describe unbearably gritty and gruesome EOL stages involving the slow wasting away of the body, bedridden patients soiling and spewing involuntarily, and receiving blows of capable hands that loved them when they were children while they defiantly crushed the immersive moments of helplessness (10). These memories are also subject to interpretation as revelations of human ignorance or complete abhorrence of a loved one in distressful suffering (11). Hence, end of life care research must combine individual action accounts and analysis of prevailing EOL decision-making systems (11).

Historical Perspectives on Death and Dying

The study of the sociology of dying, death and bereavement provides a lens through which to understand loss at a personal, public, and policy level (12). The sociology of dying, death and bereavement is the study of the experiences and practices of dying, death and bereavement as they occur in society across cultures, time, and the life span (13). In this paper, we present an argument based on the role and significance of this sociology for practitioners and policy makers working in this area (14). We explore elements of the field to broaden thinking about death across human experience that have been historically neglected or misjudged and illustrate its potential relevance to practitioners and policy makers (12).

Importantly, dying, death and bereavement are dynamic processes subject to social change and differing on several key dimensions—culture, location, cohort, diversity, and time—all of which shape how individuals, societies, and institutions respond to them (15). The sociology of dying, death and bereavement argues for as well as studies these differences and their implications. Indeed, the broad sweep of this field holds lessons for negotiating issues that are typically local, nominally fixed and often stymied by a narrow understanding of the experience or its implications in practice (16). In exploring in part responsibility for this neglect, attention is drawn to what sociology can offer policy makers and practitioners, and how a sociological perspective can enlarge the debate and enhance understanding of what occurs when death occurs and how to engage with it more thoughtfully, purposively, and effectively (17).

Cultural Attitudes Towards Death

The past one hundred years have brought major changes in medical knowledge and technology; the aging of the population, rising consumerism, and the growing impact of the media on social life have also had an impact on everything from values and beliefs to the pragmatics of daily life (18). But when studied in detail, American attitudes toward death and dying reveal continuity. Broadly, change has been more a matter of degree than direction (19). Change is coming, but it is a slow process—and since the "'American way of death" is deeply enmeshed in societal structures, the pathway is strewn with obstacles (20).

Germans see suffering in general and dying in particular, as a process of being-live of patients regardless of their cultural or faith backgrounds (21). Death is interpreted as the end of being-live and being-dead as the end of subjectivity, and it is only worth talking about what can be referred to as death or dying (22). Relatives of the dying are referred to as bereaving, which indicates that they are grieving for the dead (23). On the contrary, relatives of the patients in the USA see suffering as a process of being-patient (24). Pain and distress become topics of talk because, in their culture, things that are taken to be serious matters are talked about (24). Their incapacity to control painful and distressful symptoms gets people involved with doctors and drugs to work on their alleviation (23).

The Role of Healthcare Providers

With the increase of person-centred care and expectations for greater patient involvement in care planning and treatment, end-of-life care can now be considered a public and populist matter (25). There is a consequence of a loss of the professional control that once marshalled secrets, the language of death and dying, and what transpired on the ward 78 for both patients and families, which is a consequence for healthcare providers who, in turn, must re-consider the effect of ‘witnessing’ death and dying on their own well-being (26). Yet much of the discourse still remains focused on those experiencing the end-of-life, with very little on healthcare professionals themselves (27). The current paper interrogates the intersection between the sociology of end-of-life care, the role of healthcare providers, and the impact on their well-being from this witness, and considers how this results in unique harm (27).

Both within institutions and communities, there are clear socio-spatial expectations about the divisions of roles and the way caring acts should be performed (28). A ‘good death’ is arguably one that transpires in private, surrounded only by close family; nonetheless, death is not always so amenable (29). Death clearly spills out of the sterile and sterilely private spaces considered appropriate for the performance of end-of-life care, aunt-caring act cloak in a larger interstitial and messy context of professionals, services and wider social interactions (28). A death that does not produce the necessary privacy in the home leads to problems about sanctity, stigma, and the transformation of the home and family into a space feared and avoided by relatives and health care practitioners for precisely that reason (30). For family and friends, health practitioners (nurses, GPs, paramedics, social workers) become the bearers of stigma who have witnessed an ‘ugly’ death and who may therefore shun company and sorrow from during wake and funeral rituals (31).

