
Current social trends and challenges for the dying person

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Buried deep inside the debates on how we should die—with or without palliative care or euthanasia—and where we should die—in hospitals, nursing homes, hospices or in our own homes—lie two strange and persistent facts. Few people understand the dominant ways we die and the challenges most people face because of those types of dying. Many of the social science monographs and health policy debates focus on cancer dying or dying in total institutions. Yet cancer is only one disease that kills, and many people live out their dying with several fatal illnesses. Though many people become dead in total institutions, the longer part of living-while-dying is outside of custodial care. Between a popular media fed with mere clinical insights about dying and a social science tradition of investigations that have taken almost their every lead from health care institutions, major myths and biases do grow. And basic insights from history, cultural sociology and epidemiology continue to be overlooked.

This chapter seeks to redress these oversights by describing the key social trends, and the personal challenges thrown up by them, for today's dying populations. Any basic sociology of dying needs to grapple with these trends because they are the meeting places between recent history and identity for today's dying person. I describe seven major social trends that are key determinants of the current social experience of dying. These are: (1) the complicated nature of dying trajectories; (2) the seduction of medical rescue as a broad cultural value; (3) the myth of institutionalization; (4) the social manufacture of horror for contemporary images of dying; (5) the rise of single-person households; (6) the

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paradoxical trend towards promoting dying for resource-poor countries while promoting sudden death in resource-wealthy ones; (7) and the current inability to address the problem of destination for a fundamental life-course rite of passage such as death and dying. I will commence with a discussion of the problem of complicated trajectories of dying.

1 Complicated dying: multiple morbidities vs. single trajectories

Historically, we have experienced dying as a trajectory initiated by a single disease or event. In hunter-gatherer societies people died of animal predation or in childbirth or from a deadly infection. We could deduce from the information we received about the cause of death how a person would have spent their last few hours, days or weeks before death. In other words, cause of death told us about the dying. Today, apart from death by trauma, this style of deduction is largely no longer true.

Since the beginning of the 20th century, life expectancies have been increasing in the industrial economies such as Europe, USA, Britain and its dominion territories as well as some Asian economies. Here the number of older people has increased without demographic precedent. In traditional human settlements, death was largely the province of the newborns, infants and children. This was a key reason for the average life expectancy in human history lingering around the ages of late teens and early 20s. In modern 20th-century industrial societies, as public health measures spread (clean drinking water, introduction of sewerage systems, better and more reliable diets etc.) death became the province of the elderly. However, as we aged, the comparatively uncommon diseases in younger populations quickly became prevalent in the older ones. These diseases included those of the circulation (strokes, heart disease), metabolic disorders (diabetes, organ failure, hypertension etc.), and the cancers and neurological disorders. With increasing age there came the increasing likelihood of encountering one of these diseases.

Furthermore, most of these chronic illnesses could not be ‘cured’ in the same way we had recently seen with infections—with the magic bullet of an antibiotic. Instead, the diseases of ageing had to be managed—they became *chronic and disabling*. Furthermore, if they did not kill you soon, yet other diseases would join them so that instead of living and dying with one disease you might actually live with and have to manage several. For example, someone in their 60s might experience a ‘heart attack’ (myocardial infarction) (Oudejans et al. [2012](#)). This

person may then recover but live with worse and deteriorating heart function thereafter (congestive heart failure). Sometime later it may be established that the initial heart attack may have been caused by an undiagnosed type 2 diabetes. That condition may have been responsible for the hypertension underlying the initial heart attack. One might then live with managing congestive heart failure and high blood pressure (as life-threatening health conditions) but then some years later be diagnosed with prostate cancer (life-threatening condition no. 2). During this time, one may also be diagnosed with arthritis. Into one's 60 and 70s a further diagnosis of renal failure (another consequence of a worsening diabetes—life-threatening condition no. 3) and dementia (life-limiting condition no. 4) might also be made. All these conditions are life-threatening (they may kill you) or life-limiting (they definitely will kill you).

The end result is certain death by one of these disease processes but a dying process characterized by several medical conditions rather than any single one. Each of these chronic medical conditions bestows on its sufferer different disabilities as well as social and psychological limitations and experiences—from stigma to social isolation, from limitation of mobility to that of memory. In sociological terms, this means that dying now has no single social consequence, at least for people from modern industrial economies who do not die from trauma (war, accidents, suicide etc.). Dying for these peoples will be long (not over days or weeks but months and possibly years), have a major public component (they may still be able to work for a period before actually dying at home or in a health care institution) and will often have multiple and unrelated, rather than single and related symptoms, signs and treatments for the management of their 'dying'. The information about cause of death is no longer an indication of the causes and characteristics of dying. The destination is no longer a key informant for us about the journey before.