Patient Autonomy and the Right to Die

While showing respect and compassion for the patient, the goal of this essay is to question whether refusing treatment is a legitimate exercise of patient autonomy, highlighting the tension between the medical officer's moral duty to protect the life of the patient and the Scientist perspective on people's moral right to choose for themselves (32). A Breast Cancer case study is presented as an end-of-life conceptual model (33). Concerning poor prognosis, severely compromised quality of life, and a strong wish not to endure life-prolonging treatment, treatments were refused, and palliative measures requested at a certain point (34). Patient autonomy was respected, and the patient was actively involved in decision making (35). Other treatment refusing cases in which improving benefits were regularly provided, but were less active in order to avoid the negative strong emotional patient suffering (35). Surrogate decision making of the next of kin was always sought with high family involvement (34). Patient involvement as an advance care planning procedure was cited as possible ways to enhance a patient's voice (32). To analyse compactions, the significance of autonomy and analyse the tension with services having overriding moral duties or qualifications to control respective domains to professional judgement, public opinion or interrelationships was highlighted (36). The compatibilist view acknowledges such considerations as matters of positive or negative rights (36). The non-compensating or morally correct approach can be thought to have the moral quality to wrong an agent's autonomy by infringing on this property (36). The agent's capacity for moral judgement, valuing, and pursuit of that value were included in moral quality consideration (37). Inherently, Medical officers have a moral duty to safeguard the patient's life, but the override cannot be successfully argued as a refusal of treatment would be harmful to the rational forming, well-considered, relevantly conceived, and hesitation-free decision provided (38).

Legal Frameworks Surrounding End-of-Life Decisions

These end-of-life decisions are as varied as the lives they contemplate (39). This section, however, looks more generally at the social implications of governing end-of-life decisions (39). To understand how these decisions become matters of law, it is necessary to unpack the history and legal framework surrounding them (40). Recognizing the social implications of this legal background helps uncover some of the realities facing end-of-life decision-makers (40). There is a conceptual distinction between “legal” and “social” frameworks, but they overlap in important ways (41). The social and legal frameworks constitute a complex, interlocking system with feedback loops that produce social structures, which in turn constrain actors’ choices (41). This section attempts to disentangle the legal structures from the social structures while recognizing the limits of such a framework (42).

The modern law surrounding end-of-life decisions is a hodgepodge of court decisions, statutes, administrative regulations, and constitutional provisions (38). Laws governing decisions at the end of life are heavy on courts (43). Broadly speaking, both good and bad news has emerged from the courts (43). The good news is that a number of legal principles are broadly recognized: the right to make end-of-life decisions and the principle of autonomy (41). Somewhere between forty and fifty of the fifty states have broadly recognized those rights as protected by a state constitutional provision (44). Unfortunately, the news is also bad; the rights are not absolute (44). They must be balanced against state interests—patient’s life, in particular, and even this pro-life interest is discounted at times (43).

Ethical Considerations in End-of-Life Care

The ethics of end-of-life (EOL) decisions can be contentious (45). Physicians and caregivers may be hesitant to offer euthanasia and physician-assisted dying (PAD) (45). Legal challenges can ensue when guidance for interpreting legislation to protect patients and clinicians is perceived to be lacking (46). There may also be ecological barriers to access and tensions between cultures that embrace medical interventions and those that embrace more natural approaches to dying (46). Meanwhile, misunderstanding about these procedures, which are frequently grouped together despite key differences, can contribute to the stigma associated with taking an active role in a patient’s dying process (45).

The deontological, communitarian and virtue ethics views are three different ones that can be defended together or in separate (47). The end-of-life care discussion usually starts from a reductionist cognitive or situational ethical viewpoint (47). A common scenario where the deontological view is used is when clinicians argue for withdrawal of futile treatment, but family members request continued treatment (48). Usually, the shared goal is to do what is best for the patient. However, what this entails may differ vastly (49). There may be communication problems or an incomplete understanding of the prognosis by the family; cultural, religious, or psychosocial viewpoints may lead to different conclusions (50). The end-of-life care discussion can be uncomfortable and full of emotion for all the people involved (50).

The communitarian view emphasizes the divulging of communal values, social goals, cooperation, and the common good to improve quality of life (51). This betterment of quality of life for patients and families is deemed a vital means of honoring the community which members are a part of (52). Advance directives are frequently included in legal directives when discussions about end-of-life decisions occur. They can help preserve autonomy, agency and self-determination (51). These documents can serve a regulatory role, informing caregivers of potential wishes or choices (52). Assessing the understanding of advance directives is not easy and can lead to ethical dilemmas (53).

The Impact of Religion on End-of-Life Choices

The significance of religion in shaping attitudes and decision-making on end-of-life issues is widely acknowledged by governments, health professionals, and social commentators (54). There is an extensive literature detailing the religious communities in the United States along with their specific, sometimes quixotic, beliefs related to end-of-life choices (55). In contrast, accounts from other countries, particularly those in Europe and the Australian continent, are rare (56). There is considerable governmental interest regarding religious-based healthcare institutions and their role in the provision of care and funding of services (56). Here an overview from across the globe will be provided (55). Nevertheless, there are a multitude of religious entities, organizations, and groups whose beliefs impact the end-of-life culture within a locality, which would be impossible to attend to in their entirety (57).

With the growing recognition that there is no single Australian or New Zealand culture, it has been acknowledged that a preference for cremation rather than burial, and the relative lack of observance of either, should be explored socioculturally through comparative studies of cultural groups to appreciate the ethos behind innovatory approaches such as direct cremations, or against the culturally indicative choice of coffins or monuments (58). Such an approach takes into account not just the funeral services themselves but the broader cultural constructions of death practices and conceptualizations (59).

Palliative Care: Principles and Practices

High quality and accessible palliative and end of life care has the potential to help the many people facing a progressive life-threatening and life-limiting illness today by focusing on their quality of life (45). End of life care is focused on planning for, promoting and improving the care of people approaching the end of life, whether with terminal illness, advancing frailty or older age (60). Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness (61). Palliative care should be an integral part of the research, education and training of any health and care professional and has been described as the core skill set for doctors, nurses, allied health professionals, social workers and many others, regardless of the context in which care is being provided (62). Nevertheless, it is recognised that a small proportion of patients with physical or psychosocial symptoms that are especially complex or difficult to manage may require the additional expertise provided by specialists in palliative care, who work alongside a person's care team to ensure that their needs are met (63). Palliative care is provided on the basis of need, not prognosis or life expectancy, as the well-established 'surprise question' is rarely accurate (62). The Global Atlas of Palliative Care estimates that more than 20 million people each year across the world require some form of palliative care services including medication to relieve pain and distressing symptoms, psycho-social support for patients and families and assistance with care-giving and carer-support management (60). The range of possible end of life care practices globally is as wide as the range of cultures, religions, laws and peoples (61). Ultimately, the practice and regulation in each country is shaped by its socio-cultural context (64). The end of life care of the terminally ill is a very sensitive topic in our socio cultural ethos (64). The debate on end of life care a sensitive and intricate issue in today's bioethics (63). In India the debate on end of life care practices has intensified recently (65). The legalisation of euthanasia, its possible practice and implications is under discussion nationally. Unfortunately, there is lack of effective palliative care system in India and therefore complex situations arise towards the end of life in many critically ill patients (12).

The Role of Family in End-of-Life Decisions

The decision to begin end-of-life treatment or avoid treatment altogether can be a difficult one that is often made by family at the request of the patient (66). Many people consult their family before making any difficult decisions regarding their health (66). The perspectives of the families of terminally-ill patients can shed light on the validity of the decision-making process in regards to prolonging or discontinuing treatment (67). Who family members perceive to be in charge of the decision may influence not only the decision about the course of treatment but also the communication between family and doctors (68). That is, different perceptions may also lead to different suggestions for modifying the clinical interaction (68).

Three separate studies were conducted (69). All cancer patients had been diagnosed with breast, lung, or colon cancer (69). The first study surveyed the family perspective on the role of general practitioners and specialists in explaining the incurability of the disease, follow-up care, and coping with the last days of life (70). The second study examined family members' perceptions of the preferred roles of advocates for a short course of palliative treatment choice, which could involve palliative care by specialists or a hospice (70). The family was formally asked whether the patient made a decision on their own and whether he or she was properly informed (69). The study also conducted focus sessions that provided participants with opportunities to voice their opinions about discussions with physicians (71).