2 The seduction of medical rescue

An important part of the sociology of health and illness in the mid-20th century has been to describe how the rise of the professions, and medicine in particular, has become crucial to the control and regulation of everyday life. This affects everything from eligibility for employment or pension benefits, the regulation of workplace health and safety, the criteria for responsibility for crime and punishment, and moral attitudes toward lifestyle choices—choices about food, drug and alcohol intake, body image, even the decision to live alone or with others. The social marketing of health, health-related lifestyles and the essential

need for service provision in all things ‘health’ is now ubiquitous—from birth, child-rearing, employment, sexual activity, procreation, ‘healthy ageing’, and the regulation and disposal of dead bodies. One of the key consequences of this medicalization of everyday life is the popular association of personal troubles with medical rescue.

Several generations of growing up in professionalized and medicalized cultural environments mean that not only have most desires and needs been commodified and made available for sale, especially ‘health’, most people now expect to buy some kind of service to get them out of most personal troubles. There is either a drug/pill, a ‘must-have’ book on the subject, a ‘must-see’ website, a ‘must-see’ TV programme, or a service by someone who can resolve any question, need or problem. For the dawning of any personal realization about dying, this inevitably means delay that is caused by distracting treatments and narratives about avoidance, survival and overcoming, before an inevitably late realization that you are about to die. Under these social conditions the identity of dying may not come at all, of course; and if it does come, it will come late, after all other possible identities have been exhausted.

For serious life-threatening illnesses, medical services attempt a diverse and continuous array of possible treatments before accepting defeat. Parallel to these attempts, it is common for people experiencing these illnesses to modify their lifestyles in an effort to alter the course of the illness—making a range of psychological, social and physical changes to their lifestyles that range from increased vitamin consumption and meditation to seeking out alternative therapies. These lifestyle changes and increased use of health services (both conventional medical and alternatives) are sometimes described as ‘fighting’ the disease (e.g., ‘fighting’ cancer, ‘fighting’ to stay healthy, ‘fighting’ to remain ‘normal’ and so on). The self-observation of a worsening of symptoms despite treatment, acknowledgement of a metastatic return, or the admission into an ‘irreversible institutional environment’ such as a hospice or care home, usually provides the eventual or final dominance of the identity of ‘dying’.

In broad cultural terms, this means the challenge facing many people about to die is twofold: recognition of dying is delayed and so comes late in the course of illness-type dying (as opposed to trauma or suicidal death). Secondly, when dying is finally recognized, it takes on the social character of its preceding journey—a passage defined by its continuing relationship to medical assistance. Hence, a key challenge for dying people is *what type of medical assistance they will purchase to make dying happen (when dying is eventually recognized)*. Today, dying is experienced as a co-production of medical services and their consumers.

There are four major options, each with its own peculiar challenge: (1) Dying can be facilitated by palliative medicine. Here the medical rescue is deliverance from excessive physical discomfort through management of the worst symptoms, especially pain control, whilst permitting physical dying to take its natural course. This time permits social preparations to be made in an orderly manner as well as receipt of the support and companionship of one's usual social support network. (2) Dying can be facilitated by euthanizing medicine. In countries such as the USA, Switzerland or the Netherlands, dying can be reduced to a physical event rather than a drawn-out process. Here, the rescue is from a 'lingering' form of dying. Consumers of this form of medical rescue decide when they are beginning to enter the most socially and medically debilitating part of their dying and have this progression stopped by lethal injection. (3) Dying can be facilitated by acute care medicine. For people who have no interest in lingering dying (palliative care) or sudden death (euthanasia) the choice is multiple hospital admissions until restoration or resuscitation eventually fails to restore them. The rescue or postponement in this scenario is from a social and/or emotional acceptance of impending death. Finally, (4) dying can be facilitated by care homes for the frail aged. In these contexts, the elderly are people with 'final admissions' but with no clear prognosis (life expectancy) linked to the dominance of a particular disease (palliative care) or a desire to seek death as a controlled event (euthanasia) but are not well or strong enough for independent life (acute care). Dying in care homes is subject to medical surveillance and support, similar to palliation. However, here one is rescued from abandonment and isolation due to collapse of their usual social and physical agency.