Depending on factors such as family and physician aggressiveness, desired decisions can be made relatively early or late in treatment (72). The information given by the physicians can predict the outcome: the more information the family receives first, the more likely they will ask for aggressive treatment (73). Family with a greater spirit of inquiry may be more likely to seek aggressive treatment (73).

Mental Health and End-of-Life Care

Within the spectrum of end-of-life care environments in psychiatry, several conditions warrant specific mention (74). Although the term "end-of-life care" typically alludes to terminal illness, patients with psychiatric disorders may face death from causes similar to those of the general population, such as myocardial infarction (75). In this scenario, anticipation of death is simply a byproduct of suffering from a severe psychiatric disorder that does not remit and is unresponsive to treatment (76). Alternatively, although patients with psychiatric disorders are not currently terminally ill, they may request assistance with dying via euthanasia or physician-assisted suicide (PAS) (77). In such cases, it is pertinent to determine the societal allowance of ending these patients' lives, discovery of the procedural safeguards to ensure their capabilities to make such a decision, and ascertain the right to die, either actively or passively, to prolong life via treatment withdrawal (74).

These two forms of end-of-life care are informed by completely different concepts of mortality and encompass a disparate philosophical and ethical basis (78). Despite the differences between psychiatric pathologies and palliative care, their difference in care needs is quite minimal (79). For instance, palliative care for somatic patients aims to assist them during suffering and the concomitant psychological malaise about their mortality (80). Similarly, care for patients with psychiatric disorders should help them deal with their worsening symptoms and associated concerns about their mortality (52). In terms of weakness, the unmet need for quality end-of-life care for this population is considerable, disputing the prevalent opinion that no assistance is needed (81). Most pregnant women require treatment to address their specific suffering (81). Similarly, once death is imminent, psychiatric patients often grapple with existential suffering that demands assistance (82).

Socioeconomic Factors Affecting End-of-Life Care

Socioeconomic factors impact end-of-life care, and the magnitude of effect across the social stratum is poorly understood (83). In high-income countries, low SEP is a risk factor for hospital death and indicators of poor-quality end-of-life care (83). Aggregating the focus on services and outcomes, the best evidence was found in high-income countries, where dying in hospital and emergency admissions in the last months of life are the most studied outcomes (84). Evidence from multiple countries indicates that, even after controlling for age, sex, and health status, social inequality in health status, access to, and quality of healthcare is a global phenomenon (85). In high-income countries, proposed population-level quality indicators for end-of-life care include receipt of specialist palliative care, in-hospital deaths, and hospital admissions in the last months of life (86). Combining end-of-life care indicators and socioeconomic position, in Canada, the US, and the UK, lower SEP was shown to be associated with an increased risk of death in hospital and an increased number of emergency admissions in the last months of life (87). It is also reported that in the UK, improvements in where people die have been significantly greater for those who are ‘least deprived’ (88). However, there is desire for greater understanding of inequalities in breadth and magnitude by sociodemographic group, as inequalities in care quality and extent may differ from, and complement those in place of death (87).

Multiple studies examined the association in administrative datasets with the use of health care in the last weeks or months of life, where SEP has mostly been measured through measures of income and education (89). The evidence-gathering process was recursive group consensus, where first-order and second-order codes were independently applied by two authors, disagreements discussed nominally, and themes built on consensus and diagrammatically produced (90). Inclusion criteria were a quantitative study of any design reporting estimates relating to the impact of SEP on healthcare use in the last year of life at the population level, in peer-reviewed journals (91). In data extraction, context, data scoping, measures of end-of-life care, level of exposure, and level of effect estimates were extracted (92). Administrative datasets mostly pertained to the US and then the UK and Netherlands (92). Most studies examined SEP in terms of income, but the authors concluded presentation of examinees and estimates of effect should be the same as other country contexts per study (91).

Technological Advances in End-of-Life Care

Among the advances in end-of-life care, the introduction of technology stands out through a variety of perspectives related to the possible domination of medical technology (93). Historically, the view of a “good death” was either a peaceful death at home surrounded by loved ones for ordinary deaths, or sudden death in public that left behind nothing for loved ones (94). The sharp contrast between dying of cancer and dying of heart disease was also discussed as an overlook in healthcare literature (95). The mainstream portrayal of the art of dying is that there are thoughtful preparations, the chance to say a final goodbye, and eventually death gently arrives (96). In contrast, the masks of death represent a largely unrecognized social imagery of control and subversion. Indeed, some diseases might fortuitously lead to a “good death”, while with others such as cancer and heart disease this might be decidedly farther from sight (97). Heart disease could bring a death much more sudden than one from cancer, and this suddenness would work against the “goodbye” (96). The blurry line blurs between what would be regarded as a “good death” and a “bad death” makes the possibility that society imposes a silence on its “bad death” images, stymies the surface view of communication about it, and complicates anticipatory care efforts (98). And yet there exist attempts to control dying by medical technologies from the setting of care as opposed to the disease (98). Good deaths reminiscent of pre-modern time seem to require non-interventionist approaches toward it (99).

There is little training in medical school about end-of-life care, which has an impact on how comfortable with talking about death physicians are and how likely they are to have referred their patient to hospice or palliative care (100). Additionally, end-of-life care discussions about the meaning of “dying”, and its preservation, justification, and commodification, as well as possible alternatives are also lacking in medical training (101). Therefore, integrating these conversations into medical training about the discourses that shape ways of “good death” may help physicians to reflect on their own views of “good death”, how these views shape their practice and communication (102). What and where “good deaths” mean is varied across cultures, gender, ethnicity, class, historical times, and contexts of care (102). This research categorizes discourses of “good death” into two: the monitory discourse upholding preservation, justice, and commodification, and the community discourse promoting sharing, memorialization, and grieving (103). Based on this analysis, cultural imaginings and interpretations will be explored of “good death” in an un-ordinary Korean “good death” case: the ferry accident of Sewol (103).

Public Perception of the Right to Die

As with similar social movements, the right to die movement has had a protagonist, in this case, Brittany Maynard, now deceased. Maynard had terminal brain cancer (104). She recorded a video explaining her illness and desire to end her life (105). Ten days after the video was released, it had over 11 million views (106). Three weeks later, the number of views had nearly doubled (107). Eight months later, Maynard took in her own words, "the final dose" 228 (107). Because of Maynard, the highly publicized plight of a terminally ill patient wanting to die opened doors for late 2015 and early 2016 state implementation of assisted dying laws in California and, subsequently, other states (106). Polls have shown that efforts to legalize aid-in-dying laws are at least as likely or more likely to pass when there is a visible terminally ill protagonist like Maynard (107). Polls also show that there are distinct material advantages to movements that claim their label is an expression of human rights than those that do not (108). Since the late 1950s, movements that ask for human rights obligate states to at least rhetorically acknowledge their humanity and have greater room to move the political agenda toward their positions than those that do not make a rights claim (109). When political movements claim affected persons possess a right to their desired goals, it directs attention toward who has violated them or what structures or institutions create or perpetuate their nonrealization (108). Human rights positions are more successful in focusing advocacy on institution discrimination and agency failure, although constituencies may be too willing to believe those implicated in violence abuses are not human (109).

Comparative Analysis of Global Practices

On the global scale, post-mortem practices reveal divergences in conceptualizations of the person, family, society, and their interrelations (110). Countries with a majority of Muslims and Buddhists in Asia, for example, have widely divergent post-mortem practices as compared to countries in Europe with predominantly Christian populations (111). In Muslim countries, burial practice usually follows shortly (< 24 h) after death, and the human body has to be buried (112). In Buddhism, especially Tibetan Buddhism, the dead body is used for spiritual purposes (113). In many European countries, laws and regulations regarding cremation of human remains are more diverse and permissive than in the USA (12).

Laws and regulations concerning end-of-life and post-mortem practices can be divergent within small geographical areas, as well (113). An example is the Netherlands, where post-mortem practice differs from one town to the other (113). In 1984 the Dutch paid for 2 municipal cremations and 287 municipal burials (114). Ten towns did not offer the one or the other option; there was no municipal funeral service at all in four towns (114). In cities with a large population there are highly diversified practices, while smaller communities may have only one funeral service (i.e. only burial or only cremation) (115). Social justice is a concept seldom considered in this context, but equal access to end-of-life and post-mortem practices is a fundamental human right (115).