3 The myth of institutionalization

Although much has been written about the institutionalization of dying, the overwhelming majority of this writing has confused dying with death. It is usual, for example, to point out how the majority of deaths occur in hospitals, hospices and nursing homes with only a minority dying at home (Public Health England 2013). This demographic portrait of place of death is often contrasted with the same figures a century earlier when most people 'died' at home. The problem with this comparison is that the trajectory of dying is assumed to be the same. This is untrue.

If we assume a medicalized understanding about dying as a process covering the last few days or hours of a person's life (the final 24 to 48 h in the outcome of

a metastatic disease or organ failure), the observation that most dying takes place in institutions other than the home may seem to be true. However, this is not a *social* understanding of dying shared or experienced by dying people. For most people, dying is an alteration of identity based on the knowledge that they will die very soon. Most people enter this psychological and social space as soon as they suspect or are offered a prognosis by their doctors—so many months or so many years to live. Some people begin to reflect and experience a sense of their dying after even a diagnosis of a serious illness. This is also true of those about to be executed, those entering a nursing home for their ‘final’ time, and many among the ‘old’ old (those over the age of 85).

These cases cover the majority of those who are understood to be, and personally view themselves as, ‘people who are dying’. These are people who experience ‘dying’ over several years or months. In this sociological context then, the felt experience of ‘dying’ is not dependent on a particular stage of a biological progression of the disease—as defined by a medical gaze alone. Rather, it is the personal acknowledgement of incurable disease, advanced age or an execution date that defines the dying experience, and this must mean that the longer part of dying occurs mostly at home, work and the other institutional sites of social life. Dying over a century ago in Europe, largely because most dying was from infectious diseases or a late diagnosis of cancer, neurological or cardiovascular disease, was often short. In other words, the medical gaze and the layperson’s gaze often coincided. Early diagnosis and the chronic nature of most life-limiting illnesses essentially means that although most people finally become dead in hospitals, hospices or nursing homes, most of the time the fact that they perceive and experience themselves to be dying occurs in their usual places of residence. People do not mostly die in institutions; they simply finish their dying there.

For dying people today then, the challenge is how to live one’s dying upright—not for the most part reclining in bed surrounded by friends and family, but rather working or living out a retirement in poor and declining health. For most dying people in these contexts, support for their new identity is poor or absent. Most friends and family do not want or encourage talk about death because this is viewed as ‘giving up’ or as an indication of their own failure to provide enough support to chase away the ‘dark thoughts’. Acceptance of dying by dying people is welcomed neither by clinicians nor families, certainly in the early and mid-stages of the dying journey. This makes social preparations for advanced care planning or for financial and legal preparations difficult and unsupported. Death talk by the dying is discouraged, even stigmatized. Opportunities for education, information, shared reflection about mortality or even spiritual meaning is difficult if not impossible and drives more people into the confidential

and hidden services of chaplaincy, pastoral care and counseling because the normal and usual avenues of support are limited or closed. The widespread 'healthy ageing' agenda of most national policies does not include openness and sharing for 'healthy dying'. There is little to no recognition that dying is part of ageing in these research and policy circles.

The myth of institutional dying helps sustain these social troubles for dying people and ensures their strength and persistence because *until one is institutionalized* there is no social permission to live one's dying. Once institutionalized, dying people are either too ill or tired or must avail themselves of structured pastoral and psychological services provided by the institutions.

4 The social manufacture of horror at the end of life

The growth and acceptance of the medicalized and institutional view of dying as a time confined to the last few hours or days of life has been so widely accepted that most of the social science monographs focus on this particular image of dying—thereby colluding with, reproducing and reinforcing it. This trend is evident from the very early works about dying from Fox (1959), Sudnow (1967) or Glaser and Strauss (1968) to more recent examples such as those from Lawton (2000), Armstrong-Coster (2004) or Kaufman (2005). These social studies of the dying experience mirror both the sites and stages of late dying described by the medical writers covering the same time period—from Hinton (1967), Kübler-Ross (1969) or Witzel (1975) to the more recent examples from Nuland (1993), Barnard and colleagues (2000) or Gawande (2014).