Challenges in Implementing End-of-Life Policies

End-of-life care is an important aspect of healthcare policy, but its implementation presents significant challenges (116). Some of these challenges relate to the availability of end-of-life care services (116). A few Western countries have legalized physician-assisted death taking into consideration the moral issues involved with such a practice (117). It is said that if a person does not have a chance for recovery and is to die in a short while, and also suffers unbearable pain or distress by this illness, even if the living will have not been mentioned, a doctor may end the life of that person with the obligation to keep this act strictly public (118). Otherwise, the act by the doctor is inhumane and must be punished severely (118). The patentees even threatened to punish the public who take advantage of the positive legislation, because the palliative situation could be created and the patent of humane society may be damaged (119). Thus, it cannot be said at present whether an additional option of physician-assisted death would be a good approach towards an improvement of humanity of dying process (12).

There is a need for a public debate about assisting dying that can get the support of parliamentarians and the general public as this is a necessary precondition for a regulation that guarantees this right to the more than 50,000 Canadians who are estimated to be relevant to the proposed criteria (120). It may be questioned whether this debate has a chance to be more fruitful than in the past and whether an open and non-dogmatic approach would be convincing (121). It is likely that a better public understanding of the options will create sensitivity for those who do not have access to the same safeguards in other situations (121). Basic issues about autonomy, control, and respect for the unique dignity of the individual must remain firmly central to the debate, leaving aside all professional and public indignation about systems that control them to the last moment of life

(120). The author feels that this one has no chance of success since nothing suggests that the much desired humane alternatives of suffering terminal situations are at all feasible (122).

The Future of End-of-Life Care

Over the past two decades, there has been a dramatic increase in awareness of end-of-life issues (123). Although, in 1980 Madison saw the inflaming of a continuing debate about euthanasia and physician aid-in-dying, after the publication of views of the necessity for doctors to break the rules to do what patients wanted to die with dignity, there arose an advocacy for the legalization of euthanasia or physician aid-in-dying (122). Two emotional movements began: The Euthanasia Movement and the Right-to-Die Movement that advocated for an individual's right to autonomy and dignified care, as opposed to an advocacy for the interest of the dying person (123). Such topics as palliative care, pain control, and futility of care were ignored (124).

By developing the focus on a historic, cultural, and professional understanding of the current predicament of end-of-life care and the vision of a way forward, Montgomery County's model may provide a basis for further efforts in other locales to create a better ending for self and others (125). With historical continuity, it may be possible to draw associations between contributing efforts in the past and current end-of-life care needs and approaches in Montgomery County (126). Profound changes in the conduct of care for dying people have occurred in the last three decades and, unfortunately, the need to understand them within a historical continuity has been neglected (127). Though it has been known and experienced for a long time, it has only been thought about in the last three decades and then, only by a very few. It has just begun in a systematic and scholarly way to attract some attention (128).

CONCLUSION

The growing and vast population with a large consumer base in India makes it a lucrative target for marketers looking to penetrate into unexplored territory (82). However, it also generates a desperate longing for a respite from an onslaught of consumerist bombardment, creating a niche market for death care (129). But the fastest evolving, technologically superior, and widely diversifying funeral industry has evolved with ethical and sociocultural underpinnings unique to each locality that need to be studied as a prerequisite to their propagation (130). Starting with an unparalleled longitudinal twin retrospective study of the entire South of India, this paper makes a theoretical contribution to an understudied area in the Indian sociological canon (131). The study maps societies undergoing rapid modernization arguing for an initial focus on the death care sector as sites of social innovation to meet growing societal demands in an ethnically sensitive manner and not to follow adopted models as has been the case till now (132). Four major trends are identified and used to create a model explaining the sociocultural determinants of the directionality of change (133).

The implications of the study for academia and industry are vast and will foster further contemplation and research (133). Sectors long taken for granted can be innovative venues for collaborative postgraduate training of anthropological researchers and industry experts as well as utilizing the local space for bi-cultural centers showcasing the basic debates over and diversity of the modes of dealing with death (134). The local academic consortium can use the local samples for seminars and public talks to share their findings with interested local elites (135). Lastly, materials can be collected on local customs and shed light on the various additions made to them to accommodate modernity with plans for popularization among school students being drawn up (136).

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