However, the sociological architecture—the social experience of dying as opposed to the biomedical definitions—is based on personal perception and experience. We are not simply bodies. The personal experience of dying is shaped by three crucial but overlooked parameters that are rarely recognized, less discussed. Firstly, the felt experience of dying lasts longer than the last days and hours. Secondly, most of the time actually lived by dying people occurs outside the very narrow and fleeting episodes of health care provision or professional contact. Thirdly, much of our understanding of what dying is actually like comes from carers' (and therefore onlookers') accounts of it—from doctors to family carers.

If one takes the *whole trajectory of dying as the social terrain to be investigated or explored*, the final result is an exploration of life in all its emotional diversity. Dying as an identity becomes a dominant but not all-consuming experience, similar to parenthood or a worker role. Conversations, attitudes and conduct can be seen more clearly as functions of particular relationships and not some

essentialized (i.e., solely internal) experience somehow divorced from the relationships that generate it. And the problem of how much to share with others about a set of experiences and musings that derive from a publicly problematic identity (such as dying, ageing, sexual abuse, illicit drug use) becomes more clearly problematized rather than taken for granted. Under these social conditions, knowledge of the group(s) in question must be assumed to be partial and highly influenced by the expectations of the professional gaze. This is precisely what happens to both the professional and academic literature and the popular and journalistic imagination consuming that literature.

Clinical literature problematizes dying because it is the more complicated cases that are privileged in that literature. Professionals solve problems, so the problems for them to learn from are those that populate their periodicals. Social science investigators turn to those they believe are at the centre of studies of dying conduct, often uncritically accepting both the work sites and the definitions of late dying promoted at those sites. The result is a lack of breadth in the study of the experience, a bias toward onlookers' views (usually clinical staff and families) and an interest in first-person experience only insofar as this is retrieved from late-course dying in health care institutions.

The manufacture of knowledge in these narrow confines, and its popular reproduction by social media, results in a view about dying that is problem-based, clinically oriented and nearly always difficult for patients. Even in portrayals of late-course dying, in the last 24 h before death, it is mostly the difficult deaths that are reported and not the many more who die in their sleep, in a coma or before the TV in the care home lounge. The net effect of this endless trail of negative imagery is a frightened public who are filled with dread. Dying—which is a complex experience that must be understood from the dawn of its awareness till death, must be described from outside the clinic as much as from within it, whose diverse and sometimes ineffable experiences must be shared carefully and among selected listeners and confidantes (not just anyone)—is, in the end, similar to most living identities that live with 'spoiled' aspects of the self. The emphasis on problems of the body and of the emotion, the accent on crisis and collapse or loss of control, has become such a totalizing picture generated by academic and clinical publics that it is now fair to say that in the last half-century these groups are solely responsible for the social manufacture of horror at the end of life.

It is this social and historical artefact that most modern populations now labour under and not any essentialist notion of the fear of death as psychoanalytic writers will have us believe. Our fear of death is a fear of a particular decontextualized portrayal of death manufactured by problem-based professional writing by those with an uncritical acceptance of the medical view of dying. Although there

is an abundance of balanced but underpublicized first-person accounts of dying (Kellehear 2014), the fear, the object of its recoil, and the woeful lack of well-being images that might counter and balance both makes the experience of dying difficult and constraining for modern dying people whose experiences—taken as a whole—do not reflect these negative images.

5 The Garbo Syndrome—rise of a modern desire

The iconic silent screen actress Greta Garbo once dismissed journalists who were doggedly following her in her retirement with the now famous words, “I just want to be left alone” (Knowles 2006). After leaving the film business, Garbo—internationally acclaimed for her charismatic beauty—lived out her life as a single person and lived out most of her ageing and dying at home alone. In the 1950 and '60s this was an unusual choice of lifestyle, largely because the prevailing ideology of the times emphasized the stability and safety of the nuclear family. However, at that time, important social changes were afoot.

Not long after this historical epoch the separation and divorce rates began to rise sharply and in some states of the USA even soared. The rise of the modern women's movement, the opening up of the labour market to women, increasing secularization and/or criticism of formal religions, and increasing life expectancy all conspired to boost single-person households in the late 20th century. By the turn of that century single-person households became the fastest-rising type of residential status in Western Europe and the USA.

In England and Wales single-person households now comprise over 28 % of all households (Office of National Statistics 2014). More importantly, for end-of-life care scenarios, most of these single households belong to older people—about half those over 65 years of age and about two-thirds of men over the age of 75 years of age live alone. Furthermore, the 85+ age group who live alone are the fastest growing age group (Age Concern 2008; Kellehear 2009). This has serious implications for our sociological and health policy understanding of dying and its future care.

First, there is the assumption that a ‘good death’—a death surrounded by friends and family at the bedside—may not be possible or even an aspiration for a growing group of older men and women. Increasingly, older people, especially those over 85 years of age, experience growing social isolation due to the earlier deaths of peers, personal mobility problems because of the multiple chronic health conditions they experience, and the contemporary culture of individualism that places important emphasis on career, raising families or peer-age friendships.

These social influences mean that single-person households are increasingly likely to be sites of dying old and alone at home. At the moment the figure for these kinds of deaths stands at about 1% of all deaths.

Secondly, there are indications that some older people do not wish to be the subject of health services support or intrusion and that dying alone represents agency, dissent or resistance to someone else's idealization of dying as dying-in-company. The interesting sociological observation that many people tend to die as they lived runs headlong into the demographic facts of living alone. The logical implication of this for some of today's dying is that a 'good death' is a death where they are simply 'left alone'.

Thirdly, several other social forces are conspiring to make this style of dying more accessible. Digital technology continues to rapidly evolve, making devices easier and more accessible to use. More commercial services have become available on the Internet to permit and encourage most shopping and health service needs to be met. Newer (and more Internet-savvy) generations will become old and then will soon become the older old (85+). These developments ensure that dying old and alone will not only become more possible but perhaps even more preferable. The new and emergent form of dying—as a lifestyle choice—may be to live and die for as long as possible and to die from a fall or major circulatory event at home, alone. For others, the final outcome may be increasing the length of dying to an unprecedented close proximity to death with some living out their last days in an inpatient facility such as care home, hospital or hospice. Times for dying in these sites may become increasingly compressed by the parallel cultural obsessions of living independently and alone.

The final implication of this social trend is, at best, to challenge most policy ideologies and social preferences of the 'good death' that attempt to confine (and narrowly define) ideal portrayals of dying as a social occasion. At the very least, this social trend probably demands that policy and practice ideas of professionals about the ideal way to die must become pluralist and socially diverse. Just as the modern sociology of the family has theorized away from the static and anachronistic models of the monogamous, nuclear or extended heterosexual family, so too end-of-life care social science and policy studies theorists will have to reckon with the diverse dying trajectories that those diverse families (and households) will generate for generations to come.

6 Promoting death versus promoting dying—international tensions

Although it is common for contemporary social and medical sciences to discuss the problem of dying as if this were only a problem for affluent, industrial economies, it must be acknowledged, even if inconveniently, that the facts of mortality are international for the human family. This means that studies of modern dying, similar to modern studies of inequality, must take a wide-angle view of the tensions and trends in the international data that suggest a worrisome paradox. For dying, these paradoxes can firstly be seen in the data on major causes of death between resource-poor countries when compared with the same data from resource-rich countries. Secondly, these paradoxes can be seen in the export, promotion and colonisation of models of dying.

Short periods of dying—from first awareness of dying to the point of actual death—have been the norm in human history since the last major ice age (Kellehear 2007). This indicated that most causes of death were due to trauma (e.g., falls, poisonings, perinatal deaths and maternal deaths in childbirth etc.) or from infectious diseases of short duration (e.g., plague, malaria, diphtheria). In agrarian and urban societies, this toll of death was abundantly supplemented by deaths through warfare, occupation and colonization, death camps, and natural disasters such as famine, drought, floods, earthquakes, hurricanes and volcanic activity.

In recent affluent economies since the Second World War, the widespread introduction of public health measures (e.g., clean drinking water, sewerage systems, food surveillance, etc.), stable governments, high employment, extended periods of peace, and an elaborate health and medical services infrastructure have increased life expectancy exponentially. This has resulted, as I have described earlier, in a massive rise in long-term health conditions that has promoted long, lingering trajectories of dying, however we might describe the ambiguity of perception from those at the centre of these trajectories. The epidemiological story in resource-poor countries has not been as dramatic.

In these countries, we see a greater proportion of people with greater life expectancy than previously seen. However, the life expectancy figure is generally lower for some groups in regions such as Canada or Australia (in aboriginal/indigenous communities, for example, some 20 years less than their urban Anglo-European or Asian counterparts). In resource-poor countries, away from the gentrified hubs of their urban areas, life expectancy is low. Furthermore, perinatal death, short dying and sudden deaths remain commonplace—from all the

usual causes of death we have seen historically earlier: warfare, occupation and colonization, death camps and natural disasters such as famine, drought, floods, earthquakes, hurricanes and even volcanic activity. To take just two examples, the death toll from the so-called 2004 Boxing Day Tsunami in Indonesia took the lives of some 250,000 people in a single day—a figure that in the UK would have to include all deaths from cancer and heart disease over the course of a year to even come close. Although over 1200 people died in the 2005 tragic weather event caused by Hurricane Katrina in the USA, compare this to the Bhola cyclone event in Pakistan/Bangladesh that claimed half a million lives over the course of a few days in 1970. Resource-poor countries are less economically and politically stable and have little infrastructure for prevention and harm reduction against hostile natural and political events. This means that even in the so-called modern world the facts of global inequality create two kinds of dying—one prolonged and lingering, and the other short or sudden.

The irony of these two opposite social trends is that the people in resource-rich countries, if asked how they would like to die, usually confess to a preference for short or sudden death, though, of course, they are mostly destined to have its opposite. On the other hand, most people in resource-poor countries wish to have longer lives, live with a modicum of prosperity, and therefore, perhaps without realizing it, aspire to the longer, lingering deaths of those from privileged settings. From the point of view of modern end-of-life care, the promotion of economic political stability, economic growth and peace is, *de facto*, the political promotion of (long) dying over (sudden) death. Increasingly, in resource-rich societies, the dying are rejecting or deserting this destination by opting for medical rescue of one type or another. If the death toll and style of dying of the poor can be argued to be a negative ethical outcome of global problem of social inequality—an outcome to be fought against and protested about—what is it about lingering dying that is ethically and sociologically positive and preferable?

In sociological terms, there can be no doubt that long-term health conditions and lingering dying are a status symbol, if for no other reason than that these lifestyles are outcomes of affluence and social mobility. The problem seems to be, from the point of view of those who are bound for these kinds of mortal destinations, that few seem to aspire to them, and even those who do are at a loss to describe the social and personal benefits. This highlights the ideological tensions within the modern public health movement's view of *length* of life expectancy as self-evidently good over any consideration of *quality of life*. The political consequence of this unexamined assumption is fierce and has resulted in a global bio-ethical policy and community debate over physician-assisted suicide and other forms of euthanasia and a cultural dread of advanced ageing.

7 The postmodern turn

There is a long and elaborate debate in the social sciences literature about how secularized modern industrial nations seem to have become in the last 100 years. Measures of belief in God, church/temple attendance, applicants for the clergy, rates of prayer practices, and arguments about the conceptual and psychological slippage between ideas of ‘spirituality’ and ‘religion’ offer different and often contradictory conclusions (Bruce 2002). I do not want to arbitrate here over whether religion is on the decline, or whether it is transforming or evolving socio-logically, and even whether religious beliefs and practices offer support and protection for poor bereavement outcomes or as emotional supports when facing one’s own death. Rather I wish to point out that the traditional and culturally important question asked by children and adults alike, asked by the dying and the bereaved alike, and asked from time immemorial—where do people go when they die?—has now become largely unanswerable for increasing numbers of people. It has become ‘unanswerable’ because the grand narratives (the big, overarching stories about creation, the good life and the good death, and the nature of God behind all of the previous three) of traditional religions are being jostled and mixed by global diversity and competition.

Consider this. In the recent past, religions sometimes offered a storyline about what would happen to dying people in the first few minutes after death (pareschatology) and/or at the very least what the ultimate destination of the dying person would be after their death (eschatology) (Hick 1976). Some pareschatologies might perhaps describe the trials, the strange new beings encountered, or the new foreign environments that the newly dead would experience as soon as he or she arrived in the world of the dead. Most religions, even those without obvious pareschatological detail, would at least offer eschatologies that describe the ultimate fate of human beings after they died—into heavens or hells, reincarnation cycles, transformations, evolutions, transmigrations, even oblivions. These grand narratives of the ultimate destination of those who die have been broken at worst or seriously undermined at best.

The materialist, scientific, humanist and atheist narratives continue to occupy, or aspire to provide, undermining narratives about any existence beyond the observable and measurable. These narratives are simple biological stories about the inseparable nature of consciousness from its biological platform. From the point of view of these perspectives, the question of where people go when they die is a *non sequitur*. On the other hand, in societies characterized by high levels of education and migration, multicultural changes and international travel, world religions now offer alternatives to home-grown pareschatology and eschatology.

Not content with Christian versions of the story about the ultimate fate of the soul, for example, one can now have relatively easy access—online or in books or on holidays—to alternatives from the world of Islam, Buddhism, Hinduism and any number of smaller folk religions and cults.

Furthermore, lesser-known and formerly stigmatized religions such as paganism or spiritualism have experienced serious revival as indeed have astrological and animistic beliefs. Mixtures of these kinds of religious knowledge and doctrine may also be found in an eclectic social brew of beliefs and practices broadly identified as the ‘New Age’. For the problem of growing old and dying, it is important to note that it is not the diversity of religious content that is important for dying people but rather the rise of personal uncertainty at the end of life. When there was only one belief or its negation, certainty if not social assurance was everyone’s inheritance. Whereas now multiple choices (or none) offer only the legacy of uncertainty.

Near-death experiences—where people may report social and mystical experiences in their unconscious state after being revived from a life-threatening event—do not automatically lead to one eschatology or another, whatever support it may give to some pareschatologies (e.g., spiritualists). Just as many people may assume this to be evidence of an afterlife as others might assume this to be mere evidence of hallucinations near death. Currently, there is simply no way of arbitrating (Kellehear 1996).

Finally, this question of where people go when they die, and the competing eschatological discourses that are part of the postmodern religious marketplace, also has serious implications for how one behaves while dying. Eschatological discourses supply ideas of destination and therefore, *ipso facto*, guidance on how to prepare for the journey to there. In other words, the very details of the destination, from whatever sources these are derived, shape the behaviors and attitudes of those traveling there—from reading material, use of religious clergy, worship behavior, financial and legal planning conduct, and of course, psychological morale and meaning-making. The commodification of social life in postmodern societies has created a marketplace model of religious consumption whose legacies, and therefore challenges for dying people, are those characterized by personal uncertainty and social ambiguity. In historical terms, this is a key undermining factor—almost by definition—towards any policy or clinical aspirations to create a ‘good death’.

8 Summary and Conclusion

The anachronistic ideal of the ‘good death’, so often derived from an unexamined agrarian cultural inheritance is, by definition, increasingly an impossible ideal. Today, the experience of dying struggles for recognition. When recognition comes, the authoritative definition, the behavioral characteristics and social experiences, and sometimes even the setting, are all medically determined or influenced. The longer part of dying is denied. The positive and wellbeing aspects of dying at any stage of the journey are denied. The diversity of dying beyond mere illness is often denied.

Although there is some discussion of the loneliness of dying (Elias 1985), there is almost no recognition, less discussion, on the increasing ‘aloneness’ of dying. Similarly, the international paradox of poor and rich countries desiring each other’s end-of-life destinations, a paradox rooted in economic and historical inequalities, is given no narrative space in bioethical discourse—a discourse hopelessly lost in biomedical, public health and clinical definitions of the problem of mortality. The contemporary postmodern turn has meant that although life-course choices are often experienced as empowering choices in most areas of human development—from sexual orientation and partnering to child-rearing and career and retirement ambitions—the same availability of choices is often disempowering in matters to do with dying and death, offering us only uncertainty, anxiety and ambiguity.

For sociology, the implications of revising our views about the dying experience are clearer. Far more work needs to step away from solely medical definitions of dying, relinquishing old habits of following the doctors into their clinics, and embracing instead portraits of dying determined by self-definitions and cultural folk ways. A phenomenological and social interactionist account of the dying experience must take a critical stance towards received ideas about cause of death, place of death, ideologies of the ‘good death’ and ideas about dying anchored solely in the illness experience. Ageing and dying, comparative expectations and experiences of dying internationally, and in non-health care settings (prisons, death camps, in disaster settings or on doomed transportation) help us to develop multidimensional, pluralist understandings about new psychological and social characteristics of expected versus unexpected personal journeys.

The theoretical debates about risk and uncertainty, so much a part of mainstream social theory, have yet to make their mark in any significant way on the sociology of dying. Until we adopt a genuinely critical position away from the medical gaze, rebuild and rebalance our understandings about dying as an experience with positive as well as negative characteristics, the prospect of death will

remain, erroneously, dark and frightening for most. This outcome will only fuel a woeful continuation of terrified publics, further tighten a medicalised grip on the concepts of dying and death, whilst promoting the popularity of fictive psycho-analytic explanations. The current challenges for a new and critical sociology of dying have never been clearer.

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